

# High Acceptability of Donating Hair and Other Biological Samples for Research Among People Living with HIV in an Outpatient Clinic in Lagos, Nigeria

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## Abstract

Willingness to donate hair samples is a rate-limiting step for assaying antiretroviral (ARV) concentrations in hair, an emerging technique for HIV prevention and treatment monitoring. We surveyed ethnically diverse Nigerians to determine their willingness to donate hair for biomedical research. A cross-sectional survey of people living with HIV on ARV therapy (ART) was conducted at the HIV clinic of Nigerian Institute of Medical Research, using systematic sampling. The researcher-administered questionnaire was designed to capture sociodemographic data, length of time on ART, and willingness to donate hair. Univariate analysis was performed on sociodemographic characteristics, and independent-samples *t*-test and chi-square tests were used for bivariate analysis. Multivariable logistic regression analysis was performed to assess factors associated with willingness to donate hair samples, with a significance level of 0.05. Of the 398 participants enrolled in the study, 258 (64.8%) were female, the average age was 40 years ( $\pm 9.8$ ), and the average time spent on ART was 7.3 years ( $\pm 4.2$ ). More than half (64.8%) of the respondents were willing to donate hair samples for biomedical research and they were 1.5 times more likely to donate hair than blood. For one-third of the participants, the anticipated benefit from the eventual research findings was the primary motivation to donate hair samples. Fear of use of hair for rituals was the most common stated reason for unwillingness to donate hair samples (21.2%). In an ethnically diverse, urban-based Nigerian study population, nearly two-thirds of the participants were willing to donate hair samples for biomedical research. These findings support the feasibility of hair sampling for future HIV clinical research conducted within Nigeria.

**Keywords:** antiretroviral therapy, acceptability rate, ARV concentration, hair ARV level, hair collection, HIV treatment monitoring, predominantly female

## Background

HIV IS CURRENTLY MANAGED as a chronic illness by using antiretroviral therapy (ART) to achieve established treatment matrices.<sup>1</sup> The main goal of HIV treatment is to achieve sustained virologic suppression, measured clinically by plasma RNA. Therefore, plasma is the most frequently collected biological sample in laboratory HIV testing. However, due to the expense of performing frequent HIV RNA levels, other

methods to assess adherence to ART, such as examining drug levels in urine<sup>2</sup> and hair,<sup>3</sup> have been explored as alternative lower-cost techniques to predict virologic suppression.

Hair has been used as a biological sample as far back as the early 1970s to 1980s to determine systemic levels of mercury, arsenic, opiates, and trace metals in humans.<sup>4-6</sup> Analyzing hair antiretroviral (ARV) concentrations as a predictor of virologic suppression was first reported more than a decade ago.<sup>7</sup> This technique of analyzing ARVs in hair is now an

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evolving field of study that is being used to determine toxicity, exposure, and adherence to ARVs for both HIV prevention and treatment.<sup>8–10</sup> Unlike drug levels in blood, urine, or other biological samples that give information over a snapshot of time, hair levels of ARVs can provide information on adherence or exposure over weeks to months.<sup>9,11</sup> Hair levels of tenofovir have been established as an inexpensive, easy-to-collect biomarker for measuring adherence to pre-exposure prophylaxis<sup>12</sup>; concentrations of lopinavir, ritonavir, and efavirenz in the hair of neonates have been linked to *in utero* transfer of ARVs from maternal consumption to the fetus.<sup>13</sup> The ARV hair levels as biomarkers of adherence are strongly associated with ART outcomes, including HIV viral RNA load.<sup>8</sup> Finally, in this era of individualized medicine, hair can be a useful sample for pharmacogenomic studies.<sup>14</sup>

Hair has several advantages over other biological samples used in biomedical research. First, drug is deposited in hair from the systemic circulation over weeks to months, allowing hair levels to serve as metrics of adherence over long periods, compared with 2–4 days with blood or urine.<sup>9</sup> Drug levels in hair are more stable than in blood and other biological samples,<sup>9</sup> so hair samples can be analyzed for medications or poisons decades later. Moreover, segmental hair analysis allows for the assessment of adherence at various time points over the past months depending on the segment of hair that is analyzed,<sup>9,15</sup> for example, analyzing narcotics in sequential segments from the scalp demonstrates the history of narcotic use over time.<sup>11</sup> The collection of hair sample is easy, non-invasive, cheap, and does not require use of sterile equipment.<sup>11</sup> Hair can be stored for more than 5 years at room temperature.<sup>16</sup> Finally, concentrations of ARVs in hair samples collected at home by research participants correlate with samples collected at research study sites.<sup>17</sup> With the advantages of hair as a biological sample, hair could be a useful tool for monitoring ART in resource-limited settings such as Nigeria.

Assessments to determine willingness to donate hair samples have been carried out in various settings before collection of hair samples for research. Willingness to donate hair varies widely across different study populations worldwide: An Indian study reported 100% willingness to donate hair samples<sup>3</sup>; Kenyan and Ugandan studies reported rates of 95% and 84%, respectively<sup>18,19</sup>; and studies in the United States reported a wide range, from 3.4% to 84.3%,<sup>20,21</sup> with improved knowledge about the process being a key factor influencing the willingness of research participants to donate hair samples.

In earlier work by our group, 51.4% of participants from an ethnically homogenous population in southwest Nigeria were willing to donate hair for research.<sup>22</sup> To better understand acceptance of this technology, we assessed factors associated with willingness to donate hair and biological samples in a more ethnically diverse and urban-based population of Nigeria.

## Methods

### *Study design, study site, and study population*

This was a cross-sectional study design; the study site was the Outpatients HIV Clinic, Nigerian Institute of Medical Research, Lagos. The study population was people living with HIV (PLWH) ( $\geq 18$  years) and on ART for more than 3 months. Pregnant women and adolescents younger than 18

years were excluded from this study, because their drug pick-up days did not fall within the days of the week for data collection in this study.

### *Sample size and sampling procedure*

A calculated sample size of 398 was determined for assessing a single proportion by using a cross-sectional design.<sup>23</sup> An estimated proportion of 51.4% in willingness to donate hair from our earlier study<sup>22</sup> was used in the calculation. Assumptions made in the sample size calculation are: 5% precision, 5% type 1 error, and population size  $< 15,000$ .

Our sampling method was systematic; every fifth patient who arrived at the pharmacy for ARV pick up on Mondays, Tuesdays, and Thursdays were offered enrollment and those who agreed to participate and signed an informed consent were enlisted. The next person on the queue was offered enrollment when the fifth person declined participation. The study period was from November 2019 to January 2020.

### *Study instrument and data collection*

The study instrument was adapted from the questionnaire used in our prior study by Nwogu *et al.*<sup>22</sup> Additions to the questionnaire included length of time on ART, and willingness to donate other biological samples, which included saliva, stool, and urine. The participant's length of time on ART was verified from the pharmacy records. The question on willingness to donate hair required a "yes" or "no" response, whereas the question on other biological samples required the selection of each sample type that respondents were willing to donate for research. There was also a question, where the respondent could indicate the desire to donate none of the listed biological samples, including hair; if the answer to this last question contradicted the response to the initial two questions, it was likely due to misunderstanding and was, therefore, excluded from data analysis. Other questions in the questionnaire provided multiple options, as reasons for the respondent for agreeing or declining to donate hair and other biological samples. The questionnaire was either self-administered by those who could read or administered by research assistants in English, Pidgin English, Yoruba, Ibo, or Hausa, depending on the participant's level of literacy.

### *Data analysis*

Data from the questionnaire were transcribed to a database software, SPSS version 26 (IBM, Chicago, IL) and analyzed. Univariate analysis was performed on sociodemographic characteristics by using descriptive statistics. Independent-sample *t* tests and chi-square tests were used for bivariate analysis. Logistic regression was performed for a multivariable analysis of factors that influenced willingness to donate hair samples. Significance level was set at 0.05.

### *Ethics statement*

Ethical approval (IRB-19-051) was obtained from the Institutional Review Board (IRB) of the Nigerian Institute of Medical Research. Informed consent was presented in written English language for the literate participants to read and sign before responding to the questionnaire. Informed consent was read out aloud in English language, Pidgin English, Yoruba, Ibo, or Hausa for those participants who could not read.

## Results

### Sociodemographic characteristics

Overall, 398 participants consented to be enrolled into the study over the study period. More than half of the respondents—258 out of (64.8%)—were female; average age was 40 years ( $\pm 9.8$ ), and the average time spent on ART was 7.3 years ( $\pm 4.2$ ). All three major ethnic groups in Nigeria, Hausa, Ibo, and Yoruba, and some minority tribes (Bini, Ibibio, Tiv, etc.) were represented in the sample. Other sociodemographic characteristics of the respondents are shown in Table 1.

### Willingness to donate hair and other biological samples

Overall, 258 (64.8%) respondents in this study were willing to donate hair samples for biomedical research. On an average, respondents in this study were 1.5 times more likely to donate hair than blood, urine, saliva, or stool for research ( $p < .001$ ). A minority of individuals, specifically 48 (12%), indicated unwillingness to donate any of the listed biological samples; the majority, 350 (88%), expressed willingness to donate at least one biological sample for research (Fig. 1A).

### Motivation and factors associated with willingness to donate hair samples for biomedical research

Anticipated benefits from eventual research findings were the motivation for a third of the respondents, 86 (33%), to donate hair samples for research (Fig. 1B). In bivariate analyses, factors that were statistically significantly associated with willingness to donate hair for research included having a tertiary (university) education or higher, being on ART for

>6 years, and willingness to donate at least one biological sample (Table 2). These statistically significant variables at bivariate analyses were pooled together in a logistic regression model for multivariable analysis.

The best fit logistic regression model was obtained by including marital status, religion, and age to the earlier mentioned three factors as independent variables, and “willingness to donate hair sample for biomedical research” as the dependent variable. The logistic regression model was statistically significant,  $\chi^2(6) = 44.920$ ,  $p < .001$ . Three independent variables—education ( $p = .012$ ), time on ART ( $p = .040$ ), and willingness to donate at least one biological sample ( $p < .001$ )—contributed significantly to the model.

### Reasons for unwillingness to donate hair samples for research

Out of the 137 participants who provided reasons for unwillingness to donate hair samples, 75 (54.7%) indicated personal reasons, whereas 29 (21.1%) wanted to “avoid their hair being used for rituals.” Other reasons given are shown in Figure 1C.

## Discussion

Our study indicates that nearly two-thirds of PLWH in an urban center in Nigeria are willing to donate hair samples for biomedical research. Since hair samples can assess ART adherence over time, it may be measured in between HIV RNA levels as an adherence matrix and can be analyzed in laboratories in low-income settings.<sup>3</sup> This high acceptability of hair collection could, therefore, help in treatment monitoring in the setting.

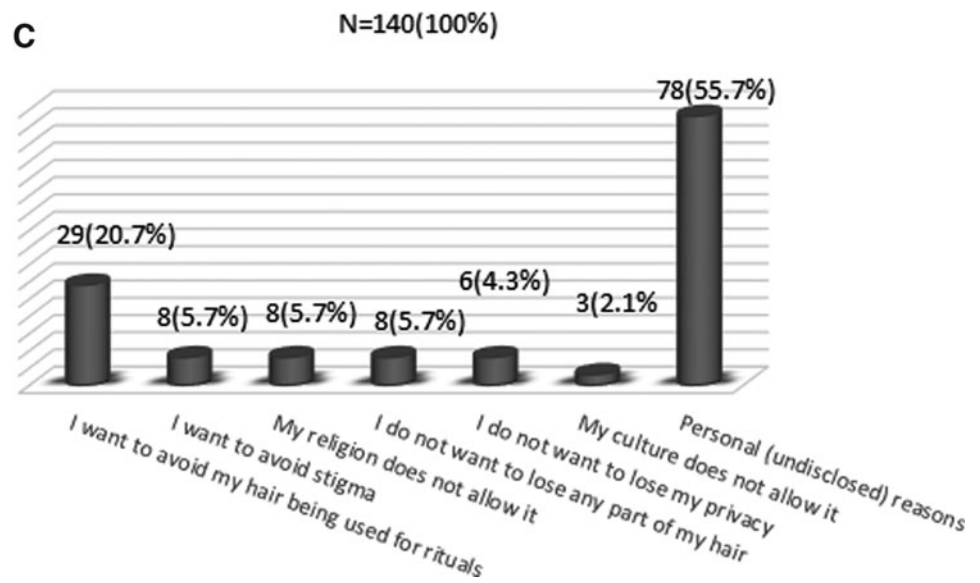
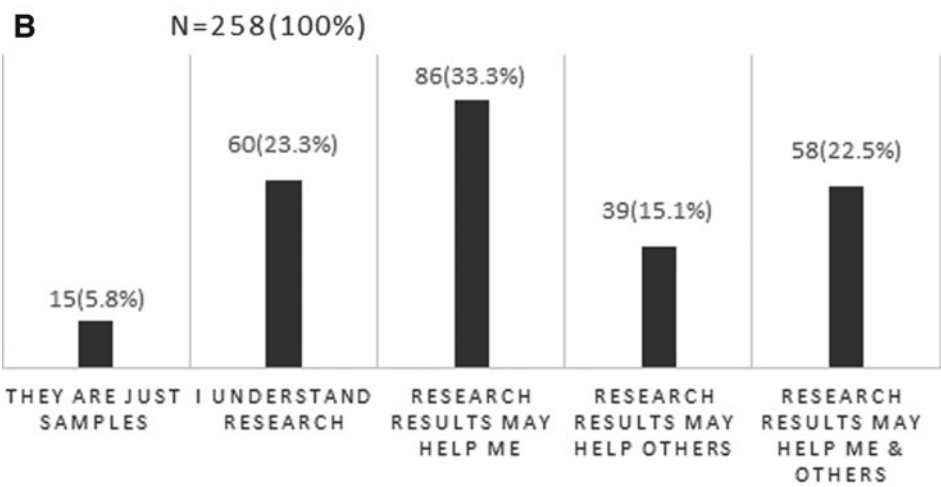
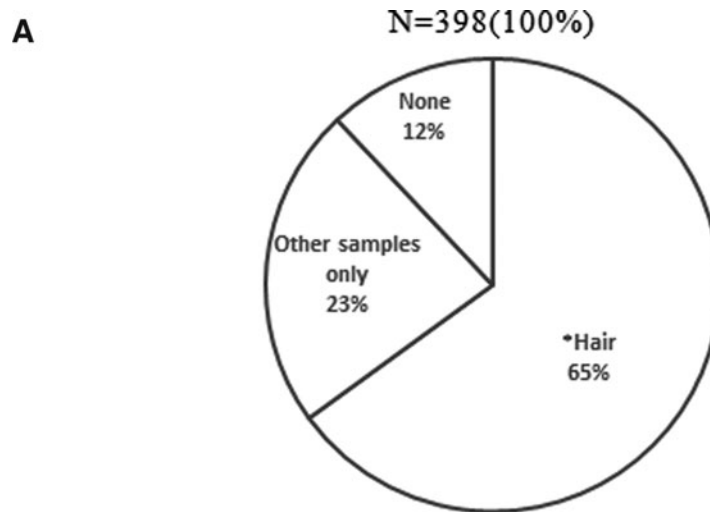
The proportion of PLWH willing to donate hair samples for HIV research in our study (64.8%) was higher than that reported from an earlier study conducted by our group in Ibadan, Nigeria, where a 51.3% willingness was reported.<sup>22</sup> Respondents in this current study are more ethnically diverse and are residing in a more urban environment, which could explain the difference. Of note, 65% of our sample was female, which was representative of the clinic population, thereby increasing generalizability.<sup>24</sup> Though this study was conducted in Southwest Nigeria, only 31% of respondents were Yoruba, the major tribe in Southwest Nigeria, unlike the Ibadan-based study where 79.5% of participants were Yoruba. The Igbo and other tribes of Southern Nigeria, which make up 52% of the Nigerian population,<sup>25</sup> constitute 62% of our study population. Another likely reason for the difference in proportions between both studies could be that participants in our study are more exposed to biomedical research. The HIV Treatment Center at the Nigerian Institute of Medical Research, the site for this study, was established in 2002 as a clinical research center for the National HIV Treatment Programme,<sup>26</sup> resulting in the conduct of multiple research studies involving PLWH since its establishment. The rate reported in our study is, however, lower than the rates reported from India, Kenya, and Uganda.<sup>3,18,19</sup> Higher rates in these studies could be explained by the participants' active involvement in existing research, whereas in our study, the survey was administered in anticipation of a future study.

Anticipated personal benefit from the research was the primary motivation to donate hair in this study. These findings are consistent with a report by Goldenberg *et al.*, which

TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

N = 398	n (%)
Sex	
Female	258 (64.8)
Male	140 (35.2)
Age	
Mean (SD)	40.9 (9.8)
Time on ART (years)	
Mean (SD)	7.33 (4.19)
Marital status, N = 396 (100%)	
Married	250 (63.1)
Not married	146 (36.9)
Religion	
Christianity	346 (86.9)
Islam	52 (13.1)
Education, N = 394 (100%)	
<Tertiary	214 (54.3)
≥Tertiary	180 (45.7)
Ethnicity, N = 397 (100%)	
Hausa	25 (6.3)
Ibo	180 (45.3)
Yoruba	123 (31.0)
Idoma/Igala/Tiv	16 (4.0)
Edo/Delta	23 (5.8)
Ibibio/Efik	28 (7.1)
Non-Nigerian	2 (0.5)

ART, antiretroviral therapy; SD, standard deviation.



**FIG. 1.** (A) Willingness to donate biological samples for research. \*121 (47%) of those who will donate hair, will also donate at least one other biological samples. (B) Reasons for willingness to donate hair for biomedical research. (C) Reasons for unwillingness to donate hair for research.

TABLE 2. FACTORS ASSOCIATED WITH PARTICIPANTS' WILLINGNESS TO DONATE HAIR SAMPLES FOR BIOMEDICAL RESEARCH

Independent variables	Cross-tabulation		Logistic regression		
	Willingness to donate hair	p	Exp (B)	95% CI for Exp(B)	p
Gender		.779			
Female	166				
Male	92				
Age (years)		.085			
≤30	42				
31–40	79				
41–50	99				
≥51	38				
Religion		.688			
Christianity	223				
Islam	35				
Education		.006*	0.658	0.475–0.910	.012*
≤Primary	25				
Secondary	99				
≥Tertiary	131				
Marital status		.141			
Married	169				
Not married	88				
Time on ART (years)		.045*	0.578	0.343–0.975	.040*
<6	67				
≥6	178				
Willingness to donate at least one biological sample		<.001*	6.332	3.086–12.992	<.001*
No	22				
Yes	219				

\*Statistically significant *p* values.

showed that a potential benefit to an ethnic group was a factor associated with the decision to donate samples for genetic research.<sup>27,28</sup>

Several reports show a significant association between education or knowledge and willingness to donate human biological samples or solid organs.<sup>29–33</sup> Educational interventions have been reported to significantly improve willingness to donate biological samples.<sup>34,35</sup> This study reports a significant association between higher (tertiary) level of education and willingness to donate hair. Although other studies also reported similar findings,<sup>22,27</sup> this stands in contrast to our earlier work in Ibadan, Nigeria<sup>22</sup> where less educated participants were more willing to donate hair. This discrepancy could be attributed to their understanding of the processes and benefit of research, as reported by Babatunde *et al.*<sup>27</sup> where participants who were health care professionals (with tertiary education) were well versed in the research and willing to donate biological samples. Moreover, pharmacy records showed that the mean time on ART by participants in this study was 7 years, and 69% of those willing to donate hair had been on ART for at least 6 years. Those willing to donate hair may, therefore, have been more familiar with the medical system compared with those who were not, which could have generated trust.

Respondents in this study were more willing to donate hair than blood, urine, saliva, and stool; this finding is consistent with a report from a South African qualitative study, where participants indicated preference to donate hair compared

with blood, due to the fear of pain from phlebotomy required in collecting blood specimens.<sup>36</sup> Fear of their cut hair being used in rituals was the highest stated reason for unwillingness to donate hair. African cultural views and superstitious beliefs about hair are likely to play into reduced acceptability in certain African populations for hair donation.<sup>22,37</sup>

#### Study limitations and strengths

Our study has some limitations. The factors associated with willingness to donate other biological samples were not studied; the inclusion of these factors to future studies may provide better insight into the factors influencing willingness to donate hair for research compared with other biological samples. Moreover, asking participants about their intent to donate biological samples is not the same thing as assessing acceptability of actual hair collection in an ongoing study. An additional limitation is that those who came to the clinic to be offered study participation might inherently be more adherent to care. Therefore, our findings are limited to those who are in care and not poorly adherent and out of care.

In terms of strengths, this survey was conducted in an ethnically diverse Nigerian population of PLWH. Though Yoruba is the major ethnic group in Lagos, South-west Nigeria, most participants in this study had ethnic origins from other regions of South Nigeria, making the study generalizable across urban regions and southern Nigeria. The participants in this survey were predominantly female (64.8%),

which is a true representation of the clinic population (66% female), and in contrast to the low female representation (19.2%) in many other HIV clinical studies, as reported in a systematic review by Curno *et al.*<sup>24</sup>

### Conclusion

In conclusion, our research shows that nearly two-thirds of PLWH in an ethnically diverse, urban center in Nigeria were willing to donate hair samples for biomedical research. Our study population was predominantly female and ART-experienced, generalizable to the PLWH in the region. The implication of our findings is that studies involving hair collection for ARV monitoring in both HIV treatment and prevention should be feasible to conduct in Nigeria.

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### Disclaimer

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

### Authors' Contributions

All listed authors contributed significantly to the conception, design, data acquisition, data analysis and interpretation, article drafting, article revision for intellectual and technical content, and approval of the final version. All authors agree to be accountable for all aspects of the work.

### Author Disclosure Statement

No competing financial interests exist.

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