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Decision-making and role preferences for receiving individual pharmacogenomic research results among participants at a Ugandan HIV research institute

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Abstract

Little is known about how people living with HIV should be engaged in the decision-making process for returning individual pharmacogenomic research results. This study explored the role people living with HIV want to play in making decisions about whether and how individual results of pharmacogenomic research should be presented to them. A convergent parallel mixed methods study was conducted, comprising a survey of 221 research participants and five deliberative focus group discussions with 30 purposively selected research participants. Most participants (122, 55.2%) preferred the collaborative role, 67 (30.3%) preferred the active role and 32 (14.5%) preferred the passive role. Factors that significantly influenced preference for an active role compared with a collaborative role were marital status (OR: 0.282, $p=0.013$), research experience (OR: 4.37, $p=0.028$), and religion (OR: 2.346, $p=0.041$). The reasons proffered for the active role included prior experience with antiretroviral treatment and increased exposure to research activities. The reasons given for preferring the passive role included limited level of awareness about the interaction between patients' genes and drugs, trust in researchers to make the right decision, and fear of making decisions with harmful implications. Overall, findings from our study show that participants want to be engaged in the decision-making process. Research teams ought to provide adequate and simple information about the pharmacogenomic research and implications of the results to support participants' informed decisions.

Keywords Decision-making, Role preferences, Pharmacogenomics, Individual research results, People living with HIV

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Introduction

The global call for precision medicine has made pharmacogenomic studies increasingly common [1]. Pharmacogenomics research involves studying how an individual's genes influence response to a given medication specifically, the drug efficacy, adverse events, and dosing requirements [2]. Pharmacogenomic research has shown promise in determining the appropriate dosage of antiretroviral drugs for certain populations of people living with HIV (PLHIV) [3] and understanding the influence of single-nucleotide polymorphisms (SNPs) in the gene encoding for proteins in drug disposition for patients co-infected with HIV/AIDS and other infectious diseases such as tuberculosis [4]. However, pharmacogenomic test results may reveal more sensitive information beyond the research question. People living with HIV suffer social exclusion [5], reduced chances of finding a marriage partner [6], and fear of abandonment, divorce and domestic violence [7, 8]. Any of these scenarios may present ethical dilemmas on how to share and communicate results to the affected individuals. Prior studies in sub-Saharan Africa (SSA) show that the majority of PLHIV want to receive their individual pharmacogenomics results including those that may not be actionable [9, 10]. However, deciding which results should be shared with participants is quite complicated given the ethical, legal, and social issues (ELSI) that could arise from these results. Of concern, the scientific community and bioethicists have raised issues about risks of stigmatization, discrimination, the possibility of misinterpreting these results due to the complex nature of describing genetic terms, and unnecessary anxiety to the participants [11, 12]. These ethical issues do not only affect participants but can be extended to family members since genes are shared across generations. The Uganda national research ethics guidelines recommend appropriate return of results to research participants, key stakeholders, and communities. The guidelines also require researchers to be sensitive about the ethical implications of the research results and take appropriate measures to protect the research participants and their communities [13]. However, the national guidelines do not address how the decision-making process should be conducted. Thus, it is important to understand the role(s) PLHIV want to play in decision-making on whether and how individual pharmacogenomic research results should be returned to them. In making such decisions, participants may prefer different levels of participation. Some participants might prefer to make decisions on their own (active role), some might prefer the researcher to make the decision (passive role), while others might prefer shared decision-making with the researcher (collaborative role) [14]. Involving participants in decision-making promotes understanding of the available medical evidence while the providers appreciate the participants' needs, values and preferences regarding the decisions [15]. Thus, minimizing the possibilities of misinterpreting and unnecessary anxiety among research participants.

Several factors such as age, gender, level of education, socio-economic status, type of disease, cultural and religious beliefs influence participants' decision making in research settings [16, 17]. When it comes to pharmacogenomics research for HIV treatment, there is very little known about how PLHIV want to engage in the process of deciding the kinds of results they would like to receive. Given the ethical and social issues mentioned above, decision making on the kind of results to be returned to participants should be made after adequate understanding of the implications of those results at individual and society levels. Whereas PLHIV have been exposed to information through government and non-government organizations' initiatives on how HIV/AIDS is spread, treated, or prevented especially to unborn children, information about how genes interact with antiretroviral treatment (ART) is still new in the Uganda setting. To better understand what role PLHIV want to play in making decisions about whether and how individual results of pharmacogenomic research should be fed back to them, we conducted a survey and focus group discussions with PLHIV who have been enrolled in five ongoing clinical trials with a pharmacogenomic component.

Methods

Study design and setting

A convergent parallel mixed methods study was conducted at the infectious Diseases Institute (IDI), a research institution affiliated to the College of Health Sciences, Makerere University in Kampala, Uganda. We conducted a cross-sectional survey and deliberative focus group discussions (dFGDs) among PLHIV who were currently enrolled in five on-going clinical trials with a pharmacogenomic component between May 2021 and February 2022.

Recruitment and data collection procedures

For this study, we approached PLHIV who were at least 18 years and able to speak English or Luganda (the most commonly spoken local language around Kampala City). The survey and dFGDs were conducted concurrently. To estimate the sample size for the survey, we aimed to achieve a precision of 5%. A total of 231 respondents were estimated using the Yamen (1967) sample size calculation. Using sampling proportionate to size of the clinical trials with the pharmacogenomic component, we enrolled respondents from each trial to achieve the calculated sample size. Participants were randomly selected from each trial and invited to participate in this study.

Collection of Survey Data

Survey data were collected using an interviewer-assisted structured questionnaire with closed ended questions that was developed from the literature [14, 16, 17]. Depending on the participants' preference, the questionnaire was administered in either English or Luganda. A brief overview of how genes interact with antiretroviral (ARV) drugs was provided to each research participant during the informed consent process. The questionnaire comprised of questions on socio-demographic characteristics, clinical history, and participants' preferred role in decision-making. 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. On average, questionnaire administration took approximately 10–20 min.

Focus Group Discussions

Thirty individuals were purposively selected from the survey participants, to participate in five deliberative focus group discussions (dFGDs) based on their preferred role in decision making and the primary study (clinical trial with a pharmacogenomic component) for fair representation. Each dFGDs comprised of six participants segregated by sex and age. The dFGDs provided an opportunity to educate participants about the topic of interest prior to the focus group discussion to promote more quality data from informed opinions [18]. 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 the possible individual results that could culminate from pharmacogenomic research; and these were categorized into primary and incidental findings. Prior information aimed to help 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 for their preferred role in decision making. The interview guide was informed by literature on the return of individual genetics and genomic results to participants [11, 17, 19–21]. The tool was first piloted on five volunteers who were later excluded from the study. 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 and 90 min. Deliberative FGDs were conducted until when no new insights were obtained.

Data analysis and integration

Quantitative and qualitative data were analyzed separately and later triangulation was done as described below [22].

Quantitatively, data from the survey were captured electronically using EPI DATA Version 3.02 and later exported to STATA version 14 for analysis. The study outcome was categorized into preferences for either the "Active role", "Collaborative role" or "Passive role". The independent variables included demographic characteristics such as age, sex, education level, employment status, religion, and type of family, and clinical history. Data were summarized using descriptive statistics. Categorical variables were summarized using frequencies (percentages). We then fitted the data using a multinomial logistic regression model since the outcome had three non-ordered categories (Active, passive and collaborative). The collaborative role was selected as the reference for each outcome since it was the most frequently occurring category. The statistical significance was assessed at $p < 0.05$.

Qualitative data was collected and analysed following the consolidated criteria for reporting qualitative research (COREQ) [23]. All audio recorded interviews were transcribed verbatim and translated into English. The transcripts 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 [24] 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). We then deductively generated themes using our pre-existing analytic framework, which we developed from the literature on participants' reasons for their preferred roles in decision-making, as represented in the interview guides. We also inductively considered new themes that merged from the transcripts. Three authors DK, BM and CW examined the themes for patterns consistency until consensus was achieved on the final themes. All the authors compared the emergent themes with the existing literature to confirm that the final themes accurately represented the participants' preferred roles in decision-making. We also returned some transcripts to the participants to verify whether the data collected was a true reflection of their statements on the subject matter.

> *We then did triangulation by comparing and integrating the findings from the qualitative data with the quantitative results as presented in the discussion [25]. The integration of both datasets allowed*

us to interpret the participants' key factors influencing their preferred roles in decision-making.

Results

Results of quantitative data

Demographic characteristics of participants

Out of the 231 participants contacted, 221 respondents were enrolled in the survey, 10 individuals declined participation. Table 1 presents a descriptive summary of the participants' demographic characteristics and research experience. The majority were female (60%), with a median age of 36 years [range 31–42]. More than half of the participants 123/221 (55.7%) had at least attained secondary level education, 160/221 (72.4%) were self-employed, 180/221 (81.4%) had monthly earnings of less than 500,000 UGX (approximately 130 USD), and 132/221 (59.7%) had participated in three or more research studies.

Participants' preferred role in decision making for receipt of individual pharmacogenomic research results

Slightly more than half of the participants (122–221, 55.2%) preferred the collaborative role, 67/221 (30.3%) preferred the active role, and 32/221 (14.5%) preferred the passive role (Fig. 1). The collaborative role referred to the process in which the participant and the researcher each contribute to the final decision. The active role referred to when the participant preferred to make a decision solely, and the passive role referred to when the participant preferred the researcher to make the decision on their behalf.

Factors associated with participants' preferred role in decision making for receipt of individual pharmacogenomics research results

At multivariate analysis, only religion, marital status and research experience significantly influenced the participants' decision-making role preference for receiving individual pharmacogenomics research results, as shown in Table 2. The factors associated with preference for an active role compared with a collaborative role were marital status (OR: 0.282, $p = 0.013$), research experience (OR: 4.37, $p = 0.028$) and religion (OR: 2.346, $p = 0.041$). Divorced participants were less likely to prefer the active role than the collaborative role when compared to the married participants. Participants with a research experience of more than 5 studies were 4.37 times more likely to prefer the active role than the collaborative role when compared to those with research experience of 2 years or less. Participants with a research experience of more than 5 studies were 3.66 times more likely to prefer the passive role than the collaborative role when compared to those with research experience of 2 years or less. However, this was not statistically significant (OR: 3.66, $p = 0.076$). Participants belonging to the catholic religion compared to other religions were 2.35 times more likely to prefer an active role than the collaborative role. All the above differences were significant as shown in Table 2.

Results of qualitative data

Thirty individuals who had participated in the survey were invited and enrolled in five deliberative focus group discussions (dFGDs). Table 3 describes their demographic characteristics of the interviewees. The majority (60%) of the participants 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.

Factors influencing participants' role preferences

There were five factors that influenced the participants' preferred role in decision-making for receipt of individual pharmacogenomic results.

I. Prior experience with antiretroviral treatment and research.
II. Participants trust researchers to make the right decisions.
III. Level of awareness about the interaction between genetics and drugs.
IV. Fear of making decisions with harmful implications.
V. Additional support is required for participants' decision-making to receive their results.

Prior experience with antiretroviral treatment and research

Having been on ART for several years, participants who preferred an active role in decision-making indicated they were able to learn a lot about how HIV is spread, treated, and prevented. Therefore, they believed that they were well positioned to decide on their own what results they would like to receive.

> *I have been in this clinic for so long, more than 10 years now. I have learnt so much about how HIV can be spread and how to treat it..., and I feel very empowered to make decisions on my own. I just need to receive information from the research nurse and then I decide on my own or even read more about the research on my own.... (FGD_2_participant_4)*

Another participant who preferred the active role indicated that participation in several research studies had exposed him to a lot of information, hence building confidence in making his own decisions.

> *I have been part of several research studies which has improved my health and also made me learn a lot.... Right now, if I was asked the role I would like*

Table 1 Distribution of participants' characteristics from the Survey ($N = 221$)

Characteristic	Frequency	Percentage (%)
Age group		
21–35	85	38.46
36–51	123	55.66
> 52	13	5.88
Sex		
Male	88	39.82
Female	133	60.18
Level of Education		
Primary	98	44.34
Secondary	85	38.46
Tertiary	15	6.79
University	9	4.07
Others	14	6.37
Marital status		
Single	35	15.84
Married	110	49.77
Separated/Divorced	76	34.39
Occupation		
Professional employment	31	14.03
self employed	160	72.4
Unemployed	30	13.57
Monthly Income		
Less than or equal to 100,000	44	20.09
> 100,000 to less than or equal to 500,000	135	61.64
> 500,000 to less than or equal to 1,000,000	35	15.98
> 1,000,000	5	2.28
Religion		
Anglican	71	32.13
Catholic	78	35.29
Moslem	49	22.17
*Others	23	10.41
Type of family		
Nuclear	143	64.71
Extended	78	35.29
Duration on ART		
1 to 2	43	19.46
3 to 4	22	9.95
5 to 6	37	16.74
7 to 10	71	32.13
> 10	48	21.72
Duration at the IDI clinic		
1 to 2	66	29.86
3 to 4	12	5.43
5 to 6	22	9.95
7 to 10	66	29.86
> 10	55	24.89
Research Experience		
2 studies	89	40.27
3 studies	87	39.37
4 studies	29	13.12
> 5	16	7.24
Stage of study activities		
Just been enrolled	10	4.52

Table 1 (continued)

Characteristic	Frequency	Percentage (%)
study follow up	66	29.86
completed study activities	145	65.61

*Other–Seventh day adventists, muslims and pentecostal

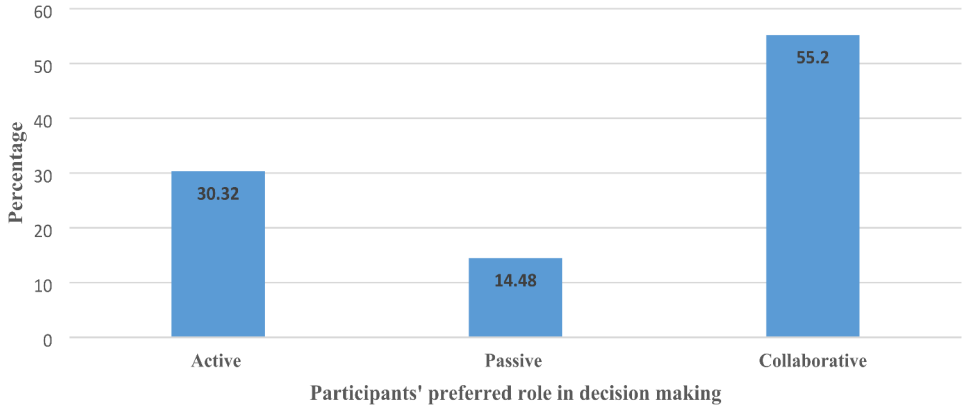

Fig. 1 Participants' preferred role in decision-making for receipt of individual pharmacogenomic results

to play in making decisions, I would go for the active role. I am now confident in myself and trust my decisions… (FGD_5_Participant_2).

On the other hand, some participants who preferred a collaborative role felt that, despite having been on ART or being part of research studies for several years, they were not used to making health decisions solely. They preferred being part of the decision-making process with guidance from the research team.

For me as individual, I have received a lot of information about HIV/AIDS and other health information from many studies where I have been a participant, but I just can't make the decision about my health alone. I prefer to listen to the researcher or health worker and we decide together (FGD_4_Participant_1).

One participant who preferred a passive role felt he was not confident enough to make individual decisions on health matters because he had been on ART for a relatively short time.

This is my second year since I started taking ARVs. I am still learning so many things about this disease (HIV/AIDS).... and so, I prefer the researcher to make the decisions…after all, I learned about my HIV status through research… (FGD_4_Participant_3).

Participants trust researchers to make the right decisions

Many participants who preferred a passive role believed that researchers were more knowledgeable and trusted them to make the right decision regarding feedback on their pharmacogenomic results.

All my life, I have respected what the researchers and other doctors say because I am very certain that their intentions are always good for me. Before I joined the […] clinic, I was on my death-bed. HIV/AIDS was going to kill me. But I joined the […] clinic through a study where I received a lot of care and support. Those research nurses really gave me a second chance to live, so I prefer the researcher to make the decision for me.... (FGD_4_participant_4)

Another participant who preferred a passive role perceived professional researchers as gifted by God to improve people's health and that their decisions should be respected.

For me I honour and respect the researchers' decisions they make for me. These people [researchers] were gifted with knowledge from God to find ways of making our health is in good shape.... so I want the researcher to decide for me the results that I should receive… (FGD_1_Participant_3).

Other participants who preferred the collaborative and active roles mentioned that despite their trust in researchers to make the right decisions, they too should have a contribution to the overall discussion on what results they would like to receive.

Table 2 Factors associated with participants' preferred role in decision making for receipt of individual pharmacogenomic research results

Preferred role (Collaborative role as reference)	**Active role**		**Passive role**	
Bivariate Analysis	**OR (95% CI)**	***P*-value**	**OR (95% CI)**	***P*-value**
Age group				
36–51	0.2778	0.385	0.591	0.182
52+	0.3677	0.5955	1.061	0.181
Sex				
female	-0.422	0.171	-0.193	0.635
Level of education				
secondary	0.675	0.842	-1.268	0.763
tertiary	0.503	0.934	-1.059	0.331
university	0.639	0.391	-0.249	0.829
other	-0.279	0.661	-14.234	0.984
Marital status				
Living with a partner	-0.377	0.372	-0.292	0.622
Living alone	-0.862	0.063	-0.1	0.867
Occupation				
self employed	-0.059	0.889	0.66	0.32
unemployed	-0.908	0.13	-1.4	0.242
Religion				
catholic	0.43	0.254	-0.622	0.895
Muslim	0.021	0.962	-0.192	0.718
others	0.371	0.507	-0.476	0.569
Type of family				
Extended	0.299	0.344	0.376	0.358
Duration on ART				
3 to 4	0.208	0.716	-1.33	0.234
5 to 6	-0.044	0.93	-0.804	0.283
7 to 10	0.2	0.652	0.213	0.691
> 10	0.074	0.878	0.534	0.928
Duration at IDI				
3 to 4	0.263	0.701	-0.178	0.876
5 to 6	0.718	0.183	0.563	0.467
7 to 10	0.293	0.464	0.726	0.17
> 10	0.195	0.643	0.563	0.313
Stage of study activities				
study follow up	0.2	0.791	0.288	0.802
completed study activities	0.0489	0.947	0.545	0.622
Monthly income				
> 100,000-=<~000	0.258	0.542	-0.565	0.218
> 500,000-=<~000	0.57	0.269	-1.376	0.099
>1,000,000	0.182	0.881	0.875	0.413
Research experience				
3 studies	0.763	0.039	0.239	0.596
4 studies	2.28	0	1.066	0.129
> 5 studies	1.338	0.037	1.221	0.089
Multivariate Analysis	**Active role**		**Passive role**	
Marital Status	**OR**	**P-value**	**OR**	**P-value**
Living with a partner	0.592	0.252	0.685	0.531
Living alone	0.282	**0.013**	0.812	0.735
Research Experience				
3 studies	2.43	**0.022**	1.265	0.606
4 studies	15.574	0	3.013	0.127
> 5 studies	4.37	**0.028**	3.66	0.076

Table 2 (continued)

Preferred role (Collaborative role as reference)	Active role		Passive role	
Bivariate Analysis	**OR (95% CI)**	***P*-value**	**OR (95% CI)**	***P*-value**
Religion				
catholic	2.346	**0.041**	1.008	0.986
Muslim	0.957	0.928	0.8	0.682
*other	2.21	0.203	0.738	0.721

* Other–Seventh day Adventists, Muslims and Pentecostal, OR stands for odds ratios

Table 3 Demographic characteristics of interviewees (*N* = 30)

Characteristics	Frequency (*n*)	Percentage (%)
Sex		
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

I appreciate all the good things that researchers do for us. They have brought us from so far. I didn't look like this five years ago. But I also want to be involved in making the decisions regarding my health... (FGD_1_Participant_1).

Level of awareness about the interaction between genetics and drugs

Some participants who chose a collaborative role mentioned that they were not sure whether their level of awareness about how genes interact with drugs would enable them to make the right decisions. They preferred to have consonance with researchers on whether and how the results should be returned to them.

For me I don't understand very well these things of science, they seem too complicated. I would like to sit down with the researcher, discuss in detail together... and agree together on what results will benefit me... (FGD_3_Participant_1).

Two participants who preferred a passive role said that information about genes is very complex for them to understand. Therefore, they would prefer the researcher to make the decisions about the results to receive on their behalf.

I just don't understand genes and what they do in my body. Besides the research nurse telling me what is expected of me in a research study and I agree to join the study, the rest of the decisions should be made by the researcher (FGD_2_Participant_2).

Fear of making decisions with harmful implications

Two participants who preferred a passive role expressed concerns about fearing the unforeseeable implications. Therefore, they did not want to blame themselves for the decision to receive their results.

I fear to make such decisions for myself. I don't know if all the risks were disclosed to me. I worry that if I decide to receive results that I might be able to accept now, but later on, may start causing anxiety to me. I would definitely blame myself and start regretting why I asked for such results. I would rather the researcher decides what to tell me (FGD_1_Participant_6).

One participant who preferred a collaborative role expressed fear of misinterpreting the results. She opined that the decision on whether and how the results are returned to participants should be made together with the researcher.

I don't think I can interpret these results correctly on my own. So, I need to sit down with the research nurse who enrolled me into this study and we decide together on what results will benefit me and leave out those that will cause worry to me (FGD_5_Participant_6).

Additional support is required for participants' decision-making to receive their results

Two participants felt that they needed additional support from non-scientists to interpret the results in very simple language before deciding on what results would be beneficial to return.

> *I am suggesting, if we can have our community representatives, or counsellors to first help us critically understand all the harms and benefits of receiving these results. I will need some help from those people to break down what the results mean to me in a very simple language as for me a lay-person' It is not easy to decide on something that you have not well understood. (FGD_4_Participant_4)*

Four participants suggested that researchers might use some visual aid tools to describe how genes interact with ARVs to help participants understand pharmacogenomic research information and results better.

> *I suggest researchers show us [participants] some videos... showing how these genes interact with the ARVs that we [participants] are taking. It will give us a better understanding of how the drugs we take when see something other than imagining the things they read for us on paper... so that I make the decision when knowing what it's all about. (FGD_3_Participant_5)*

Discussion

Findings from our study suggest that PLHIV want to be engaged in making decisions on whether and how individual pharmacogenomic results should be returned to them or not. The majority of the participants preferred the collaborative role, followed by the active role and passive role, respectively. Results from the survey showed that factors such as religion, marital status and participants' research experience influenced participants' preferred role in decision making. Of interest, the dFGDs expounded on the reasons for the participants' preferred role in decision making for receiving individual pharmacogenomic research results.

The collaborative role involves the researcher providing adequate information about the different kinds of pharmacogenomic results, and the ethical and social implications of returning such results to participants. On the other hand, the participant shares his or her experiences and values with the researcher. Thereafter, the researcher and the participant jointly reach a decision on the kind of results that should be returned, which is followed by evaluating the participant's decision [26, 27]. The collaborative role allows the participant and researcher to discuss and share information, enables a good understanding of the benefits and harms of returning individual pharmacogenomic research results, and empowers participants to make decisions about the treatment that is right for them at a specific time. More than half of the participants preferred the collaborative role when making decisions on whether to receive their results or not. Despite having lived on ART for several years and participated in several research studies, some participants mentioned that they were not used to making individual decisions, especially those related to health matters. Pharmacogenomic research is a new concept in the Ugandan setting that calls for shared decision-making between researchers and participants, who are the primary beneficiaries of these results. Genetics and pharmacogenomics information is complex and requires a certain level of literacy to comprehend. Uganda has a low literacy level [28] and this may lead to misunderstanding or misinterpretation of genetic results if not carefully communicated. Devoting time to build lasting relationships based on mutual respect and trust is one way of facilitating understanding of research information especially in low resource settings [29, 30]. A good relationship between the researcher and the participant fosters open sharing of information and co-learning from each other, thus empowering participants with adequate knowledge to make informed decisions. On the other hand, some participants preferred an active role in decision-making. The active role involves a participant making an independent choice of whether to receive their results or not. Findings from the survey showed that participants with a research experience of more than five years were more likely to prefer the active role than the collaborative role. Similar views were recorded during the dFGDs, including long term exposure to antiretroviral treatment and knowledge acquired from the ART clinics on how HIV is spread, treated, or prevented. The experience of living with a chronic disease for a long time has enabled PLHIV to live positively in their communities and build resilience to handle health-related challenges through various avenues of empowerment such as health education and skills building to boost their socio-economic status [31]. However, long-term exposure to ART does not guarantee a full understanding of pharmacogenomic research information, including results and the ELS implications. A recent study reported that only 23% of 206 PLHIV had an adequate understanding of pharmacogenomic research, where 21% had lived on ART for more than five years [32]. On the contrary, some studies have reported that younger participants and more educated patients prefer taking on the active role [33, 34]. Variances in the factors influencing role preferences may be due to the research and clinical setting, cultural values, and type of disease [35–37]. Therefore, whereas it is important to respect participants' decisions, efforts should be made to ensure

that they adequately understanding the types of results on offer and their implications. We recommend regular discussion on how genes affect drug metabolism and offering genetic counselling to promote participants' full understanding of the results.

Religion and marital status significantly influenced participants' preference for the active role. Participants who were single (neither married nor divorced) were more likely to prefer the active role than the collaborative role. This may be attributed to their primary responsibility of making life decisions solely, compared to married participants. A study conducted among newly discharged patients at a university hospital in Sweden reported that female senior citizens who lived alone preferred an active role in decision making regarding their health [38]. Participants belonging to the catholic religion compared to other religions were more likely to prefer an active role than the collaborative role. Aspects of religious beliefs in deciding 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 [39].

A few participants preferred a passive role in decision-making. The passive role involves a participant preferring the researcher to decide on their behalf whether to receive their results or not. In the qualitative results, this was attributed to participants' trust in researchers' ability to make the right decisions, fear of making decisions that could result into harmful consequences, and limited exposure to genetic information. These reasons are similar to findings from several studies in developing countries have reported passive engagement of patients and research participants in decision-making [40, 41]. In addition, participants often learn about the different roles genes play in their bodies for the first time when they are enrolled in genetic or genomic research studies. However, being a research participant in a pharmacogenomic or genomic study where information about the genes is provided on a piece of paper is not enough for a participant to attain adequate understanding and, in return, make an informed decision on the types of results to be received. Therefore, many participants would trust researchers to be in the best position to make health-related decisions on their behalf, thus promoting paternalism and regressing participants' autonomy. Researchers from sub-Saharan Africa have suggested creative ways of ensuring that participants understand the role of genes in drug metabolism adequately before deciding on what results they should receive. For example, the use of visual aids to provide a good understanding of genetic and genomic research information [42, 43]. This is because visual aids such as videos provide a pictorial and descriptive explanation of a given subject matter that enables participants to imagine or relate the research purpose with their environment.

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. In addition, the dFGDs allowed the investigators to gain a deeper understand of participants' reasons for their preferred roles in decision making on whether and how they would wish to receive their results.

Conclusion

Overall, our findings suggest that PLHIV would like to be involved in decision-making on whether and how individual pharmacogenomic results should be returned to them. Further, the findings indicated that this should be a collaborative effort between researchers and research participants based on trust and mutual respect. We recommend developing creative ways of educating participants about the role of genes in drug metabolism and the ethical, legal, and social implications of pharmacogenomic research so that participants make informed decisions on what results they want to receive. Lastly, we hope our findings will contribute to the development of institutional and national guidelines for returning individual pharmacogenomics research results to people living with HIV.

Abbreviations

ART	Antiretroviral treatment
COREQ	Consolidated criteria for reporting qualitative research
dFGDs	Deliberative focus group discussions
OR	Odds ratios
PLHIV	People living with HIV
SNPs	Single-nucleotide polymorphisms
UNCST	Uganda National Council for Science and Technology

Supplementary Information

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Supplementary Material 1

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Author contributions

SN, CW, DK, and ESM contributed to the conception SN, DK, and ESM contributed to the design of the workSN, AT, BM, and DK contributed to the acquisition and analysis of the dataSN, CW, BM, SZ, RM, BC, DK, and ESM contributed to the interpretation of dataSN, AT, and BM drafted the work, while CW, SZ, RM, BC, DK, and ESM substantively revised itAll authors

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Data availability
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
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). This study was conducted according to the ethical standards stipulated in the Uganda National Council for Science and Technology guidelines.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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