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Research Participants' Preferences for Individual Results of Pharmacogenomics Research: A Case of a Ugandan HIV Research Institute

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Abstract

Little is known about whether people living with HIV would like to receive their results from pharmacogenomics research. This study explored the factors influencing participants' preferences and the reasons for their desire to receive individual results from pharmacogenomics research We employed a convergent parallel mixed methods study design comprising a survey of 225 research participants and 5 deliberative focus group discussions with 30 purposively selected research participants. Almost all (98%) participants wanted to receive individual pharmacogenomics research results. Reasons for the desire to receive results were reciprocity for valuable time and effort, preparing for future eventualities, and the right to information about their health. Overall, participants desire to receive feedback from pharmacogenomics research, particularly if results are well established and clinically actionable.

Keywords

preferences; pharmacogenomics; research results; participants; HIV/AIDS

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Author Contributions

SN, CW, DK and ESM contributed to the conception and design of the work. RS, IM and DK contributed to the analysis and interpretation of the data. SN, CW, BC, DK and ESM contributed to drafting and revising the work critically for important intellectual content. All authors approved the final version of this manuscript for publishing.

Declaration of Conflict of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Considerations

This study was reviewed and approved by the Makerere University School of Biomedical Sciences Higher Degrees and Research Ethics Committee (SBS-855) and the Uganda National Council for Science and Technology (SS 735ES). Permission to access participants contact details was sought from the IDI Scientific Research Committee and the Principal Investigators of the five pharmacogenomics clinical trials. Written informed consent was obtained prior to participation in the study. All participants were assured of confidentiality.

Introduction

Genomics and genetics research is increasingly being used globally to study predisposing factors to genetic diseases and improve therapeutic interventions moving toward personalized medicine. Studies show a vast increase of pharmacogenomics research in sub-Saharan Africa aimed at improving HIV treatment, specifically, studying how an individual's genes influence response to a given medication. This is precisely in relation to the drug efficacy, adverse events, and dosing requirements (Aminkeng et al., 2014; Calcagno et al., 2019; Dandara et al., 2019; Mukonzo et al., 2014; Ngaimisi et al., 2013). There are about 1.5 million people living with HIV in Uganda, with 28,000 dying of AIDS-related illnesses annually (Loarec et al., 2019).

Pharmacogenomics research studies have the potential to present results that are relevant to individuals. (Shahmirzadi et al., 2014). Pharmacogenomics research results can be generated from genomics and genetics analyses (Korol et al., 2013). Expert working groups have produced sets of guidelines and policy statements to help professionals to decide on what kind of results from genomic testing should be returned to patients in clinical settings and research environments. For example, the American College of Medical Genetics and genomics (ACMG) recommends that patients be told of highly actionable incidental findings because they may potentially benefit their health (Green et al., 2013). The ACMG provides a minimum list of 56 genes based on penetrance, actionability and pathogenicity for which results should be returned to the ordering clinicians who provide feedback to the patient (Burke et al., 2013; Green et al., 2013). In addition, the Human Heredity and Health in Africa (H3Africa) guidelines for the return of individual genetic research findings generally recommend the return of medically actionable and clinically valid results (with a proven therapeutic or preventive intervention) (H3AfricaConsortium, 2018). Researchers and clinicians may utilize pharmacogenomics research results to determine the appropriate treatment regimen and drug dosage (Eriksen et al., 2020).

Research participants consider receiving their genomics and genetics results from researchers as a way of showing respect and value for their contribution to the research project's success (Ralefala, Kasule et al., 2020). Studies have reported that participants desire to receive individual results across all categories of genetic medical conditions ranging from severe, non-preventable, and non-treatable as well as personal utility (Matshabane et al., 2022; Ralefala et al., 2021). A qualitative study conducted among parents and caregivers of children and adolescents involved in an HIV-TB genomic study in Botswana reported that almost all participants wanted to receive their genetic results (Ralefala et al., 2021). However, satisfying the research participants' demand for genomics and genetics analyses remains a debate among researchers and bioethicist communities on the African continent (Kasule et al., 2022; Kisiangani et al., 2022; Mwaka et al., 2021b; Ochieng et al., 2021b; Ralefala, Kasule et al., 2022). While these studies highlight the relevance and benefits of sharing genomics results with participants, a number of ethical concerns such as the possibility of misinterpreting these results, unnecessary worry to the participants and family members, and discrimination have been raised (Kaphingst et al., 2016; Yu et al., 2013).

There is an increase in pharmacogenomics research on the African continent to improve HIV treatment. However, there is limited information on whether people living with HIV would want to receive their individual research results or not, what factors influence their preferences, and what are the reasons for participants' desire to receive these results? This study aimed to explore factors influencing participants' preferences and reasons for the desire to receive individual results from pharmacogenomics research. By exploring the factors and reasons influencing participants' preferences, we hope that the findings from this study will contribute to developing institutional and national guidelines for returning individual pharmacogenomics research results to people living with HIV.

Methods

Study Design and Setting

We adopted a convergent parallel mixed methods study design (Creswell & Creswell, 2017). This study was conducted at the Infectious Diseases Institute (IDI) in Kampala, Uganda, between May 2021 and February 2022. The IDI is one of Uganda's renowned research institution affiliated to the College of Health Sciences, Makerere University. The IDI provides treatment and care to over 8000 adults living with HIV and houses over 80 research studies annually. Participants were recruited from five ongoing clinical trials with a pharmacogenomics component hosted at the IDI. The objectives of the clinical trials are described in Table 1

Participants

Our study population consisted of 396 participants who were involved in any of five ongoing clinical trials that included pharmacogenomics. Simple random selection was carried out and 231 participants were selected to take part in this study. Each of the five clinical trials had fair representation as described in Table 2. Participants were notified about the study either during one of the study visits of the primary study or by a telephone call invitation. All participants were above 18 years.

Study Procedure

Qualitative data and quantitative data were collected concurrently. All participants provided written consent prior to enrollment. Quantitative data were collected using an interviewer-assisted semi-structured questionnaire. Depending on the participants' preference, the questionnaire was administered in either English or Luganda (the most commonly spoken language in central Uganda). A brief overview of how genes interact with antiretroviral (ARV) drugs was provided to the each research participant when obtaining informed consent. The questionnaire comprised of three sections. The first section captured the sociodemographic characteristics and clinic history. The second section comprised of questions about participants' preferences for individual primary results and incidental findings of pharmacogenomics research. The third section comprised of participants' reasons for the desire to receive primary results and/ or incidental findings from pharmacogenomics research or not. The questionnaire was informed by literature on the return of individual genetics and genomic results (Bennette et al., 2013; Johansson et al., 2019; Kaphingst et al., 2016; Matsen et al., 2019; Yamamoto et al., 2017; Ziniel et al.,

2014). Primary results were defined as findings intended to address the research questions of the five clinical trials that included pharmacogenomics. Incidental findings were defined as results discovered unintentionally and are not related to the primary research questions of the five clinical trials with a pharmacogenomics component. Participants responded to the outcome variable using a Likert scale of 1 to 5, where terms such as “Definitely no,” “Probably no,” “I’m not sure,” “probably yes,” or “definitely yes” were used. The tool was first pre-tested on five volunteers to ensure that the questions were appropriate, easy to understand, and administered. There were no significant changes made to the tool. These five volunteers were excluded from the study. On average, questionnaire administration took approximately 20 to 30 min.

Thirty participants enrolled in the ongoing pharmacogenomics clinical trials were purposively selected to participate in the deliberative focus group discussions (dFGD). A brief description of the study and details of the set date, time and venue were communicated a week before the discussions by phone. A follow-up call was made a day before the discussion to confirm availability. On arrival, a research assistant provided full details of the study and written consent was obtained in the participants’ preferred language. Each dFGD was composed of six participants segregated by gender and age. Prior to the discussions, a brief overview of how human genes interact with antiretroviral drugs was provided to research participants. This was followed by a vignette describing a hypothetical scenario of possible outcomes from pharmacogenomics research results categorized into primary and incidental findings. Prior information aimed at helping participants gain a comprehensive understanding of the subject matter. With the help of a semi-structured interview guide, open-ended questions were presented to the participants to explore the reasons to receive individual pharmacogenomics research results or not. The interview guide was informed by literature on the return of individual genetics and genomic results to participants (Bollinger et al., 2012; Daack-Hirsch et al., 2013; McGowan et al., 2018; Yu et al., 2013). The tool was first piloted on five volunteers who were later excluded from the study, and it consisted of three sections. The first section captured the socio-demographic characteristics and clinical history. The second and third sections contained questions about reasons for receiving primary results and incidental findings from pharmacogenomics research or not, respectively. Clarifications were offered prior to and during the discussions. SN and one research assistant moderated the discussions interchangeably, and a note-taker was present throughout the discussions. The interviews were audio-recorded, and each took between 60–90 min. Five dFGDs were conducted until saturation, when no new insights resulted.

Data Analysis and Integration

Quantitative and qualitative data were analyzed separately and later, we performed a mixed-method data analysis by integrating the findings as described below (Creswell & Creswell, 2017).

Quantitatively, data from questionnaires were captured electronically using EPI DATA Version 3.02 and later exported to STATA for analysis. The study outcome was categorized into preferences for “All results (all primary results and incidental findings)”, “Partial results (all primary results and some incidental findings),” and “None of the results.”

The independent variables included demographic characteristics such as age, gender, education level, employment status, religion, and type of family, and clinical history. Descriptive statistics were used to summarize all the data. Categorical variables were summarized using frequencies (percentages). In bivariate analysis, the associations between the participants' characteristics and preferences for the results were established after fitting a Poisson model to estimate the prevalence ratios between the independent and outcome variables. All variables with p-values ($p < 0.2$) at bivariate analysis were considered significant and thus included in the adjusted model. A modified Poisson model was used at the multivariate level to determine the factors influencing participants' preferences for individual pharmacogenomics research results. Variables whose p-value was < 0.05 were considered significant.

Qualitatively, all audio recordings were transcribed verbatim. Transcripts were translated from Luganda to English and later verified for accuracy by reading word by word while listening to the audio recordings for quality checks and spelling errors. This step also helped the researchers to familiarize, mark and memo the data. Three authors (SN, AT, and EM) selected three transcripts for open coding. These scripts were read line by line to generate the first set of codes and later used to develop a codebook and coding framework. The transcripts were then imported into Nvivo version 12 (International-Pty-Ltd, 2018) and coded by three researchers (SN, AT and EM). Codes were sorted into categories based on how different themes were related and linked. Four researchers conducted data analysis and interpretation continuously throughout the study (EM, DK, CW and SN). Thematic analysis was used based on an inductive approach (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006). The codebook was continuously refined to identify themes about participants' reasons for the desire to receive individual pharmacogenomics research results. Representative quotes supported themes.

We then compared and integrated the findings from the qualitative data with the quantitative results as presented in the discussion section (Creswell, 2014). The integration of both datasets allowed us interpret the most important reasons for the desire to receive the different kinds of individual pharmacogenomics research results.

Results

Results from Quantitative Data Analysis

Out of the 231 participants contacted, 225 respondents were enrolled in the survey to determine the factors influencing participants' preferences and the reasons to receive individual results of pharmacogenomics research. Table 3 presents a descriptive summary of the participant's demographic characteristics and clinical history. The majority were female (60%), with a median age of 38 [33–42]. About half (50.7%) of the participants were either not educated or had attained only primary education and were not married, 72% were self-employed, 81% had monthly earnings of less than 500,000 UGX (approximately 130 USD), and 65% lived in nuclear families consisting of biological parents and children.

Participants' Preferences for Individual Pharmacogenomics Research Results

Nearly all (98%) were willing to receive their individual primary pharmacogenomics research results. The majority of participants 149 (66%) wanted to receive all their pharmacogenomics research results (both primary and incidental findings), whereas 72 (32%) indicated that they wanted to receive partial results (all primary results and some incidental findings). Only four (2%) did not want to receive any results. Figure 1 presents participants' preferences for individual pharmacogenomics research results.

Categories of Incidental Findings from Pharmacogenomics Research

Among participants who were willing to receive partial results including all their primary results and some incidental findings (72), 93% were willing to receive well-established incidental findings, and 96% wanted results of treatable and preventable conditions. Figure 2 presents details of the different categories of incidental findings desired by participants who preferred partial results.

Factors Associated with Participants' Preferences for Individual Pharmacogenomics Research Results Using a Multivariate Modified Poisson Model

The four participants who did not want to receive any results were excluded from the analysis to avoid erroneous estimates of the outcome variable. At multivariate analysis, only religion, duration of antiretroviral treatment (ART) and duration of receiving care at the IDI clinic predicted participants' preferences for receiving pharmacogenomics research results, as shown in Table 4. Receiving ART for between 5 to 10 as compared to less than 5 years was associated with preference to receive all results (PR: 1.69, CI:1.23–2.34, P = 0.001). Similarly, attending the IDI clinic for 5–10 years as compared to less than 5 years (PR: 1.19, CI: 0.96–4.49, P = 0.045) was associated with preference to receive all results. Participants from other religious faiths, (Islamic faith, Seventh-day Adventists, and Pentecostal) compared to Catholic and Anglican faiths were less likely to prefer all results (PR: 0.76, CI: 0.59–0.98, P = 0.036).

Participants' Reasons for the Desire to Receive all or Partial Individual Pharmacogenomics Research Results.—Most participants (98%) desired to receive their primary results because they felt that these results would improve their quality of life (98%), prevent future harm (98%), and help them to plan better for their future while avoiding health risk behavior (93%). Others desired to receive primary results because of the emphasis placed on the participant's importance to the research project (99%). Participants who desired to receive all their results had similar reasons for wanting to receive incidental findings, as shown in Figure 3.

Reasons for Wanting Partial or None of Pharmacogenomics Research Results.—The reasons for preferences of partial results or none of the pharmacogenomics results were fear of misinterpreting some incidental findings (78%), fear of discrimination (73%), and worrying about family members who may be predisposed to certain health conditions (70%), as described in Figure 4.

Results from Qualitative Data Analysis

We selected 30 individuals who had also participated in the quantitative study to take part in the deliberative focus group discussions (dFGDs). The majority (60%) of the participants of them were female; 57% were below 35 years of age and 60% had attained a primary level of education. In addition, 60% were married, and 67% were self-employed (Table 5).

Three key themes merged from the qualitative data, and these included:

1. Participants' awareness about dissemination of pharmacogenomics research results
2. Reasons for participants' desire to receive either all or partial results from pharmacogenomics research analysis.
3. Reasons for participants' desire to receive partial results or none of the results from pharmacogenomics research analysis.

Participants' Awareness About Dissemination of Pharmacogenomics Research Results

Overall, majority (27) of the participants expressed a desire to receive their primary results. However, two participants mentioned that they had not fully understood the results dissemination procedure during consenting to participate in the parent studies. Some participants (08) indicated that they had no recollection of being told about the results dissemination procedure.

> … *I don't remember anyone [research team] mentioning that they were going to give us our results, whether they were good or bad. But for me, I really wanted to know what came out of the study*… (FGD 2_Female_Participant 3)

Reasons for Participants' Desire to Receive Either all or Partial Results of Pharmacogenomics Research.—Participants offered several reasons for wanting to receive their results. These included the right to know what is happening in their bodies, seek early treatment or preventive measures of future genetic diseases, and some research results that might present significant opportunities in the future. Most participants who preferred to receive primary results (25) mentioned that researchers should return clinically significant results to research participants under the principle of reciprocity. They further asserted that the human biological samples belong to research participants and as such, they have the right to be informed about any significant results to their health. Three participants indicated that it was unethical to withhold crucial clinical information from them.

> *I would like all the results to be returned so that I get to learn about them… Because even for you who took off my blood, I don't expect them [results] to be of any use to you. The blood they [researchers] took belongs to me, I need to know what you have discovered about me. I am the owner of that information*" (FGD 5_Male_Participant 4)

Among the participants who preferred all results, four of them expressed confidence in researchers and healthcare workers at the IDI to provide the necessary clinical care and moral support for all conditions that might be discovered during genetic analyses.

> … *They* [researchers] *should return all the results. Because the researchers, especially the ones here at IDI won't fail to give us a plan on how to deal with any genetic disease even if it has no treatment… because they cannot leave us to handle health problems alone. For me I almost died of HIV, not until I came to the IDI clinic. Now I have my life back…That is why I am interested in all the findings*". (FGD 4_Male_Participant 1)

Nearly all participants who wanted to receive their primary results (27) felt that pharmacogenomics results could provide an opportunity to create awareness about certain genetic conditions and allow for early initiation of treatment to save both human lives and resources. Twenty-six (26) participants opined that knowing one's results could improve adherence to treatment and behavioral modification.

> …*I can pick up the courage even when they tell me that I may get cancer, and, that nothing can prevent it, or that there is no treatment. I pick up the courage, knowing that I can live with such a condition until when God calls me. It is better than wasting all my savings on traditional healers or witch doctors yet their things do not work… I could use my money to take my children to better schools…* (FGD 1_Female_Participant 3)

> ….*I have been able to live for another 15 years since I started HIV treatment. If they [researchers] tell me that my genes are compatible with the medicines I take daily, that too is something good and unique about my genes. So I will be encouraged and will not stop seeking care at this clinic [IDI clinic] and will never become negligent about my life*". (FGD 4_Male_Participant 3)

Reasons for Participants' Desire to Receive Partial Results or None of the Results from Pharmacogenomics Research Analysis.—All participants who desired partial results (10) and those who did not want any results (03) indicated that they would rather not receive incidental findings or any pharmacogenomics results respectively, because the results would cause unnecessary worry to them and their family members. They opined that such results could affect them psychologically and demoralize them from living a positive life. Four participants who preferred partial results mentioned that learning about the possibility of developing a fatal disease could deplete family financial resources in search of treatment.

> *If they discover and tell me about a disease that is fatal, I will not remain the same. Let us assume they have told me that I have cancer, and that cancer I am having has no treatment. So even if they treat it, I are bound to die. Trust me I cannot remain the same. I would rather not know those incidental findings.* (FGD 1_Female_Participant 2)

> *It would be good not to inform me about harmful incidental findings because it could end up shortening my life, yet my attitude towards positive living has changed for the better over time. I used to have suicidal thoughts because of HIV until counsellors helped me out. They [researchers] would rather withhold that information.* (FGD 2_Female_Participant 6)

Six participants who preferred partial results and two participants who did not want to receive any results believed that learning about diseases or conditions that have no treatment would lead to stigmatization and discrimination by their family members and communities.

> *I have ever seen someone who was told that he has bone marrow cancer and that he was going to die in a very short time because there was no cure for that cancer. When his family members learnt about it, they abandoned him and told him that they were not going to help him, because there was no point of buying medicines for someone who is going to die very soon. He really had a painful death. That is why I don't want to know any incidental findings.* (FGD 4_Male_Participant 6)

One participant who did not want to receive any results expressed strong feelings against science predicting the future. She believed that only God knows the future and not human beings.

> *…..I don't want those results from technologies that predict my future. For me I do not believe in what human beings say about my life. I only stick to what God says about my future life, not those technologies…. (*FGD 3_Female_Participant 5)

Discussion

This study aimed to explore the factors influencing participants' preferences and reasons for the desire to receive individual results of pharmacogenomics research using a convergent parallel mixed method. Quantitative data enabled the research team to determine the factors influencing participants' preferences for individual results while the qualitative data provided an in-depth outlook of the reasons for participants' desire to receive individual results or not. Our findings suggest that nearly all (98%) participants wanted to receive their primary results of pharmacogenomics research. Over 60% wanted to receive both primary and incidental results regardless of the severity, likelihood, treatability, preventability, and onset. Several reasons for wanting to receive individual results are discussed in the proceeding sections. These reasons included participants' right to health information, seeking early treatment or considering preventive measures for possible future genetic diseases, and being able to prepare for the future. These findings are consistent with recent studies from Uganda and other countries about participants' demand for their genomics research results (Mwaka et al., 2021a; Ochieng et al., 2021a) (Bollinger et al., 2013; Boyce et al., 2019; Harris et al., 2013; Hicks et al., 2018; Shahmirzadi et al., 2014). However, a few participants did not want to receive any results due to concerns about possible psychological harm or fear of the unknown and religious beliefs.

The qualitative data presented concerns from participants about publishing research results in peer review journals rather than returning individual results from pharmacogenomics analyses. However, the primary studies (clinical trials that include pharmacogenomics) were not designed to return individual results to participants. A follow up discussion about the procedure of disseminating results from clinical trials (primary studies) was held with the two participants who were concerned about their individual results. Participants' concerns were an indicator that they did not adequately understand information about the procedure of disseminating the research findings before consenting to participation.

Recent studies have reported a poor understanding of the informed consent process for pharmacogenomics and genomics research in Uganda (Amayoa et al., 2022; Nabukenya, 2019). An inadequate understanding of pharmacogenomics research procedures makes it difficult for participants to make informed decisions when choosing the different kinds of results they would prefer to receive. Therefore, there is a need for comprehensive description of the results dissemination procedure to ensure that participants are provided with adequate and understandable information to balance their expectations.

Participants who had been receiving ART and attending the IDI clinic for between five to ten years compared to those who had received ART and attended IDI clinic for less than 5 years were more likely to prefer receiving all results for several reasons. First, the experience of living with a chronic disease for a long time has enabled them to live positively in their communities and build resilience to handle health-related challenges. They mentioned that learning about pharmacogenomics results, even if they are not treatable, would help them take preventive actions, encourage and support family members who may suffer conditions that are not treatable. Boyce and colleagues reported similar findings about participants' strong desire to receive personal genetic information for family health benefits (Boyce et al., 2019). Second, long-term adherence to ART coupled with research has improved the quality of life of people living with HIV (Moosa et al., 2019). For several decades, people living with HIV have developed confidence in researchers and clinicians to provide solutions to treatable and non-treatable health conditions, as mentioned by four participants during the dFGDs. However, there is a need to balance participants' expectations by providing adequate and accurate information about the implications of genomics research results, especially Africa, where genomics research is not well understood by many medical workers in Africa (Rutakumwa et al., 2020). Third, the IDI provides educative avenues through drama and skits, regular discussions with clinicians, counseling services, and opportunities for individuals to participate in several research activities. These activities provide participants with the necessary information to facilitate better comprehension and decision-making. In addition, these activities have supported the research teams in over-coming misconceptions about biomedical research.

Participants from religious faiths such as the Islamic, Seventh-day Adventists, and Pentecostals preferred to receive partial results. One of the participants did not want to receive any results because she believed that only God has the right to predict the future, not science. Aspects of religious beliefs in determining the kinds of genetic results participants would like to receive have also been reported in a study that examined the potential challenges to genetic screening in Africa (Jegede, 2009).

Reasons for Participant's Desire to Receive Individual Results from Pharmacogenomics Research.

Almost all participants opined that providing feedback demonstrates appreciation of their important role in the success of research studies. This is reflected in both qualitative and quantitative data. Recognizing the role of research participants involves respecting their rights, specifically, the right to know what is happening in their bodies and valuing their contribution to the advancement of science. Our findings are consistent with the views of

93 adolescents, parents, and caregivers participating in a pediatric and adolescent HIV-TB genomic study in Botswana. This study demonstrated the importance of reciprocity in decisions about the feedback of individual genetics results to participants as a sign of respect and value for their contribution to research (Ralefala et al., 2020). Providing individual pharmacogenomics research results may present an opportunity to create awareness about certain genetic conditions and allow for early initiation of treatment to save both human lives and resources. Thus, awareness is also essential for diseases prevention and improving participants' quality of life. Some participants expressed willingness to receive all results irrespective of absence of a proven treatment to avoid wasting time and resources searching for ineffective alternative treatments. They argued that knowing such information would help them prepare for eventualities, including planning for their children's future welfare. In addition, participants may use such information to build their confidence and support others with similar health conditions by promoting positive living. Participants also desired to know about available alternative treatment options that could present better outcomes compared to their current regimen. Individuals react differently to antiretroviral drugs. Therefore, if genotype analyses are performed before administering these drugs, patients will receive drugs suitable for their genetic makeup, thus reducing side effects or adverse drug reactions. Additionally, withholding health-related information, especially clinically actionable results, hinders further consultation with experts in search for better treatment or preventive measures hence deterioration of one's health.

Reasons for Participants' Desire to Receive Partial Results or None of the Results from Pharmacogenomics Research Analysis.

Participants contended that returning some results could cause unnecessary anxiety to them and their family members. For example, participants may worry about receiving results of conditions that have no available treatment for people with their genetic type or in situations where treatment is available in developed countries but not affordable by governments of developing countries, thus detoriating participants' quality of life. Participants also raised concerns about discrimination by members of their families and the wider community, especially after learning about genetic conditions that are not treatable. Similar studies have reported fears and concerns of genetic discrimination from family members, society, insurance companies, and potential employers (Fulda & Lykens, 2006; Wauters & Van Hoyweghen, 2016). In addition, as mentioned by one of the participants, individuals suffering from a genetic disease that have no proven treatment may suffer stigmatization from their family members for fear of depleting their financial resources. Therefore, these results should be treated with utmost confidentiality to avoid stigmatization and discriminations of participants and their families. Lastly, the possibility of misinterpreting the meaning of genomics findings, especially incidental findings, may hinder participants from wanting to receive their results. Pharmacogenomics and genomics studies are relatively new in the Ugandan population and require a certain level of education for an adequate understanding of complex genomics terms and concepts. More than half of our study population had none or attained only primary education. Studies show that low levels of formal education among our participants, coupled with limited exposure to genetic education among medical practitioners (Faure et al., 2019; Matshabane et al., 2020) (Rutakumwa et al., 2020) make full understanding of implications of genomics results quite difficult.

Therefore, researchers should devise appropriate and creative ways of communicating pharmacogenomics research information and results.

The study's main weakness was the recruitment of research participants from a single institution due to limited funds and time constraints. However, participants were recruited from five ongoing clinical trials that included pharmacogenomics with varying experiences in HIV treatment and pharmacogenomics research. This gave the investigators an opportunity to gain insights from participants about the kinds of results they would wish to receive and the reasons for their preferences. In addition, the 5-point Likert scale might not have measured all the opinions about the different reasons for their desire to receive individual results or not. However, the dFGDs provided an opportunity to identify additional opinions about reasons for participant' desire to receive results or not.

Conclusion

Overall, findings from our study suggest that people living with HIV want to receive their individual results of pharmacogenomics research for various reasons, as discussed above. However, there is a need to openly and swiftly address whether all individual research results, including results of conditions with no proven treatment, should be returned to participants. In addition, there is a need to devise creative ways of communicating accurate and understandable information about pharmacogenomics research and the implications of its results before soliciting their preferences on the different results for effective management of their expectations. Lastly, we hope our findings will contribute to developing institutional and national guidelines for returning individual pharmacogenomics research results to people living with HIV.

Best Practices

This mixed-method study allowed us to expound and understand the reasons for the high demand for individual pharmacogenomics research results among people living with HIV. A few participants are afraid of receiving their results. At the same time, a number of them (66%) want to receive all results, including those that are not actionable, which is not recommended by most international guidelines for returning individual genetics research results to participants. Results from genomics analyses have ethical, legal, and social implications that may affect the research participant and extend to family members and their communities. Therefore, there is a need for community sensitization and education on the different types of genetic results and the merits and demerits of returning the results. There is a need for genetic counseling to ensure an adequate understanding of the implications of these results. In addition, the research team should re-consent before returning their results, especially those who do not want to receive clinically significant and actionable results.

Research Agenda

Pharmacogenomics research is leading the way to the future of personalized medicines that will be very useful to sub-Saharan Africa experiencing a high disease burden. Therefore, returning such results to participants, especially people living with HIV will improve their quality of life. However, research participants need to clearly understand the implications

of receiving the different categories of results from pharmacogenomics analyses. Incidental findings can present information about conditions whose certainty (likelihood), actionability, and onset may not be well defined. Therefore, future research is needed to explore strategies that can enhance participants' understanding of the implications of these results before soliciting the different results they desire to receive. In addition, further research is necessary to explore culturally appropriate approaches that can be used to educate, explain genomics terms and assess participants' understanding of the implications of pharmacogenomics results.

Educational Implications

Engaging and educating communities about genomics and genetics research through campaigns, public talk shows, and media may increase awareness of genomics research hence improving research participants' comprehension. We recommend formative research about public engagement approaches that can be used to enhance comprehension of genomics research. Furthermore, research institutions should train more genetic counselors to convey easily understood genetic-related information.

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Biographies

Sylvia Nabukenya (SN) is the Regulatory and monitoring officer at the Infectious Diseases Institute (IDI). She is a young researcher and currently pursuing her Ph.D in Bioethics. Her interests are ethical, legal, and social issues (ELSI) in genomics and genetics research; specifically, the informed consent process, return of results from genomics analyses, community engagement, and benefit sharing.

Catriona Waitt (CW) is a clinical pharmacologist from the University of Liverpool. Her research interests are the dosing and safety of drugs in special populations who cannot be easily studied in conventional clinical trials, including pregnant and breastfeeding women and their infants, children and adolescents, patients with severe intercurrent illnesses.

Ronald Ssenyonga (RS) is a Biostatistician and data analyst at the School of Public Health, Makerere University. His interests are quantitative research methods, clinical epidemiology and biostatistics.

Barbara Castelnuovo (BC) is the head of the Research Program at the Infectious Diseases Institute (IDI). Her research interest are in outcomes of people living with HIV and in research capacity building. She is the Secretary of the Institutional research ethics committee

Ian Munabi (IM) is a Lecturer in the Department of Human Anatomy and a faculty member of the postgraduate bioethics training programs at Makerere University. His research interests are medical education, research ethics and human anatomy.

David Kyaddondo (DK) is a social scientist and a medical Anthropologist. He is a researcher affiliated with Child Health and Development Centre, Makerere University and a Senior Lecturer Makerere University, Department of Social Work and Social Administration. His interests are qualitative research methods, medical anthropology and social development.

Erisa Sabakaki Mwaka (ESM) is an orthopaedic surgeon, Associate Professor of Human Anatomy and bioethicist with research interest in the ethical, legal and social implications of bio-banking and genetic research. He chairs a research ethics committee and is a faculty member to the postgraduate bioethics training programs at Makerere University.

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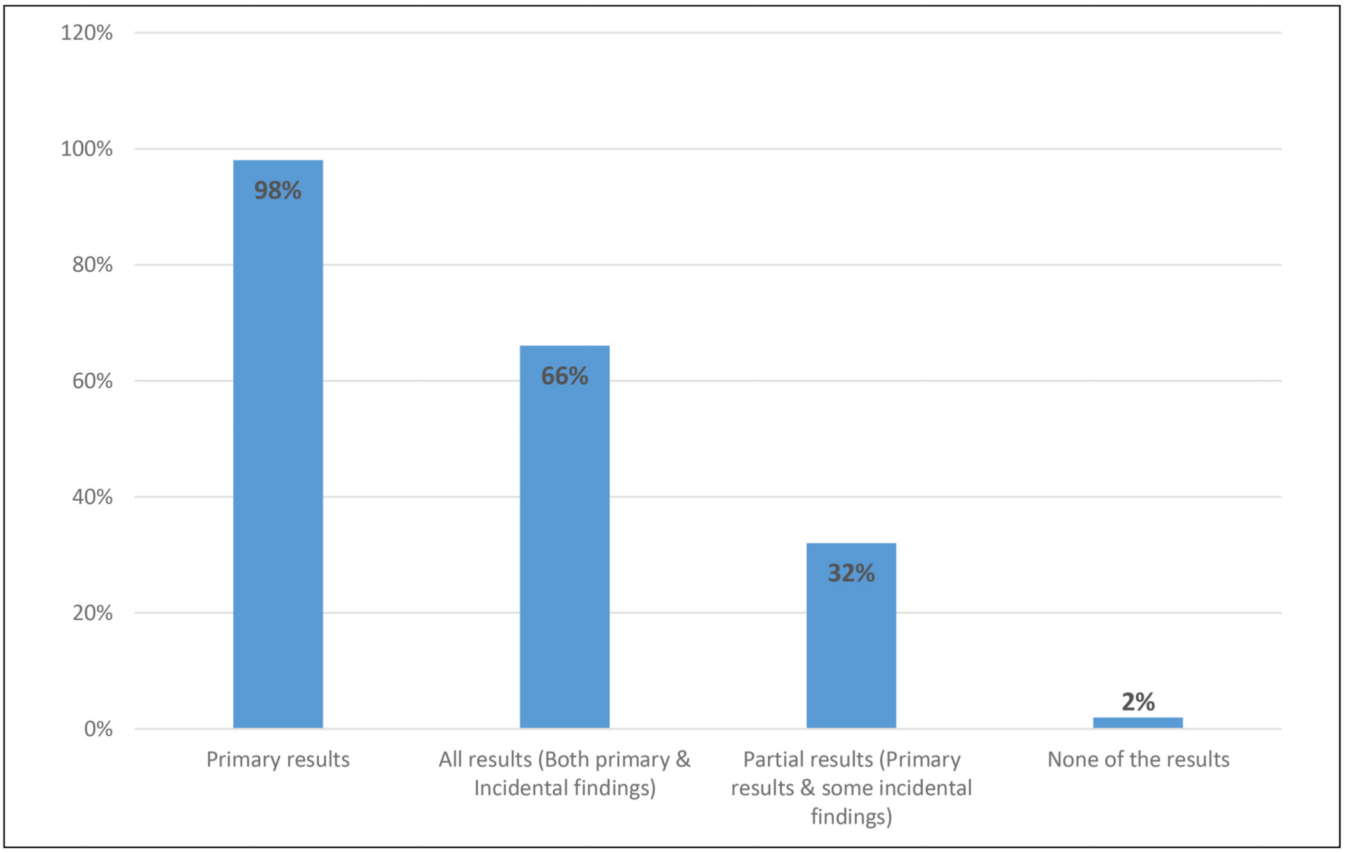

Figure 1.
Participants' preferences for individual pharmacogenomics research results.

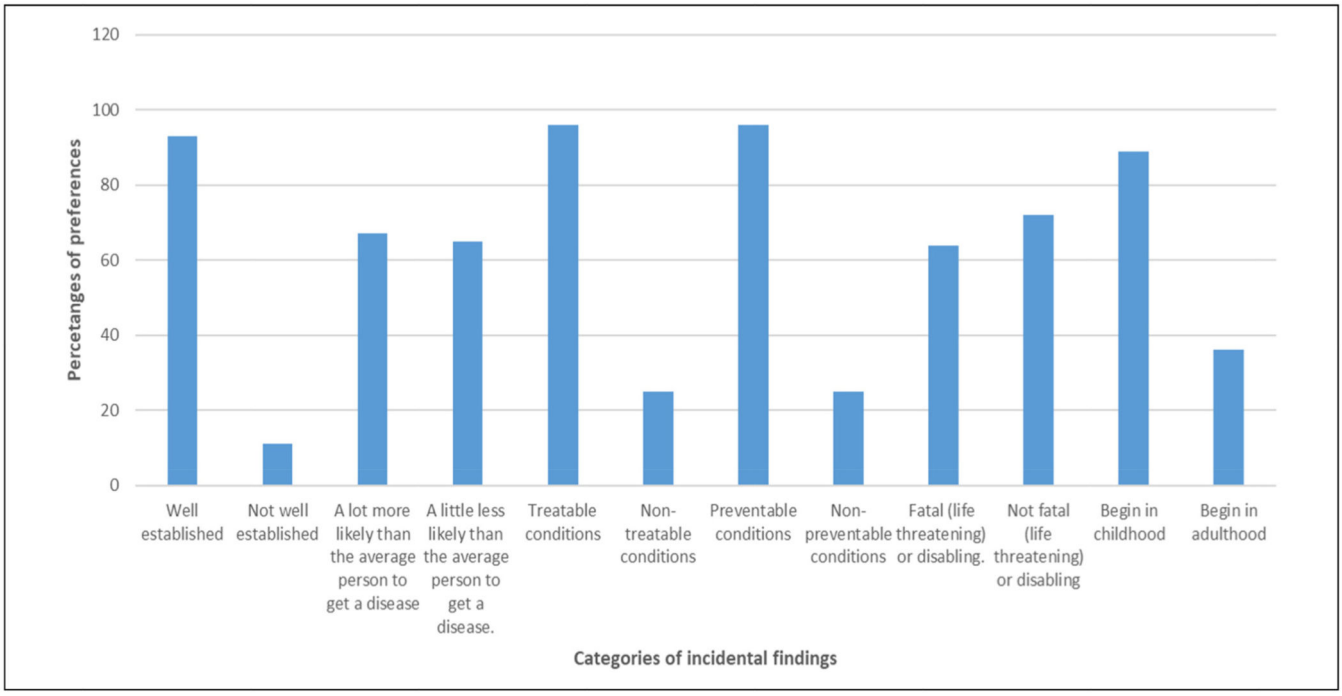

Figure 2.
Categories of incidental findings from pharmacogenomics research (N = 72).

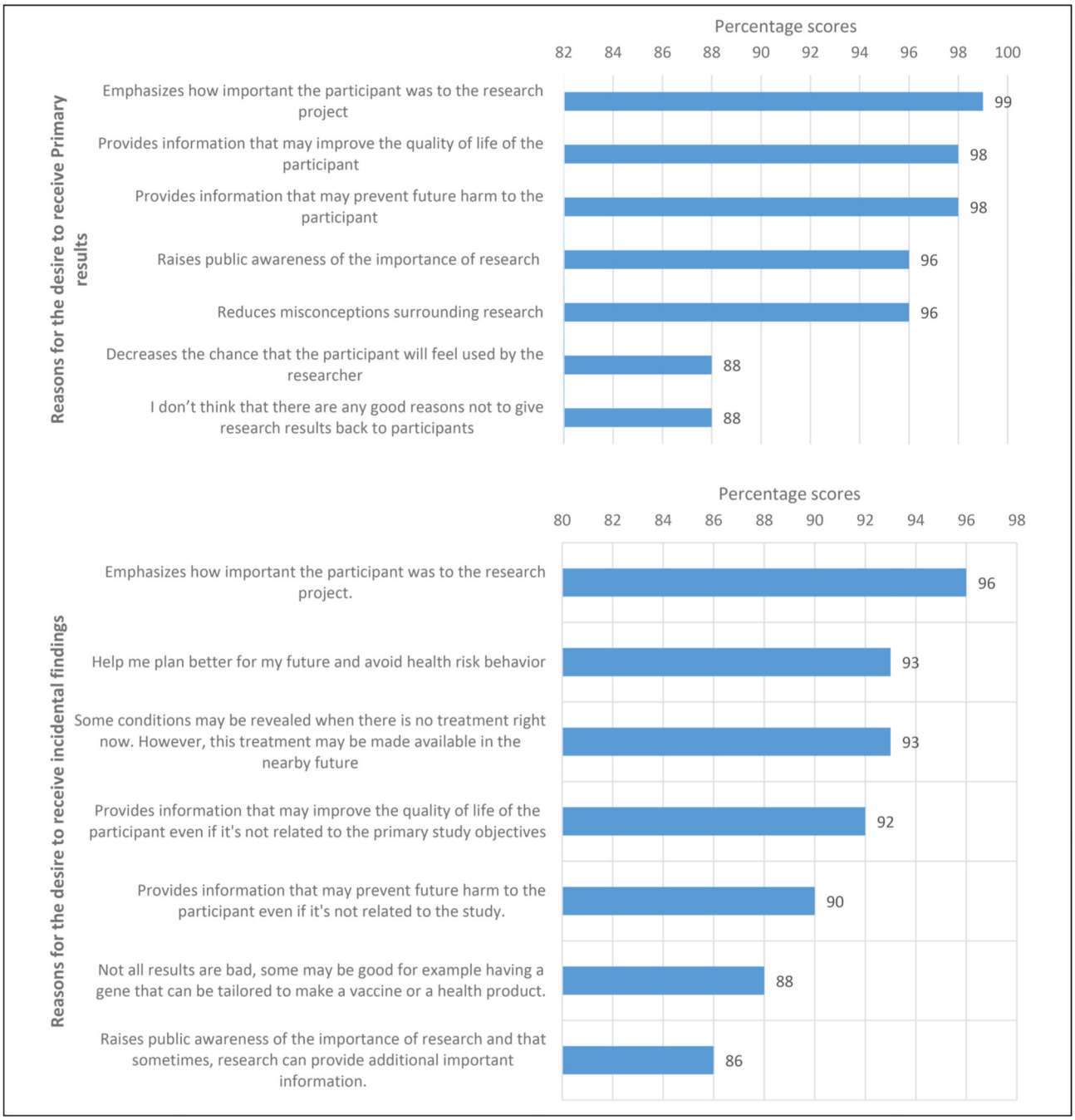

Figure 3.
Participants' reasons for the desire to receive primary results and incidental findings.

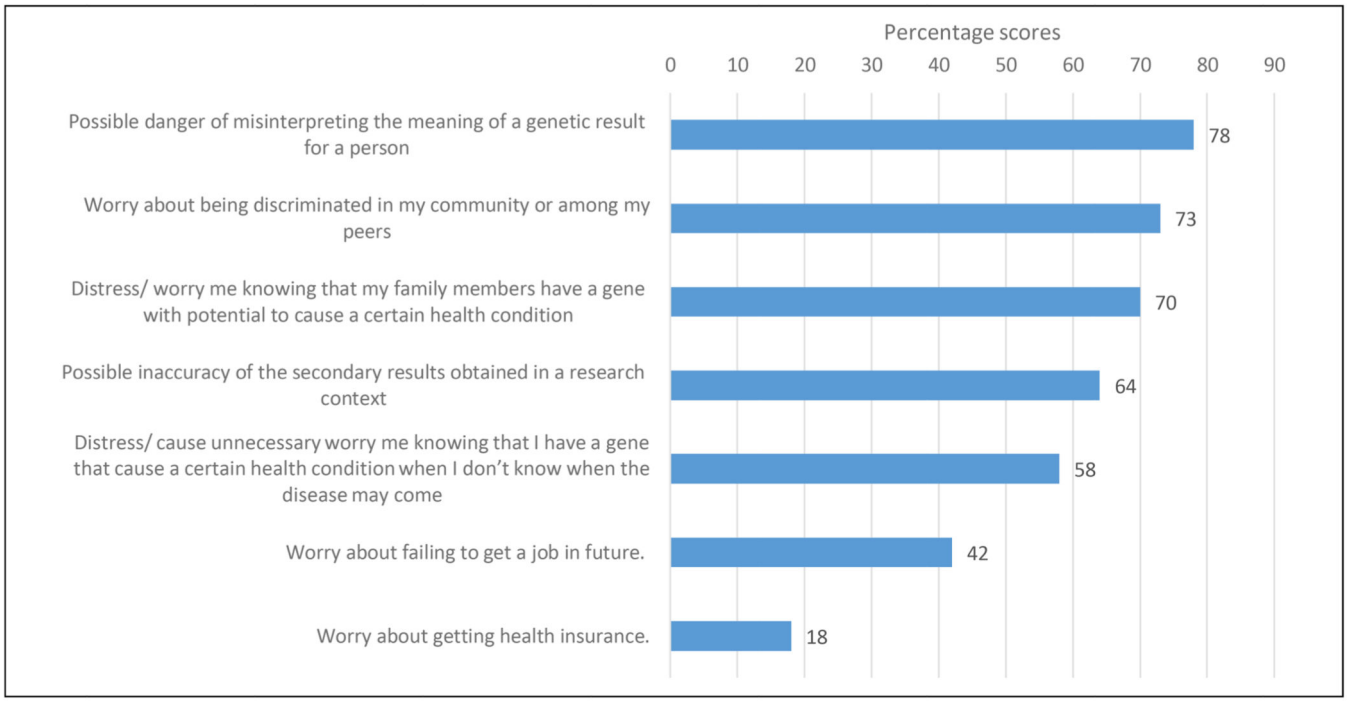

Figure 4.
Participants reasons for receiving partial results or none of the results.

Table 1.

The Five on-Going Clinical Trials That Included Pharmacogenomics.

Title of the study	Study objective
S001 - Evaluation of the pharmacokinetics of Anti-tuberculosis drugs and Tuberculosis treatment outcomes in HIV Tuberculosis Co-infected Ugandan adults	To assess the influence of single-nucleotide polymorphisms (SNPs) in genes encoding for proteins involved in antitubercular drug disposition or effect.
S002 - A Pharmacokinetic Evaluation of Etonogestrel Implant Versus Darunavir-Based Or Rilpivirine-Based Antiretroviral Therapy In HIV-Infected Ugandan Women	To describe the relationship between Etonogestrel concentrations and participant specific covariates including body weight, albumin, sex-hormone binding globulin and pharmacogenetic factors.
S003 - A Pharmacokinetic Evaluation of Levonorgestrel Implant Versus Darunavir-Based Or Rilpivirine-Based Antiretroviral Therapy In HIV-Infected Ugandan Women	To describe the relationship between Levonorgestrel concentrations and participant specific covariates including body weight, albumin, sex-hormone binding globulin and pharmacogenetic factors.
S004 - A randomized four -arm open label phase IIb clinical trial to evaluate the pharmacokinetics, safety/tolerability and efficacy of high dose Rifampicin in TB/HIV co infected patients on Efavirenz or dolutegravir based antiretroviral therapy.	To investigate the safety/tolerability of a high dose of rifampicin in TB-HIV co-infected patients on TB treatment and first-line antiretroviral therapies.
S005 A phase II trial to describe the pharmacokinetics, safety and efficacy of pharmacogenetics guided dosing of isoniazid in patients with HIV-associated TB.	To investigate the safety and pharmacokinetics of isoniazid, given at a higher dose (10mg/kg) among patients with fast or intermediate NAT2 acetylator status and a standard dose (5mg/kg) among patients with slow NAT2 acetylator status, among patients with HIV and drug sensitive TB.

Table 2.

Participants' Representation from the Five Ongoing Clinical Trials That Included Pharmacogenomics.

Study No	No. of participants recruited (x)	Study Percentage of total number (x/T*100%= y)	Estimate sample size (y*a)	Expected sample size
S001	106	106/396*100 = 27%	0.27*231	62
S002	60	60/396*100 = 15%	0.15*231	35
S003	60	60/396*100 = 15%	0.15*231	35
S004	130	130/396*100 = 33%	0.33*231	76
S005	40	40/396*100 = 10%	0.10*231	23
TOTAL	**396**	**100%**		**231**

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Table 3.

Distribution of Participants' Characteristics from the Survey (N = 225).

	Frequency (n)	Percentage (%)
Age group in years		
Less than 36 years	87	38.7
36 + years	138	61.3
Sex		
Male	90	40.0
Female	135	60.0
Level of education		
None and Primary	114	50.7
Post primary *	111	49.3
Marital status		
Not married	114	50.7
Married/living with partner	111	49.3
Occupation		
Professional employment	31	13.8
Self-employment	162	72.0
Unemployed	32	14.2
Monthly income		
Less than 500,000	161	71.6
More than 500,000	64	28.4
Religion		
Anglican/ Protestant	72	32.0
Catholic	80	35.6
Others **	73	32.4
Type of family		
Nuclear family (husband or wife and children)	146	64.9
Extended family	79	35.1
Duration of ART		
Below 5 years	67	29.8
5–10 years	110	48.9
More than 10 years	48	21.3
Duration at the IDI clinic		
Below 5 years	80	35.6
5–10 years	90	40.0
More than 10 years	55	24.4
Number of research studies ever participated		
2 studies	91	40.4
3 studies	87	38.7
4 studies and above	47	20.9

	Frequency (n)	Percentage (%)
Stage of study activities		
On going	75	33.3
Completed study activities	150	66.7
	Median	**IQR**
Age in years	38	33–42

*Secondary [87], tertiary [24].

**Islamic faith, Seventh day Adventists and Pentecostal.

Table 4.

Factors Associated with Participants' Preferences for Individual Pharmacogenomics Research Results Using a Modified Poisson Model.

	Unadjusted		Adjusted	
Characteristics	**Prevalence Ratio (95% CI)**	**P-value**	**Prevalence Ratio (95% CI)**	**P-value**
Sex				
Male	1		–	
Female	0.99 (0.82,1.19)	0.92		
Age group				
Less than 36 years	1		1	
36 + years	1.13 (0.93,1.380)	0.22	1.07 (0.86,1.3)	0.524
Level of education				
None and Primary	1			
Post Primary *	0.92 (0.76,1.10)	0.366	–	
Marital status				
Not married	1		–	
Married	1.0 (0.84,1.21)	0.958		
Occupation				
Professional employment	1		1	
Self-employment	1.3 (0.92,1.85)	0.142	1.26 (0.89,1.77)	0.187
Unemployed	1.33 (0.89,1.99)	0.166	1.25 (0.84,1.87)	0.273
Monthly income				
Less than 500,000	1			
More than 500,000	1.06 (0.83,1.34)	0.645	–	
Religion				
Anglican/Protestant	1		1	
Catholic	1 (0.82,1.22)	0.97	1.022 (0.84,1.23)	0.87
Others **	0.78 (0.61,1.01)	0.057	**0.76 (0.59,0.98)**	**0.036**
Type of family				
Nuclear family	1		-	
Extended family	1.08 (0.9,1.31)	0.393	-	
Duration on ART				

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	Unadjusted		Adjusted	
Characteristics	**Prevalence Ratio (95% CI)**	**P-value**	**Prevalence Ratio (95% CI)**	**P-value**
Below 5 years	1		1	
5–10 years	1.42 (1.09,1.84)	0.008	**1.69 (1.23,2.34)**	**0.001**
More than 10 years	1.38 (1.03,1.85)	0.03	1.91 (1.22,3.01)	0.075
Duration at the IDI clinic?				
Below 5 years	1		1	
5–10 years	1.203 (0.96,1.51)	0.107	**1.19 (0.96,4.49)**	**0.045**
More than 10 years	1.19 (0.93,1.52)	0.179	1.21 (0.94,1.57)	0.075
Number of research studies ever participated.				
2 studies	1		1	
3 studies	1.26 (1.02,1.56)	0.035	0.74 (0.55,0.99)	0.11
4 + studies	1.19 (0.92,1.53)	0.186	0.70 (0.48,1.04)	0.145
Stage of study activities				
On going	1		–	
Completed study activities	1.14 (0.92,1.41)	0.221		

*Secondary [87], tertiary [24].

**Islamic faith, Seventh day Adventists and Pentecostal.

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Table 5.

Demographic characteristics of interviewees (N = 30).

Characteristics	Frequency (n)	Percentage (%)
Gender		
Male	12	40
Female	18	60
Age		
< 35 years	17	56.7
> 35 years	13	43.3
Level of education		
Primary	18	60.0
Secondary	08	26.7
Tertiary	02	6.6
None	02	6.6
Marital Status		
Single	08	26.7
Married	12	60.0
Widowed	03	10.0
Separated/Divorced	07	23.3
Occupation		
Professional	02	6.6
Self-employed	20	66.7
Unemployed	08	26.7
Religion		
Anglican/Protestants	12	40.0
Catholic	08	26.7
Moslems	06	20.0
Other	04	13.3