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Capacity-Building for Stroke Genomic Research Data Collection: The African Neurobiobank Ethical, Legal, and Social Implications Project Experience

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Background: The fields of stroke genomics, biobanking, and precision medicine are rapidly expanding in sub-Saharan Africa. However, the ethical, legal, and social implications (ELSI) of emerging neurobiobanking and genomic data resources are unclear in an emerging African scientific landscape with unique cultural, linguistic, and belief systems.

Objective: This article documents capacity-building experiences of researchers during the development, pretesting, and validation of data collection instruments of the African Neurobiobank for Precision Stroke Medicine—(ELSI) Project.

Methods: The African Neurobiobank for Precision Stroke Medicine—ELSI project is a transnational, multicenter project implemented across seven sites in Ghana and Nigeria. Guided by the Community-Based Participatory Research framework, we conducted three workshops with key stakeholders to review the study protocol, ensure uniformity in implementation; pretest, harmonize, and integrate context-specific feedback to ensure validity and adaptability of data collection instruments. Workshop impact was assessed using an open-ended questionnaire, which included questions on experience with participation in any of the workshops,

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building capacity in Genetic and Genomic Research (GGR), level of preparedness toward GGR, the genomic mini-dictionary developed by the team, and its impact in enhancing understanding in GGR. Data were analyzed qualitatively using a thematic framework approach.

Results: Findings revealed the usefulness of the workshop in improving participants' knowledge and capacity toward GGR implementation. It further identified local, context-specific concerns regarding quality data collection, the need to develop culturally acceptable, genomic/biobanking data collection tools, and a mini-dictionary. Participants-reported perceptions were that the mini-dictionary enhanced understanding, participation, and data collection in GGR. Overall, participants reported increased preparedness and interest in participating in GGR.

Conclusion: Capacity-building is a necessary step toward ELSI-related genomic research implementation in African countries where scholarship of ELSI of genomics research is emerging. Our findings may be useful to the design and implementation of ELSI-GGR projects in other African countries.

Keywords: bio-banking, genomics, capacity-building, ELSI, stroke, West Africa

Introduction

Globally, stroke remains a significant public health challenge,[1] particularly in African countries.[2] Genetic and genomic research (GGR), along with its benefits in advancing targeted treatment approaches through precision medicine (PM), offer promising mechanisms to reduce the overwhelming burden of stroke in the region.[3] To achieve this, the region first needs to expand capacity and expertise of GGR research among the scientific communities in Africa. This capacity extends beyond infrastructure and includes training scientists and research teams to engage in GGR studies. Training should be widespread and include common language to maximize the benefits of PM and generate evidence needed for policy development and genomic research reform in Africa.[4–6]

With the support of the Human Hereditary and Health (H3Africa)'s capacity building efforts,[7] PM is gaining momentum[8] in Africa[1,9,10] as a medical model that uses individual disease risk profiles to facilitate diagnosis and targeted treatment approaches.[11] Biobanking, a related term, refers to long-term storage of collected bio-samples. Collection of bio-samples enables genomics research toward building disease cohorts, and mapping and validation of genetic disease risks.[12] Although PM and biobanks are in full operation in developed countries, both are slowly evolving in low- and middle-income countries (LMIC) and expertise and processes are needed across the continent to enable the full benefits.[13]

Materials and Methods

Study goal

We sought to build research capacity through the development, pretesting, and validation of data collection instruments to improve adaptability and efficient administration of the tools.

Study design

We used a mixed-methods design and incorporated Community-Based Participatory Research (CBPR) principles and specific levels of the Socio-Ecological Model, to identify and examine relevant ethical, legal, and social implications (ELSI) related to stroke genomics and neurobiobanking; develop novel, context-relevant, culture-appropriate interventions,[6] and explore capacity-building efforts and needs across study sites and team members. We obtained Institutional Review Board approval from each site's Ethics Board before initiating study activities and informed consent was obtained from participants before study enrolment.

Study participants/setting

Stroke patients, caregivers, stroke-free controls, health care providers, hospital administrators, researchers, public health practitioners, Ethics Committees, and lay persons were recruited from the established Stroke Investigative Research and Education Network (SIREN) project network,[14] a transnational, multicenter, hospital- and community-based study, which involved 3000 cases and 3000 controls recruited from seven sites in Ghana and Nigeria (Table 1).

Approaches adopted to build capacity in ELSI

Three-tiered capacity building sessions were set up which included:

Sites activation workshop. A 2-day workshop was conducted in October 2018 in Ibadan, Nigeria, and brought together all members of the research team across the seven study sites within Nigeria and Ghana.[15] Presentations were facilitated by experts in human genomics and genetics, biobanking, community engagement (CE), and data management, while adult-learning methodologies were adopted (Table 2).[16] Participants included multidisciplinary research team members, thus enabling the workshop to be an occasion to enlighten participants on the concept of ELSI; review types and processes of informed consent documentation in GGR; learn, discuss, brainstorm, and review context-specific issues; and logistical considerations to aid implementation across study sites.

Virtual (online) training sessions. Participants included site CE coordinators, field staff, and qualitative/mixed methods research experts from the College of Nursing, Medical University of South Carolina, USA, and the College of Medicine, University of Ibadan, Nigeria. Each training session lasted a minimum of two hours to allow the team to review standard operating procedures relating to GGR and familiarization of study protocols and qualitative data collection instruments (Key Informant Interviews [KII]; focus group discussion [FGD] guides and questionnaire survey). To

Table 1. Sociodemographic Characteristics of Stroke Investigative Research and Education Network Study Sites

SIREN site(S)	*Population*	*Ethnic group*	*Hospital/University Coordination Site*
Ibadan	3.67 million	Yoruba	University College Hospital: the first teaching hospital in Nigeriawith 850 teaching beds tertiary center with several community care centers. Blossom Center for Neurorehabilitation: serves as a first-line and referral center for the identification, treatment, management of all neurological cases to adjoining cities in Nigeria and SSA.
Abeokuta	557,000	Yoruba	Federal Medical Center: is a 250-bed regional tertiary center which receives patients from Ogun and neighboring states in Nigeria and other countries. SHH: is the oldest missionary community hospital in Nigeria focusing on underserved communities in the subregion.
Ilorin	973,671	Hausa and Yoruba	UITH is a 550-bed hospital with 130 beds for medical inpatients, of which 10 are dedicated to acute stroke care. This is in addition to 23 beds for medical emergencies. In addition, the hospital provides community-based primary health care services in three adjoining states, namely, Esie in Kwara, Ihima in Kogi, and Kishi in Oyo state.
Kano	4.10 million	Hausa and Fulani	Aminu Kano Teaching Hospital, a tertiary referral health center with 78 beds.
Zaria	736,098	Hausa and Fulani	Ahmadu Bello Teaching Hospital with 768 beds remains a major referral center for the 19 Northern States.
Accra	2.57 million	Akan, Ga-Dangme and Ewe are dominant.	Korle Bu Teaching Hospital, a tertiary center with 1500 beds. Stroke cases are referred from all levels of health care.
Kumasi	2.02 million	Akan sub-group of Ashanti are dominant	Komfo Anakye teaching hospital, a tertiary center with 100 beds.
Ilorin	950,000	Yoruba	University of Ilorin Teaching Hospital.

SIREN, Stroke Investigative Research and Education Network; SSA, sub-Saharan Africa.

enhance understanding and address knowledge deficits of field staff who were generally nonmedics, virtual sessions were an opportunity to reintroduce field staff to the concept of genomics and ELSI, including the biobanking mini-dictionary (glossary of terms). Shortly after, data collection instruments were pretested during FGD sessions at each study site.

Individual study site workshops. These sessions, which were facilitated by site CE Coordinators, included research assistants and trained field staff. These were set up to review and collect context, site-specific data on challenges encountered during the pretest. This information was collected via summaries. Summaries were reviewed and analyzed by the qualitative data experts/facilitators to identify themes and questions that required further simplification to ensure validity of the data collection instruments and its adequacy in eliciting pertinent responses during the main (large) qualitative study phase.

Table 2. Overview of Topics Presented During the Ethical, Legal, and Social Implications Project Activation Workshop

SN	*Presentation*	*Duration*
1.	What are the ELSI Issues in Biological Research?	40 minutes
2.	Overview of the African Neurobiobank for Precision Stroke Medicine: ELSI Project	40 minutes
3.	Community Engagement in Genomics Research	45 minutes
4.	Overview of CBPR and Guiding Frameworks of the African Neurobiobank ELSI Project	1 hour
5.	Data Management	45 minutes
6.	Data Storage/Security and Confidentiality	30 minutes
7.	Ethics/Taking consent from Subjects, Recruitment of subjects for qualitative and quantitative data collection; hands-on etc.	1 hour
8.	Review of ELSI study tools preliminary draft	45 minutes
9.	Communication strategies/processes to ensure effective community engagement in an ELSI research.	40 minutes
10.	Legal Issues involved in Stroke Biobanking and in the conduct of Genomic research in SSA.	50 minutes

CBPR, Community-Based Participatory Research; ELSI, ethical, legal, and social implications.

Evaluation of impact of the capacity-building sessions

An open-ended questionnaire was used to collect data qualitatively from workshop participants across the seven study sites. Data collected included participants' experience with the trainings/workshops and activities attended, specific contribution of workshops toward building capacity as genomic/genetic researchers, participants' level of preparedness toward GGR, experience with the mini-dictionary (glossary of terms), and specific areas the mini-dictionary that contributed to enhancing capacity/understanding in conducting of GGR. Data were analyzed qualitatively using a thematic analysis approach.

Results

Feedback and outcome of the site activation workshop

Forty persons, (30 males and 10 females), participated in this session. A cross-section of participants alluded to the importance of the workshop in building understanding and providing the needed direction toward commencement and implementation of a GGR across their respective sites.

> *The general activation workshop was very essential in enhancing knowledge towards effective kick-start and implementation of GGR across study sites*—(Assistant Community Engagement Coordinator).

> *The training gave me better and clearer understanding about the project*—(Research Assistant).

Workshop participation gave rise to suggestions on improving data collection. Participants expressed the need for simple terms for easy comprehension by lay persons who will be involved in this type of research. Examples of terms needing explicit definitions included "*biobanking*," "*neurobiobank*," "*precision medicine*," "*personalised medicine*," and "*blood banking*." Inclusion of ethical concepts, including informed consent, privacy and confidentiality, data sharing, and approaches for the receipt and dissemination of incidental findings in the data collection instruments were suggested. Also, a consensus type of informed consent—restricted informed consent was suggested for adoption. Other social and legal issues, such as knowledge deficits, stigma, governance in biobanking, intellectual property, materials transfer agreement, compensation for adverse effects, benefits sharing, and legal aspects of brain donation were recommended for inclusion. On evaluation, participants alluded to increased knowledge about biobanking and GGR as highlighted below:

> *This workshop has given me the relevant knowledge on brain donation, incidental findings and PM. It has also broadened my experience in genetic research*—(Research Assistant).

> *The training increased my knowledge in genomics research… it gave me a better insight about neurobiobanking and ethical issues on blood collection and other materials of a participant*—(Research Assistant).

> *It has given me more insight into what neuro-biobanking is about and the kind of positive impact it can have in the medical field and in the world as a whole*—(Qualitative Interviewer).

Participants noted the workshop further stimulated interests in pursuing careers in GGR.

> *It increased interest in GGR … and further inquisitiveness in GGR and multi-sectoral collaborations*—(Qualitative Interviewer).

> *It was very enlightening and engaging. Opened up a new career path for further exploration*—(Assistant Community Engagement Coordinator).

> *…It has also aroused my interest in further research in genomics*—(Qualitative Interviewer).

Findings and outcomes from the online (virtual) training sessions

Fifty-eight persons, which included 32 males and 26 females, participated in this session (Table 3). Findings are described under the following subheadings below:

Increased knowledge in GGR. Generally, there were positive comments on the adequacy of this expanded training in enhancing understanding of GGR.

> *This workshop improved my research capability, understanding of some terminologies as it relates to genetic research*—(Qualitative Interviewer).

> *With the knowledge and ability to translate and explain genomics terms, I see myself in a better position to explain key terminologies to participants*—(Qualitative Interviewer).

Increased understanding of dynamics of community participation in GGR. Participating in this study provided an opportunity for field teams to understand how communities perceive GGR. This broadened their understanding of community participation in GGR.

> *The workshop broadened my knowledge of biobank and helped me understand people's view on blood sample donation for medical research…community dynamics and group dynamics. It helped me to appreciate how lay people, key informants, community leaders* etc. *think about genomic research and ethical issues*—(Research Assistant).

> *I acquired knowledge in the area of genetic research as well as how to ask cultural and religious sensitive questions while conducting research…enhanced my understanding on community participation in genomic research*—(Qualitative Interviewer).

Development of a mini-dictionary on GGR. Findings reinforced the priority need for a *glossary of genetic and genomic terms* (mini-dictionary). Developing this type of resources would ensure that terms are uniformly defined, increase the likelihood of community understanding of GGR concepts, and enhance quality data collection and consistent interpretation by the field staff. A glossary subcommittee, which included site CE coordinators, CE experts, and Principal Investigators, was set up to develop a 49-item glossary of terms—in English and four indigenous languages (ELSI study mini-dictionary; Supplementary Table S1). After several iterations and reviews, final versions were adopted for use alongside the data collection instruments. Participants impressions regarding the mini-dictionary are highlighted below:

> *It was a very useful and timely resource given the evolving nature of GGR in our climes. I must commend efforts of the steering committee for coming up with this initiative*—(Assistant Community Engagement Coordinator).

Participants' experience with the mini-dictionary. Feedback on the use of the mini-dictionary revealed that it was an easy reference to use, especially in knowing how to best explain specific terms to study participants.

Table 3. Summary of Ethical, Legal, and Social Implications Participants During the Individual Site Workshop Meetings

Participating sites	*Country located*	*No. of participants*	*Gender distribution of participants*		*Participants*
			Male	*Female*	
Ahmadu Bello University Teaching Hospital, Zaria	Nigeria	4	3	1	Site community engagement coordinator, Research Assistants, *Ad hoc* field staff
Bayero University, Kano	Nigeria	7	6	1	Site community engagement coordinator, Research Assistants
Federal Medical Centre/Sacred Heart Hospital, Abeokuta	Nigeria	4	0	4	Site community engagement coordinator, Interviewer (*ad hoc* staff) and Research Assistant
University of Ilorin Teaching Hospital, Ilorin	Nigeria	13	7	6	Site principal investigator, Site community engagement coordinator, interviewer (*ad hoc* field staff), Research Assistants
University College Hospital, Ibadan	Nigeria	11	6	6	Site community engagement coordinator, program manager, Interviewer (*ad hoc* field staff) and Research Assistants
Korle Bu Teaching Hospital, Accra	Ghana	9	5	3	Site community engagement coordinator, Research Assistants
Kwame Nkrumah University of Science and Technology, Kumasi	Ghana	10	5	5	Site community engagement coordinator, Research Assistants
Total		58	32	26	

> *It was easier using this mini-dictionary as it made understanding of some of the terms easier to explain during the interviews… When collecting data and during interviews I refer to it when necessary*—(Qualitative Interviewer).

> *The mini-dictionary as a tool enhanced my understanding of certain terms which I did not readily understand; it helped me to explain better names of certain organs in the local dialect to participants*—(Qualitative Interviewer).

Consequently, it aided community/study participants' understanding of GGR concepts during discussions, which translated to eliciting appropriate responses and collection of quality data as stated below:

> *It was very helpful in … helping my respondents to understand some terminologies*—(Research Assistant).

> *It was a really helpful tool as it made the participants easily understand the concepts of interest in the study*—(Qualitative Interviewer).

Additional value of the mini-dictionary was its usefulness in GGR data entry.

> *It was very helpful in data collection and entry especially*—(Research Assistant).

> *It was very helpful in data entry and especially* collection—(Qualitative Interviewer).

There were positive comments on the development of the glossary of terms into the four local languages (Hausa, Ga, Twi, and Yoruba) spoken across the study sites. This reduced study team burden, ensured consistency in translation/interpretation, and facilitated broad comprehension and communication of the terms locally as shown below:

> *…In addition, getting the mini-dictionary translated in the local languages was the best as participants got the meaning clearer*—(Qualitative Interviewer).

> *It helped me understand some term that is difficulty to explain in English thereby making data collection from the participants' easier*—(Research Assistant).

> *Ensured appropriate use of technical words within local context without losing the original meaning*—(Qualitative Interviewer).

> *The mini dictionary as a tool … helped me to explain better names of certain organs in the local dialect to participants*—(Qualitative Interviewer).

Impact of the mini-dictionary in building capacity of field staff in GGR. Not only was the mini-dictionary useful toward implementation of and data collection in GGR, but the field teams alluded to the impact of the mini-dictionary also in enhancing their awareness and understanding of GGR concepts. One key attribute of this was the simplification of terms. In addition, it made the field staff and participants better communicators in GGR as highlighted below:

> *The ELSI Mini-dictionary (glossary of Terms) made understanding of genetic terms easy and this helped a lot in interviewing the community members. I am more enlightened with most of the genetic terms, and it has helped me to review and contribute to meaningful discussions on genomics. It has also aroused my interest in further research in genomics*—(Qualitative Interviewer).

> *It complemented my knowledge and facilitated my teaching and communication of genetic terms to data collectors; The dictionary was relevant in enhancing my understanding, implementation of GGR concepts, design of data collection instruments and collection of quality data*—(Assistant CE Coordinator).

> *…now I am freely able to explain what the genomic terms are during health education, promotion and training. It was a good initiative, and it should continue in further engagements*—(Qualitative Interviewer).

> *It made me a better communicator in the Twi and Akan languages to the interviewees who didn't speak English*—(Qualitative Interviewer).

Feedback from participants of Individual Site Workshop

A total of 58 persons, which included 32 males and 26 females, participated in this workshop. Feedback from this session is discussed below:

Duration of administration of data collection instruments. Although adequate, field staff expressed concern that the volume of questions and probes for the FGDs were too extensive and could lead to participant fatigue and decreased engagement.

Missing data secondary to a lack of understanding/knowledge. Gaps in knowledge and understanding of genomic concepts among participants resulted in several questions being skipped. This allowed for restructuring of the questions into simpler sentences for lay participant comprehension while maintaining original meaning and intent.

Pretesting content in the local languages. Pretesting in local languages and dialects presented an opportunity for bidirectional learning, a key tenet of CBPR, between field staff and community participants and provided some measure of cultural sensitivity in instrument administration. Pretesting further provided an opportunity to learn from the community participants' perspectives on how to better define and present the concepts. For instance, there were different local definitions and interpretations of the term "gene" as "*ajogunba*" or "*ajebi*" in Yoruba language; "*Kwayan halitta*" *or* "*Sinadarin halita*" in Hausa language. To ensure uniformity and clarity in conducting interviews, especially during the large-scale qualitative data collection, it was agreed to use "*Sinadarin halita*" in Hausa; "*ajebi*" in Yoruba; "*Awosuo*" in Twi; and "*Jiin, loo*" in Ga languages.

Further reports revealed a high degree of preparedness to conduct GGR, especially in facilitating qualitative and quantitative studies.

> *I am above average; prepared and more confident*—(Research Assistant).

> *In skills training, data collection and interviewing… 'I believe I am more efficient to complete genomic interviews more effectively'*—(Qualitative Interviewer).

> *I believe I am more efficient to minimize time through better communication to complete genomic interviews more effectively and efficiently*—(Qualitative Interviewer),

Overall, workshop participants highlighted the impact of the sessions in improving their preparedness and confidence to participate in future GGR across these settings.

> *…much more than ever before. In-fact now I feel more confident in dispensing my duties as a facilitator in the field of GGR*—(Research Assistant)

> *Much more improved in knowledge, communication and approaches in GGR*—(Qualitative Interviewer).

> *I would say I am well equipped, knowledgeable and skilled now as GGR…. Very prepared to take part in any GGR*—(Qualitative Interviewer).

Discussion

Findings from this study affirm the need for continuous engagement toward building capacity among nongenomic (field staff) experts in LMIC.[17] This is essential to facilitate understanding of the objectives of GGR and precludes collection of inaccurate data and eventual waste of resources. This position was supported by Adebamowo et al.[17] who recommended before study implementation that field staff should be trained to understand data collection instruments, as poorly trained research teams add to critical problems that are capable of distorting the methodology of a project.

Genomic literacy is at the center of GGR implementation. Defined as the knowledge of basic genetics, genomic concepts and processes needed to build conceptual understanding and any additional knowledge to aid its comprehension,[18] the concepts of personalized/genomic medicine and biobanking remain relatively unfamiliar, especially among nongenomic experts. This position was confirmed in a similar study conducted in Mali, under the MALGEN project, which showed that poor understanding of certain concepts thwarted efforts at engagement with community members.[19] Our study further supported this through the example provided regarding the identification of different local translations and interpretations for the term "*gene*" within the Yoruba ethnic group.

The existence of multiple definitive terms for a single word could potentially create confusion among the research team who are involved in data collection, dilute the original meaning, impair proper understanding of study concepts, lead to poor quality data, waste time, and financial resources, which are already scarce for genomic research implementation in LMICs. Our findings align with the above studies and lend credence to the importance of understanding local context pertaining to GGR before study implementation.[17]

The existence of the requisite resources for GGR implementation is still insufficient in sub-Saharan Africa (SSA).[17] The Indigenous Linguistic and Cultural Concepts of Heritability and Comprehension of Genomics Research in Africa (INDIGENE) study[20] focused on Yoruba culture and defined key words and phrases within the informed consent process while our mini-dictionary was designed as a portable tool directed at increasing comprehension, consistent interpretation and comparison of key concepts, and variations and similarities across a multisite study representing diverse cultures and languages. Both studies focus on understanding and comprehension of genomics, but the scope of the two investigations is different.

Given the growth of GGR in SSA, findings from our study highlight the need for access to simple, linguistic resources capable of facilitating understanding across the scientific and lay communities, one of which is the mini-dictionary developed by our study team. Our efforts have further elucidated the need for increased accessibility of this resource across the continent and, as such, we plan to expand to other African languages and increase accessibility of the mini-dictionary for use among other nations and teams.

Conclusion

This article highlights the growing importance of building capacity and the role of refining data collection instruments culturally and linguistically before implementing GGR. Findings from this study will be helpful during the second phase of the study, which is centered on designing appropriate culturally relevant interventions to increase participation in biobanking and to proactively address ELSI of genomic research in West Africa. This work can inform other teams in LMICs and serve as a model for those seeking to expand capacity among scientific and lay stakeholders.

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Authors' Contributions

E.O.U. and M.N. developed the draft article. C.J, O.S.A., M.N., M.A.T., A.S., and B.C.-T. coordinated the qualitative research component of the study alongside with O.O.; C.J. and O.S.A. facilitated the workshop sessions alongside with R.L., O.S.A., O.A., L.M., G.A.F., and S.A. who coordinated the workshops, interviews, and data collection process at their respective study sites. M.N., B.R.O., S.Y.I., B.C.-T., L.O., A.A., F.S.S., M.A., G.A.F., B.H., R.L., B.U., O.A., L.M., O.B., A.S., S.A., J.C., O.S.A., and M.A.T. read and edited the article. E.O.U. harmonized the final version of the article, which was read and approved by M.N., R.O., B.O., M.O.O., J.C., and R.O.A. R.O.A. conceptualized the study and obtained funding.

Author Disclosure Statement

No competing financial interests exist.

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Supplementary Material

Supplementary Table S1

References

1. Owolabi MO, Mensah GA, Kimmel PL, et al. Understanding the rise in cardiovascular diseases in Africa: Harmonising H3Africa genomic epidemiological teams and tools. Cardiovasc J Africa 2014;25:134–136.
2. Walker R, Whiting D, Unwin N, et al. Stroke incidence in rural and urban Tanzania: A prospective, community-based study. Lancet Neurol 2010;9:786–792.
3. Prapiadou S, Demel SL, Hyacinth HI. Genetic and genomic epidemiology of stroke in people of African ancestry. Genes 2021;12. [Epub ahead of print]; DOI: 10.3390/genes12111825.
4. Sarfo FS, Akassi J, Awuah D, et al. Trends in stroke admission and mortality rates from 1983 to 2013 in central Ghana. J Neurol Sci 2015;357:240–245.
5. Cohn EG, Husamudeen M, Larson EL, Williams JK. Increasing participation in genomic research and biobanking through community-based capacity building. J Genet Couns 2015;24:491–502.
6. 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. Int J Qual Methods 2020;19:1–13.
7. Lopez A. Building Capacity in Africa for Genomics and Environmental Health Research. 2018. https://www.niehs.nih.gov/research/programs/geh/geh_newsletter/2018/2/training/building_capacity_in_africa_for_genomics_and_environmental_health_research.cfm (accessed May 17, 2020).
8. Bilani N, Dagher M, Zgheib NK. Precision genetic and genomic medicine in the Middle East and North Africa Region: Are we there yet? Public Health Genomics 2017;20:149–157.
9. Akinyemi RO, Akinwande K, Diala S, et al. Biobanking in a challenging African environment: Unique experience from the SIREN Project. Biopreserv Biobank 2018;16:217–232.
10. Sarfo FS, Ovbiagele B, Gebregziabher M, et al. Unraveling the risk factors for spontaneous intracerebral hemorrhage among West Africans. Neurology 2020;94:e998–e1012.
11. Vogenberg FR, Barash CI, Pursel M. Personalized medicine: Part 1: Evolution and development into theranostics. Pharm Ther 2010;35:560.
12. Coppola L, Cianflone A, Grimaldi AM, et al. Biobanking in health care: Evolution and future directions. J Transl Med 2019;17. [Epub ahead of print]; DOI: 10.1186/s12967-019-1922-3.
13. 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 Res Bull 2019;145:136–141.
14. Akpalu A, Sarfo FS, Ovbiagele B, et al. Phenotyping Stroke in Sub-Saharan Africa: Stroke Investigative Research and Education Network (SIREN) Phenomics Protocol. Neuroepidemiology 2015;45:73–82.
15. Jenkins C, Arulogun OS, Singh A, et al. Stroke investigative research and education network: Community engagement and outreach within phenomics core. Health Educ Behav 2016;43:82S–92S.
16. Bute J. Techniques of teaching adult learners. J Health Occup 2000;14.
17. Adebamowo SN, Francis V, Tambo E, et al. Implementation of genomics research in Africa: Challenges and recommendations. Global Health Action 2018;11. [Epub ahead of print]; DOI: 10.1080/16549716.2017.1419033.
18. Hurle B, Citrin T, Jenkins JF, et al. What does it mean to be genomically literate? National Human Genome Research

Institute Meeting Report. In: *Genetics in Medicine*. Vol. 15. Nature Publishing Group; 2013: 658–663. [Epub ahead of print]; DOI: 10.1038/gim.2013.14.

19. Traore K, Bull S, Niare A, et al. Understandings of genomic research in developing countries: A qualitative study of the views of MalariaGEN participants in Mali. BMC Medical Ethics 2015;16:1–10.
20. Taiwo RO, Ipadeola J, Yusuf T, et al. Qualitative study of comprehension of heritability in genomics studies among the Yoruba in Nigeria. BMC Medical Ethics 2020;21. [Epub ahead of print]; DOI: 10.1186/s12910-020-00567-2.

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