

Study ID \_\_\_\_\_

## African Neurobiobank for Precision Stroke Medicine - Ethical, Legal, and Social Implications (ELSI) Project

### DRAFT QUESTIONNAIRE SIREN STROKE CASES, SIREN CONTROLS AND LAY PERSONS

Dear Respondent,

Good day. We are conducting a survey to explore your knowledge, attitude and perceptions, about ethical, legal and social issues related to the use of blood and stored blood fractions, brain images (CT/MRI) and brain donation in the context of stroke genomic research.

We invited you to respond to a couple of questions because we believe that you have one important thing or the other to share with us on issues related to ethical, legal and social issues relating to stroke biobanking in the African context.

Whatever we learn from today's discussion will help us develop an intervention program to address the ELSI issues related to stroke genomic and biobanking research in Sub Saharan Africa.

We will not write your name or house address on the questionnaire. Some of the questions may touch on very personal issues. Your true opinions on these issues will be greatly appreciated. Please, kindly answer all questions sincerely. You have a right to decline to participate in the study without any consequence.

Thank you.

**Willingness to participate**    Yes             No

*Please tick the category the participant belongs to.*

- SIREN Enrolled Stroke cases
- SIREN Enrolled Stroke Free Controls
- Non SIREN Stroke Free Lay Persons

**Mode of questionnaire administration (Pls tick one option as applicable)**

- Interviewer Administered
- Self-Administered

Interviewers Name/Initials \_\_\_\_\_

**SECTION A: Socio Demographic Characteristics**

1. Age in years (as at last birthday) \_\_\_\_\_ 2. Gender Male  Female
3. Type of Domicile: Rural  Semi-urban  Urban
4. Religion: Christianity  Islam  Traditional  Others (specify) \_\_\_\_\_
5. Native Language: Yoruba  Igbo  Hausa  Aka  Ga/Adangbe  Ewe  Others (specify) \_\_\_\_\_
6. Ethnic group: Yoruba  Igbo  Hausa  Aka  Ga/Adangbe  Ewe  Others (specify) \_\_\_\_\_
7. Country of birth: Nigeria  Ghana  Others (specify) \_\_\_\_\_
8. Average Total Monthly Household Income in USD: 0 -100  101 -250  251 -500  501 - 1500  1501 - 3000  >3000
9. Marital Status: Single  Married  Widowed  Separated  Divorced
10. Living Situation: Lives alone  Lives with spouse and children  Lives in a nursing home  Live with spouse   
Lives with extended family  Lives with children  Others (specify) \_\_\_\_\_
11. Primary Occupation: \_\_\_\_\_
- 11b. Classification: Highly skilled academic profession  Home maker  Skilled worker  Retired  Manual work   
Unemployed(able to work)  Student  Non-paid worker  Semi-skilled worker  Unemployed (unable to work)
- 11c. If retired, Primary Occupation before retirement: \_\_\_\_\_
12. Educational qualification: None  Informal education  Arabic School  Primary  Junior secondary  Senior secondary   
Tertiary  Postgraduate

**SECTION B: Awareness and knowledge of blood sample donation and bio-banking. Tick ( ) the option appropriate to you)**

13. Have you ever heard of the following terms?
- a. Blood sample donation for medical research? Yes  No
- b. Blood sample storage (bio-banking) for research purpose? Yes  No

**If No to both questions a and b, please go to question 18.**

14. If Yes, what do you know about blood sample donation for research? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

15. If Yes, what do you know about blood sample storage (bio-banking) for research purpose? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

16. If your answer to question 13a above is Yes, from which of the following sources did you hear about blood sample donation?

**(You can choose more than one option).**

- Hospital  Training program  Friend  Colleague  Newspaper/magazine  Internet/Online resources   
Seminar/conference/workshop  TV  Radio  Community/public outreach/engagement Initiative  Family  Others(Specify) \_\_\_\_\_

17. If your answer to question 13a above is Yes, from which of the following sources did you hear about blood sample storage for research purpose?

**(You can choose more than one option).**

- Hospital  Training program  Friend  Colleague  Newspaper/magazine  Internet/Online resources   
Seminar/conference/workshop  TV  Radio  Community/public outreach/engagement Initiative  Family  Others(Specify) \_\_\_\_\_

18. Which of the following biological samples can be stored in a biobank? **(You can choose more than one option).**

Blood and related blood fractions  Urine  Cerebrospinal fluid  Brain tissues  Others(Specify) \_\_\_\_\_

19. Are you aware of any guidelines/regulation that has to do with use of blood and its storage for genomic research purpose? Yes  No

20. If Yes, do you have a copy of any guidelines/regulation that has to do with use of blood and its storage for genomic research purpose? Yes  No

**SECTION C: Genetic Knowledge** (Please Tick ( ) the option appropriate to you)

SN	Statements	Yes	No	Don't Know
21.	One can see a gene with the naked eye.			
22.	A gene is a disease.			
23.	A gene is a molecule that controls hereditary characteristics			
24.	Genes are inside cells			
25.	A gene is a piece of DNA			
26.	A gene is a cell			
27.	A gene is a part of a chromosome			
28.	Different body parts include different genes			
29.	Genes are bigger than chromosome			
30.	The genotype is not susceptible to human intervention			
31.	It has been estimated that a person has 22,000 genes			
32.	Healthy parents can have a child with a hereditary disease			
33.	The onset of certain diseases are due to genes, environment and lifestyle			
34.	The carrier of a disease gene may be completely healthy			
35.	All serious disease are hereditary			
36.	The child of a disease gene carrier is always also a carrier of the same disease gene			

**SECTION D: Awareness of Brain Donation for Research** (Please Tick ( ) the option appropriate to you)

37. Have you ever heard of brain donation for research purpose? Yes  No  **(If answer is No, please go to question 41)**

38. If Yes, what did you hear about brain sample donation for research? \_\_\_\_\_

39. If your answer to question 38 above is yes, through which of the following sources did you hear about brain sample for research purpose? **(You can choose more than one option).**

Hospital  Training program  Friend  Colleague  Newspaper/magazine  Internet/Online resources

Seminar/conference/workshop  TV  Radio  Community/public outreach/engagement Initiative  Family  Others(Specify) \_\_\_\_\_

40. Do you know anyone who donated brain for research purposes before? Yes  No

41. Have you ever heard of the concept of collecting and storing brain for research purposes? Yes  No  **(If answer is No, please go to Q.44)**

42. If answer to question 41 above is Yes, through which of the following sources did you hear about banking/storing of brain for research **(You can choose more than one option).**

Hospital  Training program  Friend  Colleague  Newspaper/magazine  Internet/Online resources

Seminar/conference/workshop  TV  Radio  Community/public outreach/engagement Initiative  Family  Others(Specify) \_\_\_\_\_

43. Are you aware of any guidelines/regulation that has to do with use of brain and its storage for research purpose? Yes  No

44. Would you be willing to donate your brain sample for research purposes after death? Yes  No

44a. If Yes, please state your reasons **(you can choose more than one option)**

I like the idea that it will help advance medicine  I would be happy knowing that I can save someone's life

I like the idea that it will help prevent future disease  I like the idea that it can help generation to come

I have no need of my brain again after death  Others(Specify) \_\_\_\_\_

44b. If No, please state your reasons (**you can choose more than one option**)

I want to go back to God complete   
 my religion does not allow that   
 if I donate my brain, people will think I have joined occultic association   
 I am not knowledgeable of the purpose

I don't trust Africans   
 I don't trust medical system/medical researchers   
 it's like someone is destroying the work of God   
 I don't just want to

Others(Specify) \_\_\_\_\_

45. People in Africa would be willing to donate brain samples for research purposes? Agree  Disagree

45a. If you **Agree**, please state your reasons (allow respondent to give as many reasons as possible) \_\_\_\_\_

45b. If you **Disagree**, please state your reasons (allow respondent to give as many reasons as possible)

Most people are not knowledgeable about it importance  It is not commonly done in our environment   
 Nobody will agree to buried with incomplete body parts  Others (Specify) \_\_\_\_\_

46. What kind of actions should be taken in order to promote willingness to donate brain samples for research? (**You can choose more than one option**).

Media publicity  Education  Legislation  Involving religious and community leaders  Education of people on social media

Others (Specify) \_\_\_\_\_

**SECTION E: Awareness of Stroke Genomic Research.** (Please Tick ( ) the option appropriate to you)

47. Have you ever heard of stroke genomic research? Yes  No  (**If answer is No, please go to Section F**)

48. If your answer to question 47 above is **Yes**, through which of the following sources did you hear about stroke genomic research? (**You can choose more than one option**).

Hospital  Training program  Friend  Colleague  Newspaper/magazine  Internet/Online resourcess   
 Seminar/conference/workshop  TV  Radio  Community/public outreach/enagement Initiative  Family  Others(Specify) \_\_\_\_\_

49. Have you ever donated blood for stroke genomic research before? Yes  No

50. Have you ever heard of the concept of collecting blood and storing the blood for stroke genomic research?

Yes  No  **If answer is No, please go to Section F.**

51. If answer to question 50 above is Yes, through which of the following sources did you hear about banking/storing of blood for stroke genomic research (**You can choose more than one option**).

Hospital  Training program  Friend  Colleague  Newspaper/magazine  Internet/Online resourcess   
 Seminar/conference/workshop  TV  Radio  Community/public outreach/enagement Initiative  Family  Others(Specify) \_\_\_\_\_

52. Kindly tick the appropriate response for the following statements on blood collection:

SN	Statements	Yes	No	Don't Know
	<i>Research on blood collected can lead to advancement in medicine such as:</i>			
1	Drug discovery?			
2.	Better management of illness			
3.	Diagnostic tools			

**SECTION F: Awareness of Precision Medicine.** (Please Tick ( ) the option appropriate to you)

53. Have you ever heard of precision stroke medicine? Yes  No  (**If answer is No, please go to Question 55**)

54a. If your answer to question 53 above is Yes, through which of the following sources did you hear about precision stroke medicine?  
(You can choose more than one option).

Hospital  Training program  Friend  Colleague  Newspaper/magazine  Internet/Online resources   
Seminar/conference/workshop  TV  Radio  Community/public outreach/engagement Initiative  Family  Others(Specify) \_\_\_\_\_

54b. If Yes, what is precision stroke medicine? \_\_\_\_\_

**SECTION G: Awareness , Knowledge and Perception on Informed Consent Processes**

55. Have you ever heard of informed consent before? Yes  No

56. What do you know about the informed consent process for genetic research? \_\_\_\_\_

57. Types of informed consent preferred (Facilitator to please explain each type to the participants)

Broad  Restricted  Tiered  Dynamic

57a. If broad, provides reason(s) for your choice \_\_\_\_\_

57b. If restricted, provides reason(s) for your choice \_\_\_\_\_

57c. If tiered provides reason(s) for your choice \_\_\_\_\_

57d. If dynamic, provides reason(s) for your choice \_\_\_\_\_

58. Who are the persons to be involved before you can give informed consent? No one  Spouse  Children  Parents   
Religious leaders e.g Pastors, Imam etc  Others (Specify) \_\_\_\_\_

59. How should data collected from you be used in the incident of death?

Once I have given it, you can do anything good with it even after my death   
My children/family should be called to decides   
It should be discarded   
Others(Specify) \_\_\_\_\_

59a. Give reasons for your response \_\_\_\_\_

60. It is best to use generic informed consent for community? (Facilitator should please explain) Agree  Disagree

60a. If you **Agree**, please state your reasons (allow respondent to give as many reasons as possible) \_\_\_\_\_

60b. If you **Disagree**, please state your reasons (allow respondent to give as many reasons as possible) \_\_\_\_\_

For the following perception questions on Informed consent, please tick ( ) the option appropriate to you

61	Perception	Agree	Not sure	Disagree
1	Broad informed consent should be used for genomic research			
2.	Consent forms should include a separate section relating to storage and future use of samples & data			
3.	It is personal choice to give blood for research.			
4.	Any blood sample collected from me must not be used for any other secondary use (subsequent use of stored samples for researches not indicated on the informed consent)			
5.	I will participate in genomic research if my community leader agrees			
6.	Donor must be contacted each time the sample is to be re-used.			
7.	I feel it's a criminal offence to make profit from sample collected from me.			

**SECTION H: Willingness/Intention towards blood sample donation for research and biobanking** (please tick ( ) the option appropriate to you)

62. Would you be willing to give consent for blood sample donation for genetic research and saving for future use? Yes  No

63. Are there any particular reasons that can make you less likely to donate your blood sample for genetic research and banking for future use?

**You can choose more than one answer.**

- |  |   |
|--|---|
| This is against my religion <input type="checkbox"/>                           | Never thought about it <input type="checkbox"/>                                       |
| I am not fat <input type="checkbox"/>  | It may be used for rituals because I don't trust researchers <input type="checkbox"/> |
| I don't trust medical system <input type="checkbox"/>                          | My doctor warned me against donating blood . <input type="checkbox"/>                 |
| Blood is life and I don't want to reduce my lifespan. <input type="checkbox"/> | I fell terribly sick the last time I donated blood <input type="checkbox"/>           |

Others(Specify) \_\_\_\_\_

64. What is/are could be your greatest motivation towards consenting to donating blood sample for genetic research?

**(You can choose more than one option)**

- |   |   |
|---|---|
| That the result would help prevent future diseases <input type="checkbox"/> | I would be happy knowing that I can save someone's life <input type="checkbox"/>            |
| It will contribute to research activities <input type="checkbox"/>          | I like the idea that it can help us know about our problems <input type="checkbox"/>        |
| It would give me a sense of responsibility <input type="checkbox"/>         | I like the idea that it can help generations to come <input type="checkbox"/>               |
| It would give me a sense of pride <input type="checkbox"/>                  | Drugs could be developed that can impact positively on the society <input type="checkbox"/> |

Others (Specify) \_\_\_\_\_

65. If you were asked in a hospital to give consent for a family member blood sample donation for genetic research and banking for future use,

will you agree? Yes  No

65a. if yes, please give reasons for your answers \_\_\_\_\_

65b. If No, please give reasons for your answers \_\_\_\_\_

66. What kind of actions should be taken in order to promote willingness to give blood sample for research and banking for future use?

**(You can choose more than one option)**

Media publicity/campaign  Public Education/Advocacy  Legislation  Involving religious and community leaders

Education of people through social media  Education by healthcare provider  Others (Specify) \_\_\_\_\_

**SECTION I Health conscious behaviours**

66. What do you do purposely for your health (*Please choose as many as apply to you*)

Reduce alcohol consumption	<input type="checkbox"/>	Avoid eating between meals	<input type="checkbox"/>
Reduce amount of smoking	<input type="checkbox"/>	Purposely eat less	<input type="checkbox"/>
Exercise at least 30minutes or more once per week	<input type="checkbox"/>	Refrain from oily foods	<input type="checkbox"/>
Purposely move body once a week	<input type="checkbox"/>	Reduce salt intake	<input type="checkbox"/>
Try to eat fish	<input type="checkbox"/>	Others _____	

**SECTION J: Data sharing, Use and Reuse of Stored Blood/Blood products, Brain Tissue samples and images**

67. Blood/blood fractions taken from me can be shared with other researchers both locally and internationally.

Yes  No

67a. if yes, please give reasons for your answers \_\_\_\_\_

67b. If No, please give reasons for your answers \_\_\_\_\_

68. Brain tissue samples taken from me can be shared with other researchers both locally and internationally

Yes  No

if yes, please give reasons for your answers \_\_\_\_\_

If No, please give reasons for your answers \_\_\_\_\_

70. My brain images can be shared with other researchers both locally and internationally Yes  No

if yes, please give reasons for your answers \_\_\_\_\_

If No, please give reasons for your answers \_\_\_\_\_

**SECTION K: Perception of biological sample donation for research and secondary use (please tick ( ) the option appropriate to you)**

71	Perception	Agree	Not sure	Disagree
i	Donating blood sample for research is good because any discovery can help to save lives.			
ii	Blood sample availability creates important opportunities for researchers to advance medical science and contribute to collective good.			
iii	Blood collected from me can be stored for future use since I have no need of it again.			
iv.	There is no need to contact the donor of the blood sample if the need arises to conduct future studies not previously planned.			
v	Every benefit/ profit/ money got through research on my blood sample should be shared with me.			
vi.	Blood sample collected from me can be taken to another country for further use.			
vii.	My religion does not allow blood sample donation for research.			
viii.	I will give blood sample if my pastor / imam agrees.			
ix.	It is wrong in my culture to give blood sample for research purposes			
x.	It is wrong in my culture to give blood sample for storage purposes			
xi.	I will like to receive the result of genetic testing done on my blood sample.			
xii.	Clients who desire to know their own genetic status should receive pre- and post-genetic counselling.			

71	Perception	Agree	Not sure	Disagree
xiii	Genetic discrimination in the context of their marriage, employment or insurance may increase if result of finding is returned to donor			
xiv.	Returning genetic test results from genetic studies, should be done using 'face-to-face' approach			
xv.	I would support my family members who shows willingness to donate blood sample for genomic research			
xvi.	I would support my family members who shows willingness to donate blood sample for storage			

**Section L: Barriers and facilitators relating to blood donation (other biological samples) for research and bio-banking practices?**

72. Have you ever donated blood or had other biological samples/reports been collected for research purpose before? Yes  No

73a. If Yes to question 68, kindly complete the table below:

SN	Biological Sample(s)	Organisation project	Date	Location	Purpose for which sample was collected/donated
a	Blood				
b	Urine				
c	Cerebrospinal fluid				
d	Brain Images(CT/MRI)				
e	Brain Tissues				
f	Others(specify)_____				

73b. If your answer to question 68 is No, have you ever had the opportunity to donate blood or had your blood (or other biological samples/reports) collected as sample for research to which you declined? Yes  No

73bi. If Yes, kindly explain your reason(s) for declining to donate blood or have your blood (or other biological samples/reports) collected as sample for research \_\_\_\_\_

74. What factors will greatly encourage you to participate in blood donation and (or other biological samples/reports) collection for genomic research?

**Section M: Perception relating to disclosure of individual genomic Research Findings?**

75. Have you ever received genetic counselling before? Yes  No

75a. If yes, what were you counselled for? \_\_\_\_\_

76. Have you ever participated in genomic research before Yes  No  **if No go to Q.79**

77. If you had participated in a blood donation/other biological sample/reports collection activity, how was the result/research findings shared with you?

Please specify: Phone Call  Email  Letters  Feedback by a health worker  Feedback through a researcher

Feedback through a clinician  Others (please specify) \_\_\_\_\_

78. Did you have any issue relating to how your result/research finding was returned to you Yes  No

78a. If Yes, what were some of the issues you had with the means of research/result dissemination stated above? \_\_\_\_\_

79. If you are to participate in a blood donation/sample collection in genomic research, which way would you want your individual result or incidental findings

to be relayed back to you? **You can choose more than one answer** Phone Call  Email  Letters  Feedback by a health worker

Feedback through a researcher  Feedback through a clinician  Others (please specify) \_\_\_\_\_



80. Will you prefer to have your individual genetic research/result findings collected by proxy or third party? Yes  No

**SECTION N: Bio-rights**

81. Do you think participants in researches should have control on how their biological specimens will be used? Yes  No  Don't know

82. How much control should/can individuals have regarding how their biological specimens will be used in research?

None  Little  Much  Total

83. Has this interview influenced your willingness to give consent for blood sample donation for research and banking? Yes  No

83a. if yes, please give reasons for your answers \_\_\_\_\_

83b. If No, please give reasons for your answers \_\_\_\_\_