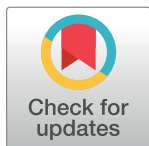


RESEARCH ARTICLE

Biological sample donation and informed consent for neurobiobanking: Evidence from a community survey in Ghana and Nigeria

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Abstract

Introduction

Genomic research and neurobiobanking are expanding globally. Empirical evidence on the level of awareness and willingness to donate/share biological samples towards the expansion of neurobiobanking in sub-Saharan Africa is lacking.

Aims

To ascertain the awareness, perspectives and predictors regarding biological sample donation, sharing and informed consent preferences among community members in Ghana and Nigeria.

Methods

A questionnaire cross-sectional survey was conducted among randomly selected community members from seven communities in Ghana and Nigeria.

Data Availability Statement: All relevant data are within the paper and its [Supporting Information](#) files.

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Competing interests: The authors have declared that no competing interests exist.

Results

Of the 1015 respondents with mean age 39.3 years (SD 19.5), about a third had heard of blood donation (37.2%, M: 42.4%, F: 32.0%, $p = 0.001$) and a quarter were aware of blood sample storage for research (24.5%; M: 29.7%, F: 19.4%, $p = 0.151$). Two out of ten were willing to donate brain after death (18.8%, M: 22.6%, F: 15.0%, $p < 0.001$). Main reasons for unwillingness to donate brain were; to go back to God complete (46.6%) and lack of knowledge related to brain donation (32.7%). Only a third of the participants were aware of informed consent (31.7%; M: 35.9%, F: 27.5%, $p < 0.001$). Predictors of positive attitude towards biobanking and informed consent were being married, tertiary level education, student status, and belonging to select ethnic groups.

Conclusion

There is a greater need for research attention in the area of brain banking and informed consent. Improved context-sensitive public education on neurobiobanking and informed consent, in line with the sociocultural diversities, is recommended within the African sub region.

Introduction

Biobanking and genomic research are becoming increasingly important for health and disease research in developing countries including the African sub region. There are increasing efforts to capture global genetic diversity in an attempt to ensure that the benefits of genomic innovation filter down to all people around the globe [1]. Neurobiobanking, the storage of central nervous system tissues, including fixed and frozen whole brain, brain sections, brain biopsies, spinal cord, associated blood fractions, and relevant datasets stored for research purposes, is also expanding in Africa [2]. With the huge human genomic diversity, coupled with an ageing population and associated brain disorders, the Ibadan Brain Ageing, Dementia And Neurodegeneration (IBADAN) Brain Bank [2], the first organized brain tissue biorepository in sub-Saharan Africa (sSA), was set up to accrue, process and store unique brain tissues for future research into a broad spectrum of neurological disorders such as stroke and dementias. Future discoveries emanating from these resources and systems have an immeasurable potential health benefit to people of African ancestry and other ancestral populations [3]. Despite these groundbreaking advancements in genomic research within the African research context, several questions related to the ethical, legal and social aspects of neurobiobanking remain unanswered. For instance, among Africans, communal informed consent is preferred to individual informed consent, given that the African context tends to prioritize values like communitarianism and reciprocity over respect for autonomy [4]. Also, relationship between people and considerations of community benefit are considered equally important [5]. However, the success of biobanking depends on people's willingness to contribute their biological samples for storage towards research. Public support is thus essential in securing the sustainability of biobanks. A review of studies conducted globally indicated willingness to donate by individuals, despite poor knowledge [6]. However, some studies have indicated that biobanking-knowledge, type of donated tissue, purpose of research, safety of the data, preferred type of consent, and trust towards biobanks are all influential factors related to willingness to donate [7–9]. Studies conducted in the African sub region such as Nigeria indicates a high level of awareness but poor willingness towards organ donation such as brain, among older Nigerians [10].

Nevertheless, studies conducted in Europe and America indicate a generally positive attitude towards biobanking and a high willingness to donate, but these concepts have not been substantially investigated within the African sub region [11–13].

Given the unique socio-cultural, linguistic and belief systems of Africans, the ethical, legal and social implications (ELSI) of emerging biobanks including neurobiobanks and data resources in Africa require detailed exploration [14]. The objectives of this study were to evaluate the awareness and willingness of community members in Ghana and Nigeria towards donation/sharing of blood and brain samples for neurobiobanking and genetic research and their preferences regarding informed consent for participation.

Materials and methods

Study design, participants, sampling and setting

A cross-sectional survey was conducted among community-dwelling laypersons from seven sites within our existing established SIREN (Stroke Investigative Research and Education Network) [1], from Ghana and Nigeria. The SIREN study has a cohort of stroke survivors, caregivers and healthy controls [15]. Participants from five (5) communities in Nigeria (Abeokuta, Ibadan, Ilorin, Kano and Zaria) and two (2) communities in Ghana (Accra and Kumasi) were included. As described in the protocol manuscript of the study community-dwelling laypersons were recruited from the seven SIREN participating sites during community engagement programmes regularly organized to promote stroke awareness in the community and also recruit suitable controls for the ongoing study [14]. The number of participants surveyed per site was proportionate to the size of SIREN recruitment from each site. Respondents were selected by stratified random sampling using the list of participants at the community engagement programme list as sampling frame. Detailed information on the seven participating sites has been published elsewhere [14]. The sample size was estimated based on preliminary data, which showed 48.7% of stroke patients and 57.0% of stroke-free individuals have knowledge of stroke heritability [16]. We used knowledge of stroke heritability as a proxy for awareness about stroke genomics research, which was one of the goals of the ELSI project. The effective sample size estimated was 975 based on a 3% degree of precision and 95% confidence level and adjusting for 85% anticipated response rate.

Study tool and data collection

A survey questionnaire (S1 File) was used to collect information from the participants. The study questionnaire was developed by a multidisciplinary expert-working group and informed by a systematic review of the literature and our findings from previous studies [1, 2, 17].

Survey measures

1. Information on participant demographics includes age, religion, ethnicity, educational qualification, occupation, marital status, monthly income and living arrangement.
2. Awareness and knowledge related to blood/brain fraction donation
3. Willingness to give consent for blood and brain sample donation for genetic research and storage.
4. Awareness and perception of informed consent.

Trained interviewers at each SIREN site administered the questionnaire and written informed consent was obtained prior to completion of the survey. All participants received a brief

education on the concepts being explored in the questionnaire such as informed consent and their meaning and in some cases an explanatory note was provided with the question eg. broad consent (Informed consent only needs to be taken once and this covers for all other use of my sample by researchers) for research on the blood collected from me as it is sometimes practically difficult to re-contact and re-consent participants.

Ethical consideration

Ethical approval was sought from the Institutional Health Research review board of each participating SIREN site (the University of Ibadan; Federal Medical Centre, Abeokuta; University of Ilorin; Aminu Kano Teaching Hospital, Kano; Ahmadu Bello University, Zaria; University of Ghana, Accra and Kwame Nkrumah University of Science and Technology, Kumasi). Confidentiality of data was ensured throughout all phases of the study. Data were analyzed anonymously, with only members of the study in charge of data analysis having access to collected data. Confidentiality of data continued until the full manuscript was finalized. After publication, the data will be safely stored with continued maintenance of confidentiality.

Statistical analysis

Descriptive statistics was used to summarize the demographic characteristics of the participants. For hypothesis testing, χ^2 or Fisher's exact test was used to investigate factors associated with awareness of brain/blood donation, willingness to share blood/brain tissues with other researchers and awareness and perception of informed consent. The Mann-Whitney U test was used to analyze ranked responses including participants' preferences for receiving genetic test results. Random-effect logistic regression models were fitted to identify the socio-demographic characteristics associated with willingness to share blood/brain fraction and awareness of informed consent. For all statistical analyses, a p-value < 0.05 was considered significant at 95% confidence levels.

Results

Socio-demographic characteristics of participants

A total of 1015 community members, mean age 39.3 years (SD 19.5) with an equal representation of males and females completed the interviewer-administered questionnaire in the selected study sites in Ghana and Nigeria. The socio-demographic characteristics of the study participants are summarized in [Table 1](#).

[Table 1](#) shows that over 70% of the participants were below 50 years of age. Over half of the participants were married (54%) and had tertiary education (51%). Two-thirds of the participants were Christians (62.9%) and close to half of the participants belonged to the Yoruba ethnic groups (47.9%) followed by the Hausa groups (15.6%) ($p < 0.001$).

Awareness of blood donation

[Table 2](#) summarizes awareness of respondents to blood donation. Only a third of the participants had previously heard of blood donation for research (M: 42.4%, F: 32.0%, $p < 0.01$) and less than a third (24.5%; M: 29.7%, F: 19.4%, ($p < 0.01$)) were aware of blood sample storage for research.

As shown in [Table 2](#), hospitals were the main source of where participants obtained information on blood donation (65.3%; M: 58.3, F: 74.7%, $p < 0.001$) followed by internet and online sources (17.7%; M: 23.2%, F: 10.5%, $p < 0.001$). Close to 90% ($n = 913$) of participants were not aware of any guidelines regulating blood sample storage for genomic research.

Table 1. Socio-demographic characteristics of study participants.

Characteristics	Male (n = 509)	Female (n = 506)	Total (n = 1015)	p-value
Age: Mean(SD)	39.62 (23.06)	38.91 (15.16)	39.27 (19.52)	0.561
Age group	n (%)	n (%)	n (%)	
< 50	387 (76.33)	377 (74.80)	764 (75.57)	0.571
> = 50	120 (23.67)	127 (25.20)	247 (24.43)	
Domicile				
Rural	21 (4.14)	27 (5.36)	48 (4.75)	0.470
Semi-urban	131 (25.84)	140 (27.78)	271 (26.81)	
Urban (Ref)	355 (70.02)	337 (66.87)	692 (68.45)	
Education				
None	16 (3.14)	50 (9.88)	66 (6.50)	<0.001
Arabic*	4 (0.79)	11 (2.17)	15 (1.48)	
Primary	45 (8.84)	74 (14.62)	119 (11.72)	
Secondary	132 (25.93)	163 (32.21)	295 (29.06)	
Tertiary	312 (61.30)	208 (41.11)	520 (51.23)	
Average monthly income				
< = 100 USD	269 (54.79)	292 (61.47)	561 (58.07)	0.004
> 100 USD	222 (45.21)	183 (38.53)	405 (41.93)	
Marital status				
Single	230 (45.19)	160 (31.62)	390 (38.42)	<0.001
Married	261 (51.28)	291 (57.51)	552 (54.38)	
Formerly married	18 (3.54)	55 (10.87)	73 (7.19)	
Living arrangement				
Alone	160 (31.43)	89 (17.59)	249 (24.53)	<0.001
With spouse and children	251 (49.31)	281 (55.53)	532 (52.41)	
With children	11 (2.16)	52 (10.28)	63 (6.21)	
With others	87 (17.09)	84 (16.60)	171 (16.85)	
Religion				
Christianity	308 (60.51)	331 (65.42)	639 (62.96)	0.091
Islam	196 (38.51)	174 (34.39)	370 (36.45)	
Others	5 (0.98)	1 (0.20)	6 (0.59)	
Ethnic group				
Yoruba	229 (44.99)	257 (50.79)	486 (47.88)	<0.001
Igbo	23 (4.52)	11 (2.17)	34 (3.35)	
Hausa	92 (18.07)	66 (13.04)	158 (15.57)	
Akan	60 (11.79)	84 (16.60)	144 (14.19)	
Ga/Adangbe	32 (6.29)	34 (6.72)	66 (6.50)	
Ewe	8 (1.57)	11 (2.17)	19 (1.87)	
Others	65 (12.77)	43 (8.50)	108 (10.64)	
Primary Occupation				
Highly skilled	69 (13.56)	34 (6.72)	103 (10.15)	<0.01
Skilled	126 (24.75)	122 (24.11)	248 (24.43)	
Semi-skilled	84 (16.50)	110 (21.74)	194 (19.11)	
Manual work	53 (10.41)	96 (18.96)	149 (14.68)	
Not working	72 (14.15)	84 (16.60)	156 (15.37)	
Students	105 (20.63)	60 (11.86)	165 (16.26)	

* Arabic schools are common in Northern Nigeria. They do some sorts of formal education, but the focus is Quran. It is not equivalent to "No formal education".

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Table 2. Awareness and knowledge related to blood sample donation.

Variable/question	Male (n = 509)	Female (n = 506)	Total (n = 1015)	p-value
<i>Ever heard of blood sample donation for medical research</i>	n (%)	n (%)	n (%)	
Yes	216 (42.44)	162 (32.02)	378 (37.24)	0.001
No	293 (57.56)	344 (67.98)	637 (62.76)	
<i>Ever heard of blood sample storage for research purpose</i>				
Yes	151 (29.67)	98 (19.37)	249 (24.53)	<0.001
No	358 (70.33)	408 (80.63)	766 (75.47)	
<i>Sources of information about blood sample donation</i>				
Hospital	126 (58.33)	121 (74.69)	247 (65.34)	<0.001
Training program	21 (9.72)	13 (8.02)	34 (8.99)	0.568
Friend	31 (14.35)	11 (6.79)	42 (11.11)	0.021
Colleague	16 (7.41)	7 (4.32)	23 (6.08)	0.214
Newspaper/magazine	18 (8.33)	5 (3.09)	23 (6.08)	0.035
Internet/online resources	50 (23.15)	17 (10.49)	67 (17.72)	0.001
Seminar/conference/workshop	23 (10.65)	5 (3.09)	28 (7.41)	0.005
TV	29 (13.43)	7 (4.32)	36 (9.52)	0.003
Radio	29 (13.43)	10 (6.17)	39 (10.32)	0.022
Outreach	27 (12.50)	13 (8.02)	40 (10.58)	0.162
Family	9 (4.17)	6 (3.70)	15 (3.97)	0.820
<i>Sources of information about blood sample storage for research</i>				
Hospital	86 (56.95)	69 (70.41)	155 (62.25)	0.032
Training program	17 (11.26)	10 (10.20)	27 (10.84)	0.794
Friend	18 (11.92)	10 (10.20)	28 (11.24)	0.675
Colleague	8 (5.30)	4 (4.08)	12 (4.82)	0.662
Newspaper/magazine	16 (10.60)	5 (5.10)	21 (8.43)	0.127
Internet/online resources	32 (21.19)	13 (13.27)	45 (18.07)	0.112
Seminar/conference/workshop	19 (12.58)	3 (3.06)	22 (8.84)	0.010
TV	24 (15.89)	6 (6.12)	30 (12.05)	0.021
Radio	18 (11.92)	6 (6.12)	24 (9.64)	0.130
Outreach	15 (9.93)	8 (8.16)	23 (9.24)	0.637
Family	9 (5.96)	1 (1.02)	10 (4.02)	0.052
<i>Awareness about guidelines/regulation for use of blood and its storage for genomic research</i>				
Yes	57 (11.20)	45 (8.89)	102 (10.05)	0.222
No	452 (88.80)	461 (91.11)	913 (89.95)	

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Awareness of brain donation

As shown in Table 3, awareness of brain donation was lower than blood donation (9.8% compared to 37.2% for blood donation), and over 60% of the respondents were unaware of any guidelines for brain donation.

Table 3 shows that nearly 9 out of 10 (89.0%) respondents were unaware of anyone who had agreed to brain donation and only 5.7% had previously heard about collecting and storing brain for research (M: 7.3%, F: 4.2%, $p = 0.032$). Likewise, less than a quarter were willing to donate brain after death (18.8%; M: 22.6%, F: 15.0%, $p = 0.002$). Main reasons for unwillingness to donate brain samples were: wanting to go back to God complete (46.6%; M: 39.9%, F: 52.8%, $p < 0.001$), lack of knowledge (32.7%; M: 32.0%, F: 33.3%, $p = 0.696$) and distrust in the medical system (27.6%; M: 30.2%, F: 25.1%, $p = 0.103$). Over 80% (85.8%, M: 82.3%, F: 89.1%, $p = 0.003$) of respondents disagreed with the statement: “people in Africa would be willing to

Table 3. Awareness and knowledge related to brain donation.

Variable/question	Male: (n = 509)	Female: (n = 506)	Total: (n = 1015)	p-value
<i>Ever heard of brain donation for research</i>	n (%)	n (%)	n (%)	
Yes	53 (10.41)	47 (9.29)	100 (9.85)	0.558
No	456 (89.59)	459 (90.71)	915 (90.15)	
<i>Sources of information about brain donation for research</i>				
Hospital	14 (26.42)	21 (44.68)	35 (35.00)	0.056
Training program	7 (13.21)	6 (12.77)	13 (13.00)	0.948
Friend	6 (11.32)	6 (12.77)	12 (12.00)	0.824
Colleague	2 (3.77)	0 (0.0)	2 (2.00)	0.179
Newspaper/magazine	8 (15.09)	0 (0.0)	8 (8.00)	0.005
Internet/online resources	16 (30.19)	8 (17.02)	24 (24.00)	0.124
Seminar/conference/workshop	3 (5.66)	2 (4.26)	5 (5.00)	0.748
TV	13 (24.53)	6 (12.77)	19 (19.00)	0.135
Radio	5 (9.43)	5 (10.64)	10 (10.00)	0.841
Outreach	3 (5.66)	2 (4.26)	5 (5.00)	0.748
Family	2 (3.77)	1 (2.13)	3 (3.00)	0.630
<i>Awareness about a brain donor</i>				
Yes	6 (11.32)	5 (10.64)	11 (11.00)	0.913
No	47 (88.68)	42 (89.36)	89 (89.00)	
<i>Awareness about guidelines for use of brain for research</i>				
Yes	10 (27.03)	9 (42.86)	19 (32.76)	0.217
No	27 (72.97)	12 (57.14)	39 (67.24)	
<i>Have you ever heard of the concept of collecting and storing brain for research?</i>				
Yes	37 (7.27)	21 (4.15)	58 (5.71)	0.032
No	472 (92.73)	485 (95.85)	957 (94.29)	
<i>Willingness to donate brain after death</i>				
Yes	115 (22.59)	76 (15.02)	191 (18.82)	0.002
No	394 (77.41)	430 (84.98)	824 (81.18)	
<i>Reasons for willingness</i>				
It will advance medicine	73 (63.48)	41 (53.95)	114 (59.69)	0.189
Prevent future disease	59 (51.30)	24 (31.58)	83 (43.46)	0.007
Don't need brain after death	38 (33.04)	19 (25.00)	57 (29.84)	0.234
Happy to save a life	63 (54.78)	37 (48.68)	100 (52.36)	0.409
It can help future generations	41 (35.65)	20 (26.32)	61 (31.94)	0.176
<i>Reasons for not willing to donate brain sample</i>				
Want to go back to God complete	157 (39.85)	227 (52.79)	384 (46.60)	<0.001
Against my religion	63 (15.99)	62 (14.42)	125 (15.17)	0.530
People will think I am occultic	60 (15.23)	34 (7.91)	94 (11.41)	0.001
Not knowledgeable about it	126 (31.98)	143 (33.26)	269 (32.65)	0.696
Don't trust Africans	18 (4.57)	28 (6.51)	46 (5.58)	0.225
Don't trust medical systems	119 (30.20)	108 (25.12)	227 (27.55)	0.103
It's like destroying the work of God	22 (5.58)	24 (5.58)	46 (5.58)	0.999
I don't just want to	17 (4.31)	33 (7.67)	50 (6.07)	0.044
<i>People in Africa would be willing to donate brain samples for research purposes</i>				
Agree	88 (17.43)	55 (10.91)	143 (14.17)	0.003
Disagree	417 (82.57)	449 (89.09)	866 (85.83)	
<i>Actions for promoting brain sample donation for research</i>				
Media publicity	325 (63.85)	329 (65.02)	654 (64.43)	0.697

(Continued)

Table 3. (Continued)

Variable/question	Male: (n = 509)	Female: (n = 506)	Total: (n = 1015)	p-value
Education	332 (65.23)	314 (62.06)	646 (63.65)	0.294
Legislation	76 (14.93)	75 (14.82)	151 (14.88)	0.961
Involvement of religious and community members	177 (34.77)	149 (29.45)	326 (32.12)	0.069
Education of people on social media	147 (28.88)	127 (25.10)	274 (27.00)	0.175

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donate brain samples for research purposes". Hospitals and the internet (online communication platforms) were the main sources of information on brain donation as for blood sample donation. The main reasons for willingness to donate brain by respondents were: advancement of medicine (59.7%), happiness to save a life (52.4%), and prevention of future disease (43.5%). Respondents indicated media publicity (64.4%) and education (63.7%) as common ways of further promoting brain donation for research as in Table 3.

Willingness for blood/brain donation/storage and sharing

Table 4 summarizes the willingness for blood/brain donation/sharing and reuse. Majority of participants were willing to give consent for blood sample donation for research for themselves (75.3%) and on behalf of their family members (73.9%).

Table 4. Willingness towards blood/brain sample donation/sharing/reuse.

Variable/question	Male (n = 509) n (%)	Female (n = 506) n (%)	Total (n = 1015) n (%)	p-value
<i>Willingness to give consent for blood sample donation for genetic research and storage</i>				
Yes	393 (77.21)	371 (73.32)	764 (75.27)	0.151
No	116 (22.79)	135 (26.68)	251 (24.73)	
<i>Willingness to give consent for a family member blood sample donation for genetic research and storage</i>				
Yes	371 (72.89)	379 (74.90)	750 (73.89)	0.465
No	138 (27.11)	127 (25.10)	265 (26.11)	
<i>Blood fractions from me can be shared with other researchers</i>				
Yes	352 (69.16)	329 (65.02)	681 (67.09)	0.161
No	157 (30.84)	177 (34.98)	334 (32.91)	
<i>Brain tissues from me can be shared with other researchers</i>				
Yes	216 (42.44)	156 (30.83)	372 (36.65)	<0.001
No	293 (57.56)	350 (69.17)	643 (63.35)	
<i>Brain images from me can be shared with other researchers</i>				
Yes	299 (58.74)	260 (51.38)	559 (55.07)	0.018
No	210 (41.26)	246 (48.62)	456 (44.93)	
Questions related to bio-rights				
<i>Do you think participants in researches should have control on how their biological specimens will be used?</i>				
Yes	214 (42.04)	228 (45.06)	442 (43.55)	0.551
No	199 (39.10)	182 (35.97)	381 (37.54)	
<i>How much control should/can individuals have regarding how their biological specimens will be used in research?</i>				
None	206 (40.47)	206 (40.71)	412 (40.59)	0.337
Little	137 (26.92)	111 (21.94)	248 (24.43)	
Much	96 (18.86)	115 (22.73)	211 (20.79)	
Total	43 (8.45)	45 (8.89)	88 (8.67)	

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Only two out of ten participants were willing to donate brain after death (18.8%, M: 22.6%, F: 15.0%, $p = 0.002$) as shown in Table 3. Over 6 out of 10 participants were willing to share their blood samples with researchers other than those they initially consent to use their data. However, just about three out of ten were willing to share brain tissues with other researchers beyond those they initial consent for participation with (36.7%, M: 42.2%, F: 30.8%, $p < 0.001$) (Table 4). Males were more willing than females to share their brain images with other researchers (58.7% versus 51.4%, $p = 0.018$). Whereas about 43% of the respondents wanted to have some degree of control over their biological samples and their usage, only 8.7% wanted total control (Table 4).

Awareness and perception of participants about informed consent

Responses to questions related to informed consent are detailed in Table 5. Only a third of the participants had heard of informed consent (31.7%; M: 35.9%, F: 27.5%, $p = 0.004$) with a preference for the broad consent (58.1%).

Table 5. Awareness and perception about informed consent.

Variable/question	Male (n = 509)	Female (n = 506)	Total (n = 1015)	p-value
	n (%)	n (%)	n (%)	
Heard of informed consent. (% Yes)	183 (35.95)	139 (27.47)	322 (31.72)	0.004
Types of informed consent preferred				
Broad	104 (56.83)	83 (59.71)	187 (58.07)	0.447
Restricted	35 (19.13)	26 (18.71)	61 (18.94)	
Tiered	9 (4.92)	10 (7.19)	19 (5.90)	
Dynamic	30 (16.39)	14 (10.07)	44 (13.66)	
Persons to be involved before giving informed consent				
No one	84 (45.90)	43 (30.94)	127 (39.44)	0.086
Spouse	49 (26.78)	50 (35.97)	99 (30.75)	
Children	14 (7.65)	16 (11.51)	30 (9.32)	
Parents	24 (13.11)	21 (15.11)	45 (13.98)	
Religious leaders and others	12 (6.56)	9 (6.47)	21 (6.52)	
It is best to use generic informed consent for community				
Agree	89 (48.63)	79 (56.83)	168 (52.17)	0.037
Disagree	92 (50.27)	54 (38.85)	146 (45.34)	
Perception about informed consent (% agreed)				
Broad informed consent should be used for genomic research.	244 (47.94)	260 (51.38)	504 (49.66)	0.546
Consent forms should include a separate section relating to storage and future use of samples and data.	314 (61.69)	339 (67.00)	653 (64.33)	0.147
It is personal choice to give blood for research.	372 (73.08)	394 (77.87)	766 (75.47)	0.206
Any blood sample collected from me must not be used for any other secondary use.	220 (43.22)	251 (49.60)	471 (46.40)	0.122
I will participate in genomic research if my community leader agrees	126 (24.75)	182 (35.97)	308 (30.34)	<0.001
Donor must be contacted each time the sample is to be re-used.	189 (37.13)	217 (42.89)	406 (40.00)	0.109
I feel it's a criminal offence to make profit from sample collected from me.	268 (52.65)	289 (57.11)	557 (54.88)	0.224

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Close to half of the participants agreed on a generic informed consent at the community level (52.2%; M: 48.6%, F: 56.8%, $p = 0.037$). While the majority (74.5%) of the participants agreed that blood donation for research is a personal choice, two-thirds indicated that consent forms should have a separate section on storage and future use of samples and data. Also, a third of the respondents indicated that they would participate in genomic research if their community leaders were involved (30.3%; M: 24.8%, F: 35.9%, $p < 0.001$) (Table 5).

Association of participant characteristics with willingness to donate share blood/brain sample

Table 6 summarizes the association of participant characteristics with willingness to donate share blood/brain fraction. Participants with tertiary education were more willing to donate brain samples for research [OR: 4.04 (C.I: 1.11–14.76) $p = 0.034$]; permit sharing their brain tissues with other researchers [OR: 3.82 (C.I: 1.51–9.68) $p = 0.005$], give consent for blood donation for genetic research [OR: 3.45 (C.I: 1.60–7.42), $p < 0.01$] and share their blood samples with other researchers [OR: 2.59 (C.I: 1.28–5.22), $p = 0.002$] as compared with participants without any formal education.

The odds of sharing of brain tissues with other researchers was 1.8 fold higher among those aged ≥ 50 years as compared to < 50 years [OR: 1.8 (C.I: 1.2–2.8), $p = 0.007$]. The Ga ethnic groups in Ghana were more willing to give consent for blood donation (OR: 6.6 (C.I: 1.7–24.3) $p = 0.005$); more willing to permit sharing their blood fraction with other researchers (OR: 5.1 (C.I: 1.7–14.8) $p = 0.003$); more willing to share their brain fractions with other researchers (OR: 3.7 (C.I: 1.5–9.3) $p = 0.006$) and also more willing to permit sharing their brain images with other researchers (OR: 3.9 (C.I: 2.1–7.5) $p < 0.001$) as compared with the Yoruba ethnic groups in Nigeria.

Association of demographic characteristics with awareness about informed consent

The association of demographic characteristics with awareness about informed consent is presented in Table 7. Similar to our findings above, tertiary education was significantly associated with awareness about informed consent [OR: 6.95 (C.I: 2.8–12.3), $p < 0.001$] as compared with those with no formal education Table 7.

Awareness about informed consent was higher among the Ewe groups in Ghana [OR: 5.4 (C.I: 1.4–20.9), $p = 0.014$] and Igbo groups in Nigeria [OR: 3.1 (C.I: 1.2–7.9), $p = 0.017$] as compared with the Yoruba groups. Compared to highly skilled groups, all other occupational groups were less likely to be aware of informed consent processes and options.

Discussion

There is a dearth of research examining concepts within genomic research including informed consent, neurobiobanking and awareness and willingness to donate biological samples such as blood and brain within sSA. Our study findings indicate that participants had lower levels of awareness about brain sample donation for research and low levels of willingness to donate brain samples (20%) as compared to blood samples (75%). These findings are consistent with findings from the IBADAN Brain Bank Project in Nigeria in which the awareness related to brain donation was found to be lower than for other organs [10]. There is generally low level of awareness of biobanking and organ donation globally, and brain donation for research is still an evolving concept in sSA [2, 18]. In our study, approximately a third had heard of blood sample donation for research, whereas only about a tenth had heard of collecting and storing

Table 6. Association of socio demographic characteristics and willingness to donate/share blood/brain samples.

Variable/characteristic	AOR (95% CI)	p-value
<i>Willingness towards donation of brain sample for research</i>		
Gender		
Male	1.37 (0.95–1.97)	0.096
Female	1	
Domicile		
Rural	0.86 (0.34–2.21)	0.760
Semi-urban	0.93 (0.61–1.40)	0.727
Urban	1	
Education		
None	1	
Arabic	3.01 (0.25–35.66)	0.382
Primary	1.65 (0.43–6.34)	0.470
Secondary	3.29 (0.95–11.48)	0.061
Tertiary	4.04 (1.11–14.76)	0.034
Religion		
Christianity	1	
Islam	1.35 (0.87–2.09)	0.184
Others	3.69 (0.31–44.68)	0.304
Occupation		
Highly skilled/professionals	1	
Skilled	1.53 (0.72–3.28)	0.267
Semi-skilled	2.04 (0.88–4.74)	0.097
Manual work	1.79 (0.68–4.77)	0.239
Not working	1.17 (0.48–2.84)	0.731
Student	3.79 (1.61–8.94)	0.002
<i>Willingness to permit sharing of brain tissues with other researchers</i>		
Age group		
< 50	1	
> = 50	1.81 (1.18–2.77)	0.007
Gender		
Male	1.31 (0.96–1.79)	0.093
Female	1	
Domicile		
Rural	0.57 (0.25–1.30)	0.182
Semi-urban	1.01 (0.69–1.46)	0.961
Urban	1	
Education		
None	1	
Arabic	0.67(0.07–6.70)	0.732
Primary	1.60 (0.61–4.23)	0.343
Secondary	2.87 (1.18–6.99)	0.021
Tertiary	3.82 (1.51–9.68)	0.005
Religion		
Christianity	1	
Islam	1.34 (0.92–1.97)	0.130
Others	1.06 (0.09–11.87)	0.963
Ethnic group		

(Continued)

Table 6. (Continued)

Variable/characteristic	AOR (95% CI)	p-value
Yoruba	1	
Igbo	1.37 (0.61–3.11)	0.448
Hausa	1.50 (0.85–2.66)	0.162
Akan	1.69 (0.72–3.95)	0.228
Ga/Adangbe	3.67 (1.45–9.27)	0.006
Ewe	3.87 (1.13–13.28)	0.032
Others	1.68 (0.96–2.92)	0.068
Occupation		
Highly skilled/professionals	1	
Skilled	1.43 (0.81–2.53)	0.221
Semi-skilled	1.88 (0.96–3.67)	0.066
Manual work	1.95 (0.94–4.06)	0.073
Not working	1.26 (0.65–2.47)	0.492
Student	3.86 (1.99–7.48)	<0.001
<i>Willingness to give consent to blood donation for genetic research</i>		
Gender		
Male	1.17 (0.82–1.67)	0.377
Female	1	
Education		
None	1	
Arabic	2.72 (0.55–13.54)	0.220
Primary	2.24 (1.04–4.82)	0.039
Secondary	2.08 (1.04–4.18)	0.040
Tertiary	3.45 (1.60–7.42)	0.002
Religion		
Christianity	1	
Islam	1.08 (0.73–1.59)	0.694
Others	3.16 (0.27–36.25)	0.356
Ethnic group		
Yoruba	1	
Igbo	1.63(0.69–3.88)	0.266
Hausa	3.29 (1.70–6.35)	<0.001
Akan	8.43 (2.78–25.55)	<0.001
Ga/Adangbe	6.55 (1.77–24.32)	0.005
Others	2.93 (1.55–5.53)	0.001
Occupation		
Highly skilled/professionals	1	
Skilled	0.74 (0.39–1.42)	0.366
Semi-skilled	1.07 (0.48–2.36)	0.870
Manual work	0.80 (0.35–1.83)	0.604
Not working	0.49 (0.24–1.02)	0.057
Student	1.47 (0.65–3.16)	0.326

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brain for research. However, the awareness levels of participants in the IBADAN Brain Bank Project was higher as compared to ours [10]. This could be attributed to the higher age group of participants in the IBADAN Brain Bank Project (mean age 46.3 years), though these differences may also stem from different cultural attitudes towards donation, religious beliefs or low

Table 7. Association of socio demographic characteristics and awareness of consent process.

Characteristics	AOR (95% CI)	p-value
Age group		
< 50	1	
> = 50	1.28 (0.83–1.98)	0.266
Gender		
Male	1.26 (0.90–1.75)	0.173
Female		
Domicile		
Rural	1.93 (0.92–4.03)	0.080
Semi-urban	1.24 (0.84–1.83)	0.227
Urban	1	
Education		
None	1	
Arabic	0.95 (0.09–9.31)	0.965
Primary	1.08 (0.42–2.83)	0.870
Secondary	2.04 (0.86–4.85)	0.107
Tertiary	6.95 (2.79–12.28)	<0.001
Marital status		
Single	1	
Married	2.44 (1.13–5.27)	0.023
Formerly married	1.59 (0.65–3.89)	0.313
Religion		
Christianity	1	
Islam	1.01 (0.68–1.52)	0.945
Others	3.37 (0.35–32.18)	0.293
Ethnic group		
Yoruba	1	
Igbo	3.09 (1.23–7.78)	0.017
Hausa	1.07 (0.53–2.15)	0.852
Akan	0.89 (0.37–2.21)	0.818
Ga/Adangbe	1.83 (0.68–4.91)	0.232
Ewe	5.42 (1.40–20.92)	0.014
Others	2.04 (1.08–3.89)	0.029
Occupation		
Highly skilled/professionals	1	
Skilled	0.52 (0.29–0.93)	0.029
Semi-skilled	0.36 (0.18–0.73)	0.004
Manual work	0.34 (0.16–0.73)	0.001
Not working	0.45 (0.23–0.89)	0.027
Student	0.18 (0.09–0.37)	<0.001

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levels of trust in public institutions (which may result from previous breaches of trust) as highlighted by Tindana et al. (2012) [19]. Some studies have indicated that biobanking knowledge, type of donated tissue, research purpose, concerns over the safety of the data, preferred type of consent, and trust towards biobanks, affect willingness to donate [6]. Indeed, over half of the participants in our study indicated that they were not willing to donate brain because they wanted to go back to God complete (religious beliefs). Studies conducted in Scandinavian countries (such as Sweden and Finland) highlight the positive correlation between knowledge

and positive opinions on biobanks with respondents' willingness to donate; where the knowledge about biobanks is highest, 83% of Finns and 86% of Swedes declared such willingness [20–22]. Awareness about biobanking is generally low globally and not only confined to the African Region. In the 2010 Eurobarometer study, for instance, two-thirds of Europeans have never heard about biobanks and less than 2% search for information about biobanking [13]. Low levels of awareness on biobanking and the increased willingness to donate (mainly blood and not brain) in our study calls for stakeholders input (general public, religious leaders, scientists, industry, and non-governmental organizations) through community-based participatory research and citizen science approaches to identify research priorities and actively involve sample donors in biobanking process and guidelines to further scientific advancements [8, 23, 24].

An important concept in genetic research and biobanking is the process of informed consent. This is required for several reasons including storage of samples (sometimes for an indefinite period) and to use samples for unspecified future research. Only a third of our study participants were aware of informed consent. This could be attributed to the profile of the participants who were largely laypersons in the studied communities with no prior information on or engagement with biomedical research. Nevertheless, participants generally had a preference for the broad type of consent (a process by which individuals donate their samples for a broad range of unspecified future studies with some restriction) [5, 25, 26]. Although, the broad type of consent has been proposed as an appropriate consent model in African genomics research and biobanking [27], it has been linked with the risk of exploitation of African research populations [4, 25, 28]. Nevertheless, this approach reduces the financial and logistical barriers to researchers, and the burden to participants, which may be a particular challenge in many African research settings [8]. Recommendations for the use of the broad consent models has been to include governance mechanisms that incentivize biobanks to promote the interests of biological sample donors as well as communities' health and research needs [8]. Indeed, it was observed in our study that over half of the participants indicated they agreed with a generic consent at the community level and a third of the participants indicated that they were more likely to participate in genomic studies if their community leaders agree. However, over half of the participants did not know of any guidelines regulating blood and brain biobanking. The role of a community engagement approach has been found to be a critical component in the ethical conduct of health research and is particularly pertinent in communitarian societies such as Africa [29]. Also, national guidelines at the country level within Africa are important for biobanking to eliminate what has been described as exploitative “parachute” research (a practice whereby scientists in high-income countries go to low-income countries to collect specimens and publish findings in prestigious journals without properly crediting collaborators in Low-and-Middle Income Countries or providing tangible benefits to study communities) [8, 24].

Other factors, such as socio-demographic characteristics, were also associated with willingness to participate in biobanking research. Educational attainment (tertiary education) and male gender were found to be important predictors of willingness to donate and share both blood and brain samples for research and having prior awareness about informed consent. While religious beliefs did not seem to influence participants' willingness to sample donation and sharing in our study, in a British study, non-believers and less religious persons were more interested in donation [18]. Although religious beliefs may not be a determining factor in biobank participation, it is expected to provide comfort into the willingness to enroll in research initiatives. For instance, the linkage of Islam with scientific knowledge and advancement, may be influential in increasing awareness towards genetics and biobanking [30]. In developing interventions, it is thus important to promote better representation of

socioeconomic diversity including religion in research leadership and ensure tailored health education materials of appropriate literacy to expand genetic education for increased public awareness and understanding. By expanding participation rates among the diverse populations within Africa, opportunities exist to better understand the genomic diversity representative across the continent [27, 28, 31]. Our study also highlights the influence of certain ethnic groups (Ewe and Igbo groups), who were likely to be aware of informed consent as compared to the others (Yoruba). This finding needs further studies to explain this observation as it is beyond the scope of this current study.

This study contributes further to our understanding of communities in Ghana and Nigeria on views and attitudes towards biological sample donation/sharing and informed consent. It also reinforces the importance of involving the public in a more transparent dialogue about the use of biological samples to encourage greater public involvement and support for this area given the low awareness levels. It indicates the need for good governance concerning biological samples and their associated data, which requires complex discussions around community engagement, public learning and understanding of science and ethical principles of informed consent. The findings of our study should be considered in light of the following limitations: first, it relies on self-reported data and not objective measurements of awareness, attitudes and biobanking knowledge, which could be influenced by a social desirability bias. Second, as no validated tools exist, the authors relied on methods that have been utilized in other genetics literature. Nevertheless, our study's large sample size, diverse coverage, and rigorous sampling strategy of participants are potential strengths.

Conclusion

Our study findings demonstrate that despite inadequate awareness of biobanking, sample donation and informed consent, there is a high level of public support for, and willingness to contribute to biobanking related to blood donation (than brain). Individuals with higher educational levels are more willing to donate samples indicating the need to inform a broader public including the older generation and people in rural areas about the role of research biobanks. Improved public education through strategies including the social media; communication with representatives of patients' organizations, local community and other stakeholders; promotion of active participation and engagement of the community/donors in promoting the idea of biobanking while taking care of the cultural and religious diversities of the donors are recommended to mitigate some of the concerns.

Supporting information

S1 File. Questionnaire_survey.
(PDF)

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References

1. Akinyemi RO, Akinwande K, Diala S, et al. Biobanking in a Challenging African Environment: Unique Experience from the SIREN Project. *Biopreservation and Biobanking* 2018; 16:217–32. <https://doi.org/10.1089/bio.2017.0113> PMID: 29733683
2. Akinyemi RO, Salami A, Akinyemi J, et al. Brain banking in low and middle-income countries: Raison D'être for the Ibadan Brain Ageing, Dementia And Neurodegeneration (IBADAN) Brain Bank Project. *Brain Research Bulletin*. 2019; 145:136–41. <https://doi.org/10.1016/j.brainresbull.2018.08.014> PMID: 30149197
3. de Vries J, Munung SN, Tindana P. Deliberation to Promote Shared Sovereignty in Health Research: Four Questions to Clarify Goals, Methods, and Scope. *American Journal of Bioethics*. 2016. <https://doi.org/10.1080/15265161.2016.1214326> PMID: 27653401
4. De Vries J, Munung SN, Matimba A, et al. Regulation of genomic and biobanking research in Africa: A content analysis of ethics guidelines, policies and procedures from 22 African countries. *BMC Medical Ethics* Published Online First: 2017. <https://doi.org/10.1186/s12910-016-0165-6> PMID: 28153006
5. Tindana P, De Vries J. Broad Consent for Genomic Research and Biobanking: Perspectives from Low- and Middle-Income Countries. *Annual Review of Genomics and Human Genetics* 2016; 17:375–93. <https://doi.org/10.1146/annurev-genom-083115-022456> PMID: 26905784
6. Domaradzki J, Pawlikowski J. Public attitudes toward biobanking of human biological material for research purposes: A literature review. *International Journal of Environmental Research and Public Health* 2019;16. <https://doi.org/10.3390/ijerph16122209> PMID: 31234457
7. Mweemba O, Musuku J, Mayosi BM, et al. Use of broad consent and related procedures in genomics research: Perspectives from research participants in the Genetics of Rheumatic Heart Disease (RHDGen) study in a University Teaching Hospital in Zambia. *Global Bioethics* Published Online First: 2019. <https://doi.org/10.1080/11287462.2019.1592868> PMID: 33343192
8. Staunton C, Moodley K. Challenges in biobank governance in Sub-Saharan Africa. *BMC Medical Ethics* Published Online First: 2013. <https://doi.org/10.1186/1472-6939-14-35> PMID: 24025667
9. Tindana PO, Rozmovits L, Boulanger RF, et al. Aligning community engagement with traditional authority structures in global health research: A case study from Northern Ghana. *American Journal of Public Health* Published Online First: 2011. <https://doi.org/10.2105/AJPH.2011.300203> PMID: 21852635
10. Akinyemi R, Ojagbemi A, Akinyemi J, et al. Gender differential in inclination to donate brain for research among Nigerians: the IBADAN Brain Bank Project. *Cell and Tissue Banking* 2019; 20:297–306. <https://doi.org/10.1007/s10561-019-09769-4> PMID: 31028517
11. Antommara AHM, Brothers KB, Myers JA, et al. Parents' attitudes toward consent and data sharing in biobanks: A multisite experimental survey. *AJOB Empirical Bioethics* 2018; 9:128–42. <https://doi.org/10.1080/23294515.2018.1505783> PMID: 30240342
12. Sanderson SC, Brothers KB, Mercaldo ND, et al. Public Attitudes toward Consent and Data Sharing in Biobank Research: A Large Multi-site Experimental Survey in the US. *American Journal of Human Genetics* 2017; 100:414–27. <https://doi.org/10.1016/j.ajhg.2017.01.021> PMID: 28190457
13. Brall C, Berlin C, Zwahlen M, et al. Public willingness to participate in personalized health research and biobanking: A large-scale Swiss survey. *PLoS ONE*. 2021; 16. <https://doi.org/10.1371/journal.pone.0249141> PMID: 33793624
14. Akinyemi RO, Jenkins C, Nichols M, et al. Unraveling the Ethical, Legal, and Social Implications of Neurobiobanking and Stroke Genomic Research in Africa: A Study Protocol of the African Neurobiobank for Precision Stroke Medicine ELSI Project. *International Journal of Qualitative Methods* 2020; 19:160940692092319. <https://doi.org/10.1177/1609406920923194> PMID: 34276269

15. Jenkins C, Arulogun OS, Singh A, et al. Stroke Investigative Research and Education Network. *Health Education & Behavior* Published Online First: 2016. <https://doi.org/10.1177/1090198116634082> PMID: 27037152
16. Akinyemi RO, Sarfo FS, Akinyemi J, et al. Knowledge, attitudes and practices of West Africans on genetic studies of stroke: Evidence from the SIREN Study. *International Journal of Stroke* Published Online First: 2019. <https://doi.org/10.1177/1747493018790059> PMID: 30040054
17. Akinyemi RO, Akinyemi JO, Olorunsogbon OF, et al. Gender and educational attainment influence willingness to donate organs among older nigerians: A questionnaire survey. *Pan African Medical Journal* 2020; 36:1–13. <https://doi.org/10.11604/pamj.2020.36.288.21125>
18. Gaskell G, Gottweis H, Starkbaum J, et al. Publics and biobanks: Pan-European diversity and the challenge of responsible innovation. *European Journal of Human Genetics* 2013; 21:14–20. <https://doi.org/10.1038/ejhg.2012.104> PMID: 22669414
19. Tindana P, Bull S, Amenga-Etego L, et al. Seeking consent to genetic and genomic research in a rural Ghanaian setting: A qualitative study of the MalariaGEN experience. *BMC Medical Ethics* Published Online First: 2012. <https://doi.org/10.1186/1472-6939-13-15> PMID: 22747883
20. Tupasela A, Snell K, Sihvo S, et al. Attitudes towards biomedical use of tissue sample collections, consent, and biobanks among Finns. *Scandinavian Journal of Public Health* 2010; 38:46–52. <https://doi.org/10.1177/1403494809353824> PMID: 19906772
21. Hemminki E, Tupasela A, Jallinoja P, et al. Finnish people's attitudes towards biomedical research and its sponsorship. *Genomics, Society and Policy* 2009; 5:67–79. <https://doi.org/10.1186/1746-5354-5-2-67>
22. Kettis-Lindblad Å, Ring L, Viberth E, et al. Perceptions of potential donors in the Swedish public towards information and consent procedures in relation to use of human tissue samples in biobanks: A population-based study. *Scandinavian Journal of Public Health* 2007; 35:148–56. <https://doi.org/10.1080/14034940600868572> PMID: 17454918
23. Rotimi C, Abayomi A, Abimiku A, et al. Research capacity. Enabling the genomic revolution in Africa. *Science*. 2014; 344:1346–8. <https://doi.org/10.1126/science.1251546> PMID: 24948725
24. Klingstrom T, Mendy M, Meunier D, et al. Supporting the development of biobanks in low and medium income countries. In: *2016 IST-Africa Conference, IST-Africa 2016*. Institute of Electrical and Electronics Engineers Inc. 2016. <https://doi.org/10.1109/ISTAFRICA.2016.7530672>
25. Tindana P, Molyneux S, Bull S, et al. 'It is an entrustment': Broad consent for genomic research and biobanks in sub-Saharan Africa. *Developing World Bioethics* Published Online First: 2019. <https://doi.org/10.1111/dewb.12178> PMID: 29063669
26. Rutakumwa R, de Vries J, Parker M, et al. What constitutes good ethical practice in genomic research in Africa? Perspectives of participants in a genomic research study in Uganda. *Global Bioethics* Published Online First: 2019. <https://doi.org/10.1080/11287462.2019.1592867> PMID: 33343191
27. Yakubu A, Tindana P, Matimba A, et al. Model framework for governance of genomic research and biobanking in Africa—a content description. *AAS Open Research* 2018; 1:13. <https://doi.org/10.12688/aasopenres.12844.2> PMID: 30714023
28. Vaught J. Biobanking and Biosecurity Initiatives in Africa. *Biopreservation and Biobanking* 2016. <https://doi.org/10.1089/bio.2016.29009.jjv> PMID: 27622547
29. Staunton C, Tindana P, Hendricks M, et al. Rules of engagement: Perspectives on stakeholder engagement for genomic biobanking research in South Africa. *BMC Medical Ethics* Published Online First: 2018. <https://doi.org/10.1186/s12910-018-0252-y> PMID: 29482536
30. WHO EMRO | An Islamic perspective on human genetic and reproductive technologies | Volume 12, supplement 2 | EMHJ volume 12, 2006. <http://www.emro.who.int/emhj-volume-12-2006/volume-12-supplement-2/an-islamic-perspective-on-human-genetic-and-reproductive-technologies.html> (accessed 30 Jul 2021).
31. Igbe MA, Adebamowo CA. Qualitative study of knowledge and attitudes to biobanking among lay persons in Nigeria. *BMC medical ethics* 2012; 13:27. <https://doi.org/10.1186/1472-6939-13-27> PMID: 23072321