Journal of Stroke and Cerebrovascular Diseases 34 (2025) 108378

Contents lists available at ScienceDirect

Journal of Stroke and Cerebrovascular Diseases

journal homepage: www.elsevier.com/locate/jstroke

Communicating the ethical, legal, and social issues in neurobiobanking and stroke genomic research in Africa: Project intervention tools development and evaluation procedures

Babatunde R. Ojebuyi, PhD [a,*], Ibukun Afolami, PhD [b], Muyiwa Adigun, PhD [c], Arti Singh, MD [d], Carolyn Jenkins, DrPH [e], Michelle Nichols, PhD, RN [e], Kolawole Wahab, MD, FMCP [f], Abiodun Bello, MD [f], Fred S. Sarfo, MBChB, PhD [g], Lukman F. Owolabi, MD, FMCP [h], Rabiu Musbahu, MD [h], Reginald Obiako, MD, FWACP [i], Albert Akpalu, MBChB, FWACP [j], Mayowa Ogunronbi, MPH [t], Olorunyomi Olorunsogbon, MPH [t], Benedict Calys-Tagoe, MD [k], Deborah Adesina, RN [l], Nathaniel Coleman, MPH [k], Abdullateef G. Sule, MD [u], Aliyu Mande, HND [h], Muhammed Uthman, MD, MPH [v], Musibau Titiloye, PhD [s], Ezinne Uvere, MPH [q], Odunola Bukola, MSc [n], Ruth Laryea, MSc [j], Adekunle Fakunle, MPH [q], Osi Adeleye, MSc [l], Nathaniel Mensah, Bsc [g], Jibril Yusuf, BSc [h], Sunday Adeniyi, BSc [f], Shadrack Asibey, BSc [d], Lanre Omotoso, BSc [f], Lois Melikam, BSc [i], Dorcas Olujobi, MSc [t], Wisdom Oguike, BSc [i], Joshua Akinyemi, PhD [m], Ayodele Jegede, PhD [n], Rajesh Kalaria, FRCP, PhD [o], Bruce Ovbiagele, MD, MSc [p], Mayowa Owolabi, MD DM [q,r], Oyedunni Arulogun, PhD [s], Rufus Akinyemi, MD, PhD [r,s,t]

[a] Department of Communication and Language Arts, Faculty of Arts, University of Ibadan, Ibadan, Nigeria
[b] Department of Human Nutrition and Dietetics, College of Medicine, University of Ibadan, Nigeria
[c] Department of Public Law, Faculty of Law, University of Ibadan, Ibadan, Nigeria
[d] School of Public Health, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana
[e] College of Nursing, Medical University of South Carolina, Charleston, SC, USA
[f] Neurology Unit, Department of Medicine, University of Ilorin/University of Ilorin Teaching Hospital, Ilorin, Nigeria
[g] Department of Medicine, Komfo Anokye Teaching Hospital, Kumasi, Ghana
[h] Neurology Unit, Department of Medicine, Bayero University/Aminu Kano Teaching Hospital, Kano, Nigeria
[i] Neurology Unit, Department of Medicine, Ahmadu Bello University Teaching Hospital, Shika, Zaria, Nigeria
[j] Department of Medicine and Therapeutics, University of Ghana Medical School, Accra, Ghana
[k] Department of Community Health, University of Ghana Medical School, Accra, Ghana
[l] Neurology Unit, Department of Medicine, Federal Medical Centre, Abeokuta, Nigeria
[m] Department of Epidemiology and Medical Statistics, College of Medicine, University of Ibadan, Ibadan, Nigeria
[n] Department of Sociology, Faculty of the Social Sciences, University of Ibadan, Ibadan, Nigeria
[o] Neurovascular Research Group, Translational and Clinical Research Institute, Newcastle University, Newcastle upon Tyne, United Kingdom

* Corresponding author at: Department of Communication and Language Arts, Faculty of Arts, University of Ibadan, Ibadan, Nigeria.
E-mail addresses: ojebabson@gmail.com (B.R. Ojebuyi), m.afolami@gmail.com (I. Afolami), muyiwa.adigun@gmail.com (M. Adigun), artisingh_uk@yahoo.com (A. Singh), jenkinsc@musc.edu (C. Jenkins), nicholmg@musc.edu (M. Nichols), kwwahab@yahoo.com (K. Wahab), reachabbey@yahoo.com (A. Bello), stephensarfo78@gmail.com (F.S. Sarfo), drlukmanowolabi@yahoo.com (L.F. Owolabi), musbahurabiu@yahoo.com (R. Musbahu), orobiako87@gmail.com (R. Obiako), a_akpalu@yahoo.com (A. Akpalu), oaridegbe@yahoo.com (M. Ogunronbi), olorunsogbonyomi@gmail.com (O. Olorunsogbon), calys75@hotmail.com (B. Calys-Tagoe), adesinaiyanuoluwa2014@gmail.com (D. Adesina), micnasam2@gmail.com (N. Coleman), gbensule@gmail.com (A.G. Sule), aliyumande88@gmail.com (A. Mande), uthmanmb@yahoo.com (M. Uthman), msbnsmtiti@yahoo.com (M. Titiloye), ezinneuvere13@gmail.com (E. Uvere), bukkyjuly2@gmail.com (O. Bukola), pinaaki2005@gmail.com (R. Laryea), fakunz@yahoo.com (A. Fakunle), osiadeleye@gmail.com (O. Adeleye), nathanieladuseimensah@yahoo.com (N. Mensah), jyusuf182@gmail.com (J. Yusuf), sundayadeniyi767@gmail.com (S. Adeniyi), shakosbey19@gmail.com (S. Asibey), waju2001us@gmail.com (L. Omotoso), loisyassat@gmail.com (L. Melikam), ogunloyedorcas@yahoo.com (D. Olujobi), wissword@gmail.com (W. Oguike), odunjoshua@gmail.com (J. Akinyemi), sayjegede@gmail.com (A. Jegede), raj.kalaria@newcastle.ac.uk (R. Kalaria), bruce.ovbiagele@va.gov (B. Ovbiagele), mayowaowolabi@yahoo.com (M. Owolabi), oyedunniarulogun@gmail.com (O. Arulogun), rufusakinyemi@yahoo.com (R. Akinyemi).

https://doi.org/10.1016/j.jstrokecerebrovasdis.2025.108378
Received 13 March 2025; Received in revised form 2 June 2025; Accepted 13 June 2025
Available online 14 June 2025

[p] School of Medicine, University of California San Francisco, San Francisco, CA, United States
[q] Department of Medicine, College of Medicine, University of Ibadan, Ibadan, Nigeria
[r] Centre for Genomic and Precision Medicine, College of Medicine, University of Ibadan, Ibadan, Nigeria
[s] Department of Health Promotion and Education, Faculty of Public Health, University of Ibadan, Ibadan, Nigeria
[t] Neuroscience and Ageing Research Unit, Institute for Advanced Medical Research and Training, College of Medicine, University of Ibadan, Ibadan, Nigeria
[u] Department of Family Medicine, Ahmadu Bello University Teaching Hospital, Zaria, Nigeria
[v] Department of Epidemiology and Community Health, University of Ilorin/University of Ilorin Teaching Hospital, Ilorin, Nigeria

ARTICLE INFO

Keywords:
Precision Stroke Medicine
Community Engagement
Community-Based Participatory Research, ELSI
Health Literacy
Persuasive Communication
Neurobiobanking in Africa

ABSTRACT

Background and Aim: Issues concerning appropriate Community Engagement (CE) and communication of research outcomes with stakeholders have received the attention of scholars in different sub-fields of clinical research. However, given its novel nature, especially in Sub-Saharan Africa, CE addressing the ethical, legal, and social implications (ELSI) of neurobiobanking and stroke genomic research has not received much scholarly attention. Therefore, this study was designed as a pioneering effort to report the procedures for developing and evaluating intervention tools for the CE component of the African Neurobiobank for Precision Stroke Medicine ELSI Project.

Methods: A community-based participatory research design was adopted. The intervention tools we developed include *general advocacy, educative, and training videos focusing on neurobiobanking, stroke genomics and precision stroke medicine in Africa; infographics; and a policy brief*. An adapted Doak and Doak's Suitability Assessment Measure (SAM), the Agency for Healthcare Research and Quality (AHRQ) Patient Education Materials Assessment Tool (PEMAT), and semi-structured interview questions based on Willis' Cognitive Interviewing Techniques were used to evaluate the suitability, actionability, understandability and cultural appropriateness of the tools.

Results: PEMAT mean percentage scores of 71.4 % for actionability and 82.4 % for understandability, and a SAM suitability score of 67.9 % were reported for the videos. Identified weaknesses captured in seven thematic areas after assessment analysis by experts and community members guided the final refinement of the tools.

Conclusion: The overall reviewers' reports and evaluation scores indicate that the intervention tools are generally suitable for community deployment in sub-Saharan Africa. Clinical researchers must partner with key stakeholders, define policy objectives and desired behaviour change, and develop appropriate persuasive communication strategies and tools for community engagement.

Introduction

Although organized neurobiobanking is still an emerging practice in sub-Saharan Africa (SSA), the Human, Heredity and Health in Africa (H3Africa) Initiative has encouraged biobanking-related research activities in the region.[1–3] This initiative has led to pioneering neurobiobanking efforts such as the Stroke Investigative Research and Education Network (SIREN) Biobank.[3] and the IBADAN Brain Bank.[4] The latest effort in this direction is the African Neurobiobank for Precision Stroke Medicine—Ethical, Legal, and Social Implications (ELSI) Project.[5] The ELSI Project was designed to investigate, identify and develop novel approaches to addressing the ELSI of neurobiobanking and stroke genomic research in SSA. One of the aims of the project was to develop novel intervention tools for Community Engagement (CE) processes that enhance community knowledge of neurobiobanking and health promotion activities and willingness to participate in neurobiobanking activities for research with an adequate understanding of the related ELSI issues.[6] The plans included the deployment of these tools to address the ELSI issues related to stroke genomic and neurobiobanking research in SSA through a community-based participatory research (CBPR) design.[6–9]

It is becoming increasingly important that researchers disseminate study outcomes to the public in such a manner that they contribute to evidence-based policy enactment and improved lifestyles of populations.[6,10,11] The current practice, especially in social sciences and medical research, is policy relevance where researchers must engage the stakeholders in the research process and share the research outcomes with them. This can guide the formulation of appropriate policies directed at solving identified social or health-related problems.[11,12] Given that research uptake and policy engagement have been recommended by ethicists as a critical component of health-related research design and implementation.[13], clinical researchers should incorporate translation and dissemination of research outcomes into all protocols and have clear policy recommendations guided by the research outcomes. This includes engaging with the key stakeholders and partnering with them to achieve such objectives. Success in this aspect also requires the identification of the social and political context, and develop appropriate tools of engagement, communication channels and strategies for achieving desired behaviour change.[6,11,14,15] To ensure the suitability of the intervention tools, they must be carefully developed, evaluated and refined before deployment.

Sub-Saharan Africa is one of the regions with peculiar, urgent development issues including stroke medicine.[3,4,16] Therefore, the region needs policy-engaged researchers otherwise known as *honest brokers* and *issue advocates*.[17] who provide options from which the policymakers could select or make the best choices for the policy actors.[12,17] Issues concerning appropriate CE and communication of medical research outcomes with the stakeholders have received the attention of researchers globally .[e.g. .[6,7,13,15,18,19-28]] However, given its novel nature, especially in SSA, community-engaged research addressing the ELSI aspects of neurobiobanking and stroke genomic research has not received much scholarly attention. Expanding ELSI communications is a pioneering effort to communicate the procedure of the CE component of the current African Neurobiobank for Precision Stroke Medicine Project.[5]

Therefore, in this study, we report the procedures for developing and evaluating the suitability and effectiveness of the intervention tools for the CE component of the African Neurobiobank for Precision Stroke Medicine Project. The messages developed within the tools address the ethical, legal, and societal issues associated with neurobiobanking and stroke genomic research activities such as donating blood for genomic research, storage and re-use of stored blood fractions for future research, donating brain tissue for research, and informed consent. To achieve these objectives, we address questions around a) the process of developing and evaluating the intervention tools; and b) the suitability of the intervention tools in engaging the general public, stroke community and stroke experts in the African Neurobiobank for Precision Stroke Medicine ELSI Project.

Literature

The community engagement procedure of neurobiobanking and stroke genomic research as a communication process

Human communication is a complex social process that involves some basic elements, including source, message, context, channel, medium, receiver, feedback, and noise.[29,30] As espoused by different communication models.[29,31-37], the source packages and encodes the message using mutually understood codes, such as language or symbols. Through the appropriate channel (i.e., technical route and other elements affecting the senses of seeing, hearing, smelling and touching), the message, which could be in verbal, non-verbal, or electronic form (medium), is shared with the receiver who decodes the message, interprets it and provides the feedback.[30] Variables such as communication skills, attitudes, knowledge, social system and culture affect how sources encode messages and how receivers decode such messages.[30,37-39]

As presented in Table 1, all components of the human communication process are realizable in the context of our ELSI project intervention tools development procedure. The message communicated by the source (i.e., the ELSI Research Team) were the ethical, legal, and societal issues relating to informed consent, donating blood fractions and brain tissue, and storage and re-use of stored blood fractions and brain tissue for genomic research. The focus was to project the African perspectives on the Ethical, Legal, and Social Implications of neurobiobanking and stroke genomic research with Nigeria and Ghana providing the study context. The ELSI intervention tools presented in textual and audiovisual forms constituted the medium, while electronic and print platforms constituted the channels through which messages would be communicated to the target audience in a manner that would appeal to their senses of seeing, hearing, smelling and touching. Messages would be targeted at the stroke community, general public, policymakers, public health professionals and organizations, researchers and academics, as the receivers/decoders. The target audiences would be expected to provide feedback in terms of change in attitudes (e.g., readiness to donate blood fractions and brain tissues for stroke genomic research), and enhanced knowledge of neurobiobanking and stroke genomics, among others. We conceptualized *noise* as those factors that could reduce the effectiveness of our messages. These included the social system, attitudes, nature and level of knowledge, as well as the cultural and religious sentiments of the target audience.

Emphasising the importance of integrated community engagement in the public health system, the World Health Organisation has described it as the backbone of universal health coverage.[40] Therefore, given this importance, development and evaluation of CE intervention tools has received substantial attention and efforts of scholars in different sub-fields of clinical and social sciences research.[41-51] These scholars, in their respective projects, have published reports of studies relating to procedures and outcomes of the CE process, participants' engagement and feedback in the development and evaluation of CE intervention tools, involvement of the community advisory boards in the development of engagement strategies, and research uptake, among other aspects. The current study is a novel contribution to community-engaged research addressing the ELSI aspects of neurobiobanking and stroke genomic research in SSA.

Theoretical framework

Health belief model (HBM) and elaboration likelihood model (ELM)

This study is anchored to the Health Belief Model (HBM) and the Elaboration Likelihood Model (ELM) as theoretical frameworks. Social scientists developed the HBM in the early 1950s at the U.S. Public Health Service.[52,53] The primary goal was to understand and explain why people fail to adopt certain disease prevention strategies among other health behaviours. The HBM suggests that an individual's belief in a personal threat of a disease or health issue together with the person's belief in the efficacy of any health behaviour or action recommended will predict the possibility the person would adopt the recommended behaviour or action.[52] In essence, the HBM explains that people's decisions and communication about issues affecting their health are always influenced by key variables including *perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, self-efficacy,* and *demographic variables*.[53-56] For example, people are likely to discuss specific health matters and adopt new health behaviours if they believe that they are vulnerable to certain health conditions or they think that the health condition has severe consequences. People's health behaviours are also influenced by demographic variables: age, gender, educational status, religious belief, location, and social status.[57] This is because the HBM is premised on the principle of the value-expectancy relationship.[58]

However, the HBM does not account for people's attitudes, beliefs, other personal factors, or non-health-related reasons such as social acceptability that determine their reception of certain health behaviours.[52] Therefore, the Elaboration Likelihood Model (ELM) is used to complement the aspects of attitudes, beliefs and other personal and non-health-related factors. The ELM is centred on attitude change and persuasion as the central focus of social psychology. Developed by Petty and Cacioppo.[59] to accommodate the dynamics of communication-induced attitude change, the model provides a general framework for organizing, categorizing and explaining the fundamental process that underlines the effectiveness of persuasive messages. It explains the cognitive route of processing persuasive communications.[60]

One of the core tenets of the ELM relevant to this study is that when an individual is exposed to some form of communication, they can process this communication message with varying levels of cognition (elaboration), ranging from a low degree of thought (low elaboration) to a high degree of thought (high elaboration). Different motivations, abilities and opportunities are some of the factors that contribute to this

Table 1
The communication dimension of project intervention tools development procedure.

Source	Message	Context	Medium	Channel	Noise	Receiver	Feedback
AfricanNeurobioabank ELSI Project Team	Ethical, Legal, and Societal issues: Donating blood; Storage and re-use of stored blood fractions; Donating brain tissue; Storage and re-use of stored brain tissue; Informed consent.	*Neurobio-banking and Stroke Genomic Research in* Sub-Saharan Africa (Nigeria and Ghana)	ELSI Intervention tools (presented in textual and audiovisual forms)	Electronic and print platforms (appealing to the senses of seeing, hearing, smelling and touching)	Social system, Attitudes, knowledge, Cultural and religious sentiments of the target audience	Target Audiences (e.g., Stroke community, general public, policymakers, public health professionals and organizations, Researchers and academics)	Change in attitude (e.g., readiness to donate blood fractions and brain tissues for genomic research), enhanced knowledge of Neurobio-banking and Stroke Genomics, etc.

cognitive process (elaboration). Another relevant tenet is that the level of sophistication of thought deployed in a persuasion context determines how consequential the resultant attitude becomes. This means that the attitudes that an individual has formed through sophisticated reasoning (high-thought) or central-route processes are likely to endure over time, resist persuasion, and be influential in guiding other judgments and behaviours of the individual to a greater extent than attitudes formed through low-thought, peripheral-route processes.[44,59,60] The ELM provides that strong arguments have been consistently established to produce more favourable thoughts in terms of attitude change, while weak arguments generate unfavourable thoughts.[59] Also, when the source of a persuasive message is credible, the message has a high tendency to cause a behaviour change in the message recipient.[61,62]

Both the HBM and the ELM are relevant to this study. While the HBM accounts for how some variables (i.e., *perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, self-efficacy,* and *demographic variables*) affect people's likelihood of health behaviour change, the ELM provides the framework for explaining how thought-processing level, argument quality and source credibility in persuasive communication influence people's attitudes. Overall, the goal of the ELSI project was to understand the barriers and facilitators of the ELSI relating to the willingness to participate in neurobiobanking and stroke genomic research activities. The interventions were developed to mitigate the barriers and encourage the facilitators. Therefore, the two models provide the theoretical context for our CE programme, which aimed to change behaviour, perceptions, and attitudes regarding the ELSI of biobanking and stroke genomic research in SSA.

Methods

Study design

The study design and protocol of the African Neurobiobank for Precision Stroke Medicine ELSI Project have been previously published.[5] The ELSI Project was designed to investigate, identify and develop novel approaches to addressing the ethical, legal and social implications of neurobiobanking and stroke genomic research in sub-Saharan Africa. The current study addresses the development of intervention tools for CE as a component of the ELSI Project. Specifically, to develop the intervention tools we used a Community-Based Participatory Research (CBPR) design.[6,8,9] Community members, the stroke community, experts and the lay public, most of whom had been part of the project from inception, were involved in the stage of interviews to obtain key components of the information used to develop the intervention tools.

Study Sites, Target Population and Sample

The intervention tools were meant to be deployed at seven sites within the established Stroke Investigative Research and Education Network (SIREN).[3] from communities in southern (Abeokuta and Ibadan), central (Ilorin), and northern (Kano and Zaria) Nigeria, and southern (Accra) and central (Kumasi) Ghana, which served as the study setting. The SIREN Study is the largest study of stroke in Africa that involved 15 sites in Ghana and Nigeria, including the 7 sites involved in this current project.[3] The target population for the intervention were the stroke survivors, caregivers, healthy controls, providers, hospital administrators, researchers, public health practitioners, ethics committee members, and laypersons who had been initially recruited for the study. Ethical approval was obtained from the institutional review board of each site. Forty-one participants evaluated the *Religious Implications of Neurobiobanking* video, while 49, 44, 40, and 44 participants evaluated videos on *the Need for Neurobiobanking, Stroke Genomics and Precision Medicine Research, Ethical and Legal Implications of Neurobiobanking,* and *How Nigerians and Ghanaians Perceive Neurobiobanking,* respectively.

Description of the assessment tools

Semi-structured interview questions based on Willis' Cognitive Interviewing techniques.[72,73] were used to complement the quantitative assessment. For the quantitative component, we used an adapted Doak and Doak's Suitability Assessment Measure (SAM).[69,70] and the Agency for Healthcare Research and Quality (AHRQ) Patient Education Materials Assessment Tool (PEMAT).[71]—adapted to the African culture. The PEMAT has two parts (*understandability* and *actionability*), while the SAM has one part (*suitability*) and three sub-parts (*superior, adequate*, and *not suitable*). The two tools are further described as follows:

Suitability assessment measure (SAM)

SAM is a validated instrument for measuring the suitability of audiovisual materials. This 22-item tool was used for the evaluation of the *Suitability* of the videos. Each item was scored 2 points if rated as *Superior,* 1 point if rated as *Adequate* and 0 points if rated as *Not Suitable* and *Not Applicable*. The total possible score was 44. For the analysis, the total score was divided by the total possible score and then multiplied by 100. The mean percentage score was then computed to provide the summary score for the suitability of each video.

Patient education materials assessment tool (PEMAT)

PEMAT is a validated instrument employed for measuring the understandability and actionability of audiovisual materials. This study adopted the 17-item PEMAT, having 13 items for Understandability and 4 for Actionability. Each item was scored 1 point for *Agree*, and 0 point for *Disagree*. The total possible score was 13 for *Understandability* and 4 for *Actionability*. For the analysis, the total score was divided by the total possible score and then multiplied by 100. The Mean percentage score was then computed to provide the summary scores for both *Actionability* and *Understandabilty* of each video.

Procedure used for the evaluation

To avoid an unbiased judgement, each evaluator was selected purposively and was asked to independently review at least two to three videos after they had been briefed about the goal of the evaluation. After completing each video, evaluators were given PEMAT and SAM assessment tools for the evaluation of the videos. The researchers were present throughout the evaluation periods to provide clarification where necessary. After the PEMAT and SAM assessments, the evaluators were further interviewed to provide more information on the scores they had allocated to the items on the PEMAT and SAM assessment tools. Evaluators were stroke-free control, stroke survivors, laypersons, stroke caregivers, Community Advisory Board members, with ELSI researchers providing necessary guidance.

Collection and processing of data for the intervention tools

The contents of the intervention tools were developed based on data accrued from the seven study sites using a mixed-method approach, as already reported in our study protocol and capacity-building studies.[5,63] This process consisted of in-depth interviews and focus group discussions with the ELSI Community Advisory Board members, stroke patients, stroke caregivers and stroke-free laypersons.[63] In-depth interviews were also conducted with six religious leaders, three community leaders and five experts in community health, bio-ethics, stroke genomics, and medical law. We also conducted key informant interviews with two community leaders and two religious leaders from Accra and Kumasi, Ghana. The interviewees from the ELSI Project team were purposively selected because of their expertise, while the laypersons interviewed were randomly selected across the study sites in Nigeria and Ghana to represent ethnic groups in the study population. We transcribed and edited the interviews and used the theme mapping technique.[64,65] to extract and cluster relevant excerpts and themes, which

were combined with selected findings from the project to develop the intervention tools.

Results

The intervention tools

The intervention tools for Community Engagement (CE) that we developed include general advocacy, informative, and training videos; infographics/case vignettes; and a policy brief. Generally, comments, testimonials and recommendations by ELSI Project experts, community leaders, laypersons and religious leaders as representatives of research participants were used as the data to develop the contents of the tools. Other sources of the data included embedded infographics, illustrative diagrams and pictures about neurobiobanking, genomics and precision medicine, and findings from the study. Therefore, the tools were developed based on team input and study data. They were then disseminated among core individuals to get input for refinement as reported later in the study. Each intervention tool is briefly described in the following sub-section with some sample images presented in Fig. 1-4.

Advocacy, informative, and training videos

The primary objective of developing the videos was to drive advocacy, information on neurobiobanking, and training. Specifically, the videos were developed to capture the general perception of Nigerians and Ghanaians towards neurobiobanking, tissue, and organ donation and offer an opportunity to explain factual content while addressing general, known community perceptions.

The videos were developed in five series: Series I described the need for neurobiobanking (https://www.youtube.com/watch?v=ABI_Lz6TuTA); Series II focused on the perception of Ghanaians and Nigerians toward neurobiobanking (https://www.youtube.com/watch?v=jsFQS9r59wo); Series III (https://www.youtube.com/watch?v=a2W2YTDik98) & IV (https://www.youtube.com/watch?v=5UPHHGytxBY) addressed the religious and ethical implications of neurobiobanking respectively; while Series V addressed stroke genomics and precision medicine (https://www.youtube.com/watch?v=lbIcaS-sGzU). Samples of still images from the video series I and V are presented in Fig. 1 and 2, respectively.

All the intervention videos were developed with an advocacy component to encourage clarity and enhanced understanding toward informed consent, donating blood and brain tissue for genomic research, and storage and re-use of stored blood fractions and brain tissue for future research. The videos also served as a means of educating the stroke community and the general public about the ethical, legal and social implications of neurobiobanking, stroke genomics and precision medicine literacy. Each video was between seven and fifteen minutes long.

Case vignette (Infographics)

A vignette is a summary or brief description of an event, a case, or a phenomenon. It combines texts, pictures and graphs illustratively to summarise a case. As a form of infographics, a vignette is a visual representation of information or a situation and provides a simple overview of a scenario or findings of a study in such a way that abstract concepts and notions are put in concrete context.[66,67] The infographic as presented in Fig. 3 contained some findings of the ELSI project.[68] to provide an overview of the ethical, legal and social implications of neurobiobanking in Nigeria and Ghana.

We considered vignettes as an effective intervention tool because the vignettes can convey a large amount of material using very little space. Infographics are good examples of vignettes. To effectively appeal to the target audience, we developed case vignettes (see Fig. 3) to present the key components of the findings in simple ways that effectively illustrate key ELSI-related scenarios.

Policy Brief

As an effective tool for reaching and influencing policymakers, a policy brief is a short report that focuses on a single subject to present summaries of key issues or findings and provides recommendations. The policy brief (see Fig. 4) provides summaries of the findings and recommendations of the ELSI study and is targeted at experts and policymakers.

Evaluating and Refining the Intervention Tools

Responses (transcripts and scoring sheets) were analysed to evaluate the intervention tools. Results of the analyses using PEMAT and SAM tools are presented in Table 2

As shown in Table 2, using a cut-off of 70 % for actionability and understandability, all the videos have high *Understandability* and *Actionability,* except the *Stroke Genomics and Precision Medicine Video*, which has lower actionability (67.1 %) compared to others.

Fig. 1. Sample image of the brain from the video series I (*the need for Neurobiobanking to improve stroke research*).

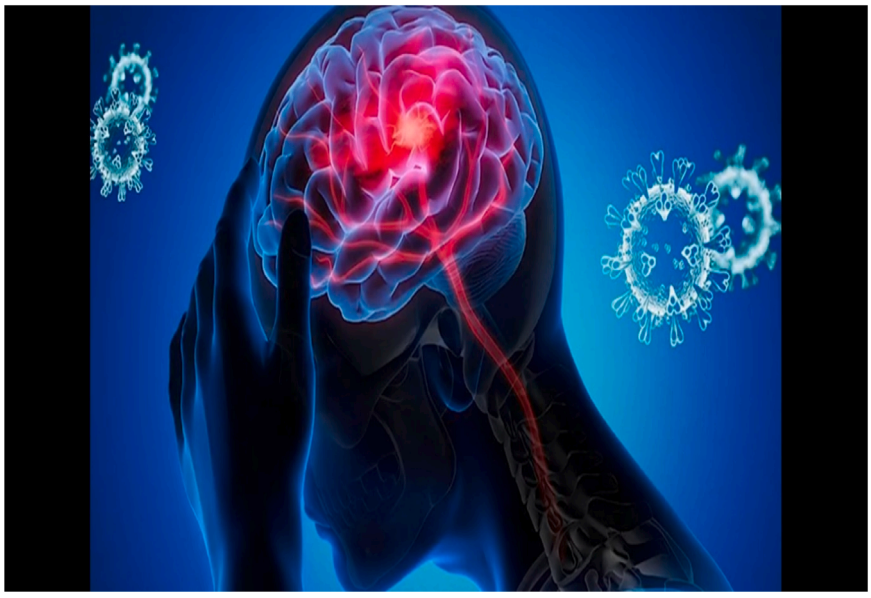

Fig. 2. Sample image from the video series V (*Stroke Genomics and Precision Medicine*).

Interestingly, despite its low actionability, the *Stroke Genomics and Precision Medicine Video* has the highest understandability score (85.7 %)

Using cut off of 70 % for superior rating, 40 and 69 % for adequate criteria for SAM rating, the videos, *How do Nigerians and Ghanaians perceive* (70.7 %) and *Stroke Genomic and Precision Medicine* (70.6 %), had superior suitability, while *Religious Implication for Neurobiobanking* (65.6 %), *The Need for Neurobiobanking* (67.2 %) and *Ethical and Legal Implications of neurobiobanking* (67.9 %) were adequate having percentage score above 40.

As presented in the summary scores for all five video series (see Table 2), PEMAT mean percentage scores of 71.4 % for actionability and 82.4 % for understandability were recorded, while a SAM score of 67.9 % was reported for the videos. The overall scores indicate that generally, the videos are suitable enough to achieve the project objectives.

Throughout the process of developing the tools, we placed particular emphasis on contextual relevance, cultural sensitivity, and a clear message, with the objective that the target audience would understand the message clearly, resolve personal bias and be motivated to participate in neurobiobanking and stroke genomic research activities. After the evaluation exercise, a committee on intervention tools development met twice to review the assessment reports, suggested steps from participants, and tasks required to revise the intervention tools. The findings and identified common themes from the analyses were used to further refine the tools. Table 3 shows examples of identified areas for refinement and tasks taken to address the shortcomings.

Discussion

The overall results of the evaluation exercise show that the intervention tools are appropriate for engaging the general public, stroke community and stroke experts in addressing the ELSI goals of the African Neurobiobank for Precision Stroke Medicine project. Specifically, as presented in Table 2, the tools have high suitability, actionability and understandability based on the evaluation results generated through an adapted Doak and Doak's Suitability Assessment Measure (SAM).[69,70] and the AHRQ Patient Education Materials Assessment Tool (PEMAT).[71] The overall results indicate that the videos were generally rated high for actionability and understandability. Although the video series on *stroke genomics and precision medicine research* got a low actionability score of 67.04 %, this does not affect the overall actionability and understandability of the videos.

Analysis of the qualitative data collected through semi-structured interview questions based on Willis' Cognitive Interviewing techniques.[72,73] revealed some weaknesses of the tools that required revisions. As shown in Table 3, the identified weaknesses were captured in seven thematic aspects as follows: *Use of complex medical terms, Benefits of Biobanking, Inclusion of local Languages, Expansion of religious views, Speed of sub-titles and font size of the on-screen text, Gender balancing,* and *inclusion of communication strategies in the policy brief*. The specific weaknesses under each of the thematic areas were enumerated, while appropriate revision tasks were performed to enhance the quality of the tools. The actual revisions carried out include the insertion of illustrations (on-screen visual and textual displays) and sub-titles to the appropriate sections of the videos, emphasizing family and community rewards for donating body parts (brain and blood) for research, translation of the videos into the local languages of the study areas (i.e. *Yoruba* and *Hausa* in Nigeria; *Twi* and *Ga* in Ghana), adjustment of the speed of sub-titles, and enlargement of the font size of the on-screen text. We also addressed the sensitive aspect of religion in the revision by providing perspectives from fairly substantial groups of participants from the three religions (Islam, Christianity, and African Traditional Religions) on the cultural issues around brain donation. The policy brief was also revised to reflect the integrated communication strategies (such as videos, comics, infographics, flyers, policy briefs, blog posts and newspaper articles) that were required to sensitise the public and address their potential concerns, such as religious and cultural sentiments about biobanking activities.

The evaluation and revision activities enabled us to ensure that the messages of the intervention tools are effective, credible, persuasive and appealing to the target audience and suitable for achieving the desired health behaviour change and action such as informed consent, storage and re-use of stored blood fractions, donating blood fractions and brain tissue for research.

As stipulated in the Health Belief Model (HBM), an individual's belief in a personal threat or health issue and the efficacy of a recommended health behaviour or action will determine the likelihood that the person would adopt the recommended health behaviour or action.[52] Also, the Elaboration Likelihood Model (ELM), used to complement the HBM as the theoretical framework, states that when an individual receives some communication message, such an individual can process messages at different levels of cognition (elaboration), ranging from a low degree (low elaboration) to a high degree (high elaboration) of thought. Some

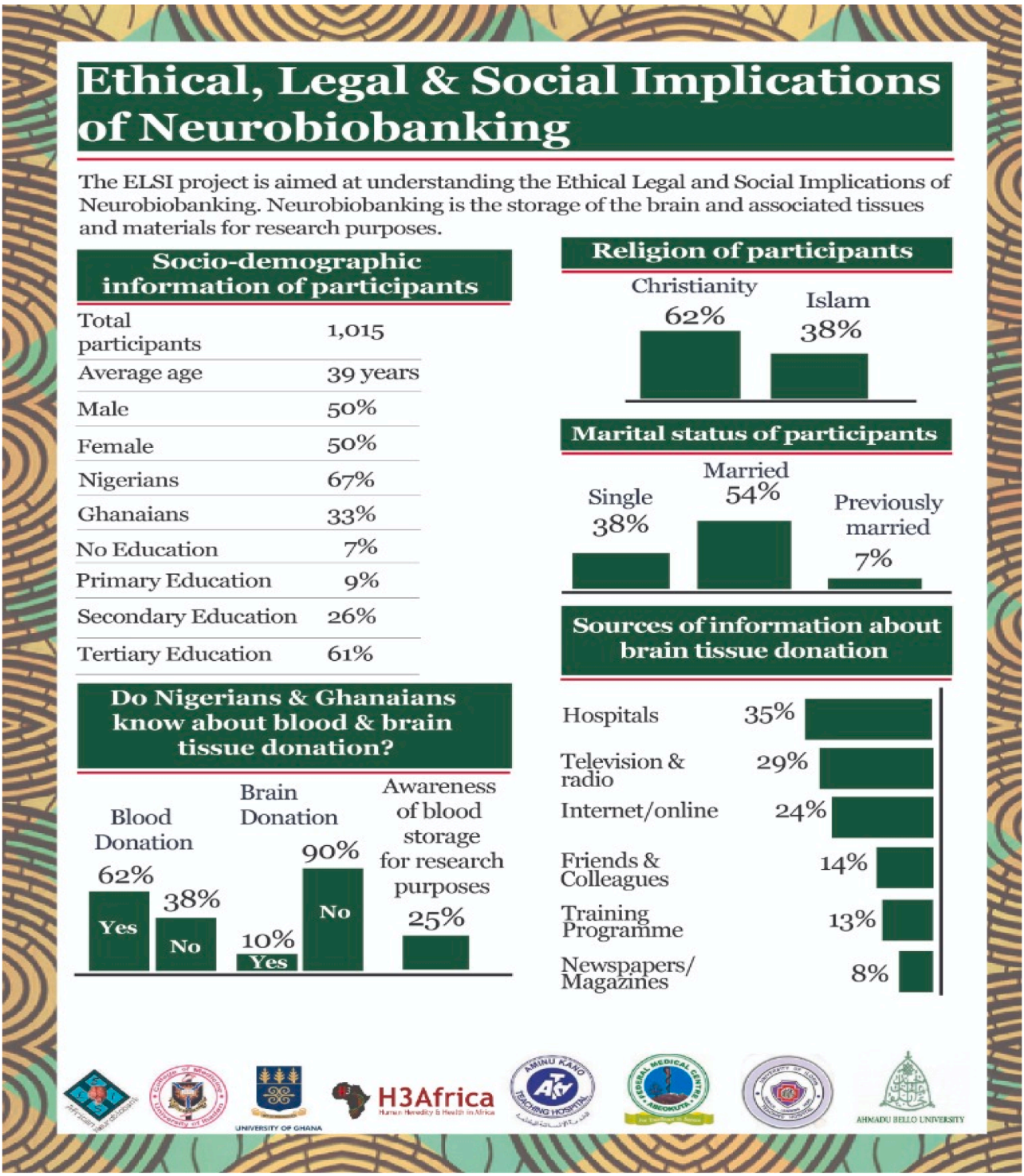

Fig. 3. Sample image from infographics summarising some key findings from the primary study.

of the factors that determine the level of information processing and the eventual beliefs and attitudes to be developed towards the message include different motivations, abilities and opportunities.[44,59,60] The ELM emphasises the role of credible, persuasive communication in creating attitude or behaviour change in the message recipient.[61,62]

The intervention tools reported in this paper meet the foregoing attributes explained in the theoretical frameworks (Health Belief Model and Elaboration Likelihood Model). The messages contained within our intervention tools are credible because they were sourced from community leaders and stroke genomic experts, among others. These messages were packaged in simple and familiar terms that would be intelligible to laypersons. Besides, the benefits of biobanking were explicated while the recurrent socio-cultural and religious misconceptions about the donation of blood and brain tissue for stroke genomic research were lucidly addressed through convincing viewpoints provided by community leaders, religious leaders and stroke genomic experts.

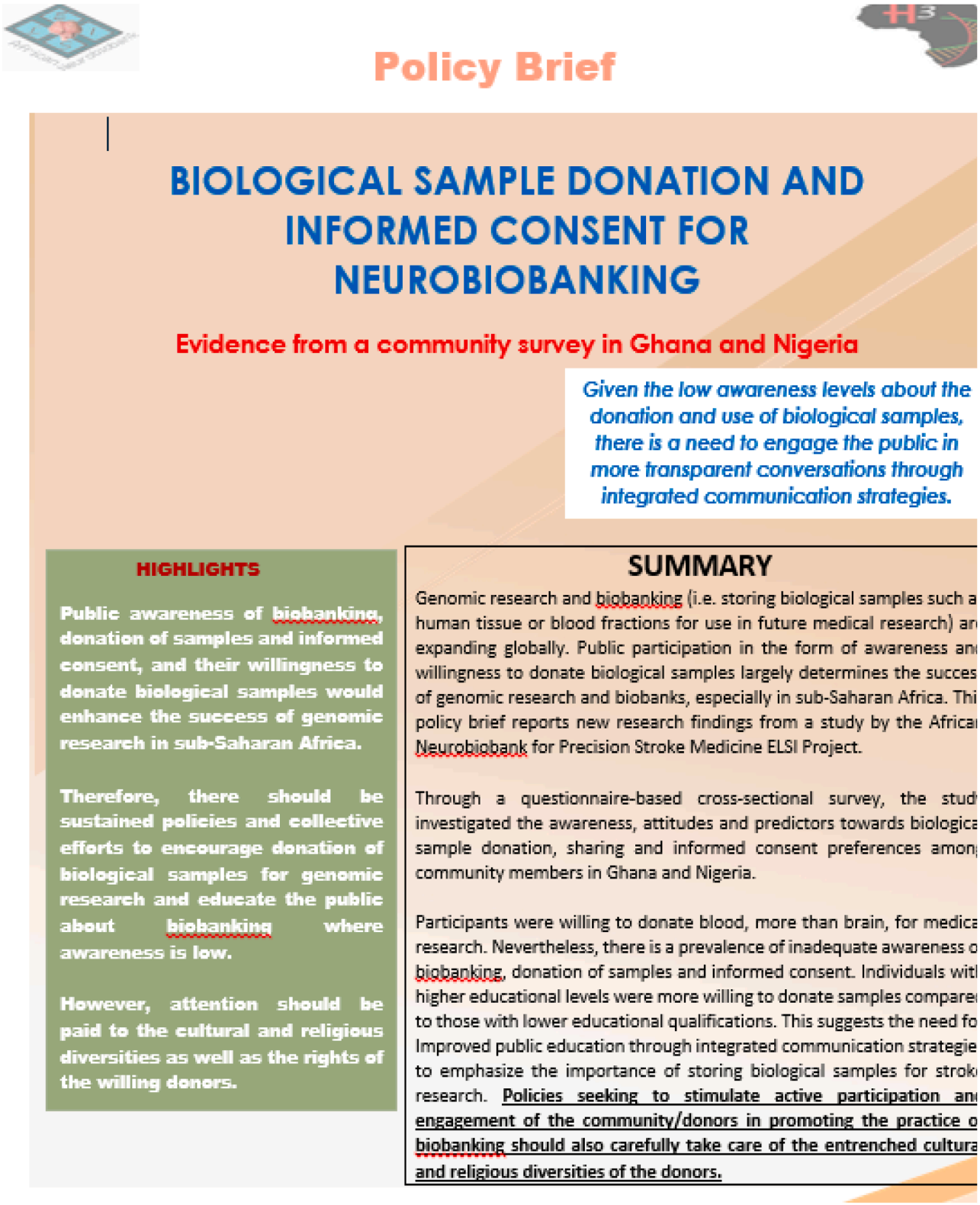

Fig. 4. Sample image from the policy brief summarising the key findings from the primary study.

Table 2
Evaluation of the understandability, actionability and suitability of the intervention videos using PEMAT and SAM assessment tools.

Videos	PEMAT		SAM
	Understandability mean±SD	Actionability mean±SD	Suitability mean±SD
Religious Implications of Neurobiobanking (n=41)	82.2±15.1	70.1±24.5	65.6 ±19.9
The need for Neurobiobanking (n=49)	81.4±15.1	72.9±20.5	67.2 ±21.4
Stroke Genomics and Precision Medicine Research(n=44)	85.7±13.8	67.1±31.3	70.6 ±18.7
Ethical and Legal Implications of Neurobiobanking(n=40)	81.9±14.2	72.5±25.2	64.4 ±22.1
How do Nigerians and Ghanaians perceive Neurobiobanking(n=44)	80.9±15.6	73.8±21.1	70.7 ±18.8
Summary	82.4±14.7	71.5±24.6	67.9 ±20.1

PEMAT: Patient Education Materials Assessment Tool
SAM: Suitability Assessment of Materials

Conclusion

We developed various intervention tools (i.e., general advocacy, educational, and training videos, infographics, and a policy brief) focusing on ELSI neurobiobanking and stroke genomic research in Africa. The tools were found suitable for addressing Ethical, Legal, and Social issues, such as storage and re-use of stored blood fractions, donating blood, donating brain tissue for genomic research, and informed consent.

The process required proper input from all the stakeholders, including the researchers, the research community, the lay public and experts in the field. Unless every group of critical stakeholders is well involved in the process of development, the intervention tools may not be as effective in achieving the objectives. Clinical researchers must clearly define their policy objectives, identify and collaborate with key stakeholders, define desired behaviour change, and develop appropriate strategies, tools of engagement and communication channels. The procedures reported in this study may serve as a template for stroke genomic researchers and other researchers in the broad fields of clinical and social science research projects.

Limitation

The current paper reports only the development and evaluation of the intervention tools. The tools' deployment and the deployment procedure's outcome will be reported in a separate paper.

Ethical Considerations

The study was reviewed and approved by the Institution Review Board(IRB) in each of the seven sites: University of Ibadan/University College Hospital Ethics Committee (UI/EC/18/0641), University of Ilorin Teaching Hospital Ethical Review Committee (UITH/CAT/189/20$^{A/}$/016), Federal Medical Centre, Abeokuta Health Research Ethics Committee (FMCA/470/HREC/04/2019/01), Aminu Kano Teaching Hospital Ethics Committee (AKTH/MAC/SUB/12A/P-3/VI/2566), Ahmadu Bello University Teaching Hospital Health Research Ethics Committee (ABUTHZ/HREC/E25/2018), School of Medical Sciences/Komfo Anokye Teaching Hospital Committee on Human Research, Publication and Ethics(CHRPE/AP/262/20), University of Ghana College of Health Sciences Ethical and Protocol Review Committee(EPRC/MAY/2019). Ethical approvals were renewed annually in each site after the submission of the progress report to the ethics committee. To ensure the principle of autonomy, all participants who consented signed/thumbprinted two (2) informed consent after adequate information had been provided by the research assistants in the language of choice to the participants, a copy of the informed consent was given to each participant and a copy kept by the research assistant in each of the sites.

Table 3
Thematic areas for refinement and revision tasks for improving the intervention tools.

S/N	Thematic Area	Specific Areas for Refinement Identified	Revision Tasks Implemented
1	Use of complex medical terms	Most of the reviewers agreed that complex medical terms were used in the videos and that this could affect the layperson's ability to understand the issues being discussed.	Illustrations (on-screen visual and textual displays) and sub-titles were added to the appropriate sections of the videos to address the medical jargon, especially those that do not have equivalents in the local languages, e.g. genes.
2	Benefits of Biobanking	Reviewers observed that the benefits of neurobiobanking were not strongly stated.	Benefits were illustrated by emphasizing family and community rewards for donating body parts (brain and blood) for research. These were added as the introduction, interludes and hospital footage.
3	Inclusion of local languages	The intervention tools were presented exclusively in the English language at the expense of the local languages of the study areas.	The tools were translated into the local languages of the study areas (i.e. *Yoruba* and *Hausa* in Nigeria; *Twi* and *Ga* in Ghana).
4	Expansion of religious views	Only views from Islam and Christianity were represented; the African Traditional Religious perspectives were missing.	Perspectives from the African Traditional Religions were added.
5	Speed of sub-titles and font size of the on-screen text	Reviewers complained that the speed of sub-titles was too rapid and the font size of the text was rather small.	The speed of sub-titles was adjusted appropriately, while the font size of the on-screen text was increased.
6	Gender balancing	Reviewers observed that only one female patient was interviewed.	One more person (a male patient) who had gone through similar experiences was interviewed.
7	Communication strategies for community engagement	The reviewer advised that we include and emphasize in the Policy Brief the communication strategies to be used for community engagement.	We revised the Policy Brief to emphatically reflect the integrated communication strategies (such as videos, comics, infographics, fliers, policy briefs, blog posts and newspaper articles) needed to sensitise the public and address their potential concerns such as religious and cultural sentiments about biobanking activities.

Availability of data and materials

The datasets used and analyzed are available from the corresponding author.

CRediT authorship contribution statement

Babatunde R. Ojebuyi: Writing – review & editing, Writing – original draft, Conceptualization. **Ibukun Afolami:** Writing – review & editing. **Muyiwa Adigun:** Writing – review & editing. **Arti Singh:** Writing – review & editing. **Carolyn Jenkins:** Writing – review & editing. **Michelle Nichols:** Writing – review & editing. **Kolawole Wahab:** Writing – review & editing. **Abiodun Bello:** Writing – review & editing. **Fred S. Sarfo:** Writing – review & editing. **Lukman F. Owolabi:** Writing – review & editing. **Rabiu Musbahu:** Writing – review & editing. **Reginald Obiako:** Writing – review & editing. **Albert Akpalu:** Writing – review & editing. **Mayowa Ogunronbi:** Writing – review & editing, Project administration. **Olorunyomi Olorunsogbon:** Writing – review & editing, Formal analysis, Data curation. **Benedict Calys-Tagoe:** Writing – review & editing. **Deborah Adesina:** Writing – review & editing. **Nathaniel Coleman:** Writing – review & editing. **Abdullateef G. Sule:** Writing – review & editing. **Aliyu Mande:** Writing – review & editing. **Muhammed Uthman:** Writing – review & editing. **Musibau Titiloye:** Writing – review & editing. **Ezinne Uvere:** Writing – review & editing. **Odunola Bukola:** Writing – review & editing. **Ruth Laryea:** Writing – review & editing. **Adekunle Fakunle:** Writing – review & editing. **Osi Adeleye:** Writing – review & editing. **Nathaniel Mensah:** Writing – review & editing. **Jibril Yusuf:** Writing – review & editing. **Sunday Adeniyi:** Writing – review & editing. **Shadrack Asibey:** Writing – review & editing. **Lanre Omotoso:** Writing – review & editing. **Lois Melikam:** Writing – review & editing. **Dorcas Olujobi:** Writing – review & editing. **Wisdom Oguike:** Writing – review & editing. **Joshua Akinyemi:** Writing – review & editing, Formal analysis, Data curation. **Ayodele Jegede:** Writing – review & editing. **Rajesh Kalaria:** Writing – review & editing. **Bruce Ovbiagele:** Writing – review & editing. **Mayowa Owolabi:** Writing – review & editing. **Oyedunni Arulogun:** Writing – review & editing, Funding acquisition, Conceptualization. **Rufus Akinyemi:** Writing – review & editing, Supervision, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors acknowledge receipt of the following financial support for the research, authorship, and/or publication of this article: The African Neurobiobank for Precision Stroke Medicine ELSI Project, the SIREN Study, and the Systematic Investigation of Blacks with Stroke using Genomics (SIBS Genomics) Study are supported by Grants U01HG010273, U54HG007479, and R01NS107900, respectively, from the National Institutes of Health as part of the H3Africa Consortium. The corresponding author Rufus O. Akinyemi is further supported by the fellowship FLAIR FLR/R1/191813, FCG/R1/201034) funded by the UK Royal Society and the African Academy of Sciences and the Alzheimer Association and Global Brain Health Institute (GBHI ALZ UK-21-24204).

However, we declare that we have no known competing financial interests, obligations or personal relationships with any individuals or institutions that could potentially compromise or influence the work reported in this article.

Acknowledgements

The authors acknowledge receipt of the following financial support for the research, authorship, and/or publication of this article: The African Neurobiobank for Precision Stroke Medicine ELSI Project, the SIREN Study, and the Systematic Investigation of Blacks with Stroke using Genomics (SIBS Genomics) Study are supported by Grants U01HG010273, U54HG007479, and R01NS107900, respectively, from the National Institutes of Health as part of the H3Africa Consortium. The corresponding author Rufus O. Akinyemi is further supported by the fellowship FLAIR FLR/R1/191813, FCG/R1/201034) funded by the UK Royal Society and the African Academy of Sciences and the Alzheimer Association and Global Brain Health Institute (GBHI ALZ UK-21-24204).

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jstrokecerebrovasdis.2025.108378.

References

1. Abimiku A, et al. H3Africa Biorepository Program: supporting genomics research on African populations by sharing high-quality biospecimens. *Biopreserv Biobank*. 2017; 15(2):99–102.
2. Mayne ES, et al. Genes for life: biobanking for genetic research in Africa. *Biopreserv Biobank*. 2017;15(2):93–94.
3. Akinyemi RO, et al. Biobanking in a challenging African environment: unique experience from the SIREN Project. *Biopreserv Biobank*. 2018;16(3):217–232.
4. Akinyemi RO, 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.
5. Akinyemi RO, 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, 160940692092319.
6. Coughlin S, Jenkins C. Engaging communities in translational research. In: Coughlin SS, Smith SA, Fernandez ME, eds. *Handbook Of Community-Based Participatory Research*. New York: Oxford University Press; 2017:251–266. Editors.
7. Ahmed SM, Palermo A-GS. Community Engagement in research: frameworks for education and peer review. *Am J Public Health*. 2010;100(8):1380–1387.
8. Ojebode A, et al. *Explaining the Effectiveness of Community-Based Crime Prevention Practices in Ibadan, Nigeria*. 479. Institute of Development Studies (IDS); 2016:1–59. Working Paper.
9. Coughlin S, Smith SA, Fernandez ME. *Handbook Of Community-Based Participatory Research*. New York: Oxford University Press; 2017.
10. Abimbola S. Beyond positive a priori bias: reframing community engagement in LMICs. *Health Promot Int*. 2020;35(3):598–609.
11. Kim SS, Haynes EN. Overview of community-based participatory research in environmental health. In: Coughlin SS, Smith SA, Fernandez ME, eds. *Handbook Of Community-Based Participatory Research*. New York: Oxford University Press.; 2017: 205–222.
12. Ojebode A, et al. Mono-method research approach and scholar–Policy disengagement in Nigerian communication research. In: Mutsvairo B, ed. *The Palgrave Handbook of Media and Communication Research in Africa*. Berlin: Springer International Publishing AG; 2018:369–383. Editor.
13. Adhikari B, Pell C, Cheah PY. Community engagement and ethical global health research. *Glob Bioeth*. 2020;31(1):1–12.
14. Overseas Development Institute, Helping researchers become policy entrepreneurs: how to develop engagement strategies for evidence-based policy-making, in ODI Briefing Paper 53. 2009.
15. Mindu, T., M.J. Chimbari, and R. Msesengwa, The role of health, learning and leadership institutions in schistosomiasis research uptake in Ingwavuma area, uMkhanyakude District, KwaZulu-Natal, South Africa. 2021, Research Square Platform LLC.
16. Akinyemi RO, et al. Stroke in Africa: profile, progress, prospects and priorities. *Nat Rev Neurol*. 2021;17(10):634–656.
17. Pielke AR. *The Honest Broker: Making Sense Of Science In Policy And Politics*. Cambridge: Cambridge University Press; 2007.
18. Westfall JM, et al. Practice-based research is community engagement. *J Am Board Fam Med*. 2009;22(4):423–427.
19. Elsabbagh M, et al. Community engagement and knowledge translation: progress and challenge in autism research. *Autism*. 2014;18(7):771–781.
20. Arulogun OS, et al. Experience of using an interdisciplinary task force to develop a culturally sensitive multipronged tool to improve stroke outcomes in Nigeria. *eNeurologicalSci*. 2016;4:10–14.
21. Hurst S, et al. The use of qualitative methods in developing implementation strategies in prevention research for stroke survivors in Nigeria. *J Clin Hypertens*. 2016;18(10):1015–1021.
22. Sheridan S, et al. The PCORI engagement rubric: promising practices for partnering in research. *Ann Fam Med*. 2017;15(2):165–170.
23. Naidu T, Prose N. Re-envisioning member checking and communicating results asAccountability practice in qualitative research: A South African community-based organization example. *Forum: Qual Soc Res*. 2018;19(3):1–16.
24. Adebisi YA, Rabe A, Lucero-Prisno Iii DE. Risk communication and community engagement strategies for COVID-19 in 13 African countries. *Health Promot Perspect*. 2021;11(2):137–147.
25. Sahoo KC, et al. Community engagement and involvement in managing the COVID-19 pandemic among urban poor in low-and middle-income countries: a systematic scoping review and stakeholders mapping. *Glob Health Action*. 2023;16(1), 2133723.
26. Akintobi TH, et al. The community engagement course and action network: strengthening community and academic research partnerships to advance health equity. *Front Public Health*. 2023;11, 1114868.

27. Andrasik MP, et al. Increasing Black, Indigenous and People of Color participation in clinical trials through community engagement and recruitment goal establishment. *PLoS One*. 2021;16(10), e0258858.
28. Tan RKJ, et al. Digital approaches to enhancing community engagement in clinical trials. *NPJ Digit Med*. 2022;5(1):37.
29. Mortensen CD. *Communication: The Study of Human Communication*. New York: McGraw-Hill Book Co; 1972.
30. Adler RB, Rodman G. *Understanding Human Communication*. 9th ed. Oxford New York: Oxford University Press, Inc; 2006.
31. Deutsch KW. On communication models in the Social sciences. *Public Opin Q*. 1952; 16:356–380.
32. Gerbner G. Toward a general model of communication. *Audiov Commun Rev*. 1956;4 (3):171–199.
33. Watzlawick P, Beavin J, Jackson D. *Pragmatics of Human Communication*. New York: Norton; 1967.
34. Sereno KK, Mortensen CD. *Foundations of Communication Theory*. New York: Harper & Row; 1970.
35. Folarin B. *Theories of Mass Communication: An Introductory Text*. Ibadan: Stirling-Horden Publishers (Nig.) Ltd; 1998.
36. Drew, C. All eight models of communication, explained! 2021; available from: https://helpfulprofessor.com/communication-models/.
37. Berlo D. *The Process Of Communication*. New York: Rinehart, & Winston; 1960.
38. Narula U. *Handbook Of Communication Models, Perspectives, Strategies*. New Delhi: Atlantic publishers&distributors; 2006.
39. Adler RB, Towne N. *Looking Out Looking In: Interpersonal Communication*. 8th ed. New York: Holt, Rinehart and Winston; 1996.
40. *Community Engagement: A Health Promotion Guide For Universal Health Coverage In The Hands Of The People*. Geneva: World Health OrganizationWorld Health Organization; 2020.
41. Dutton T, et al. Uptake and acceptability of human papillomavirus self-sampling in rural and remote aboriginal communities: evaluation of a nurse-led community engagement model. *BMC Health V Res*. 2020;20(1).
42. Smits DW, et al. Designing a tool to support patient and public involvement in research projects: the involvement matrix. *Res Involv Engag*. 2020;6:30.
43. Ceasar JN, et al. Community engagement in the development of an mHealth-enabled physical activity and cardiovascular health intervention (Step It Up): pilot focus Group study. *JMIR Form Res*. 2019;3(1), e10944.
44. Kang J-W, Namkung Y. The information quality and source credibility matter in customers' evaluation toward food O2O commerce. *Int J Hosp Manag*. 2019;78: 189–198.
45. Mathie E, et al. The role of patient and public involvement leads in facilitating feedback: "invisible work". *Res Involv Engag*. 2020;6:40.
46. Hoke AM, et al. Evaluation of a stakeholder advisory board for an adolescent mental health randomized clinical trial. *Res Involv Engag*. 2023;9(1):17.
47. Michalak EE, et al. Engaging diverse patients in a diverse world: the development and preliminary evaluation of educational modules to support diversity in patient engagement research. *Res Involv Engag*. 2023;9(1):47.
48. Micsinszki SK, et al. Delivery and evaluation of simulations to promote authentic and meaningful engagement in childhood disability research. *Res Involv Engag*. 2023; 9(1):54.
49. Morris L, et al. Evaluating a tool to improve engagement and recruitment of under-served groups in trials. *Trials*. 2022;23(1):867.
50. Garratt A, et al. The Public and Patient Engagement Evaluation Tool: forward-backwards translation and cultural adaption to Norwegian. *BMC Musculoskelet Disord*. 2022;23(1):556.
51. Kataria I, et al. Development and evaluation of a digital, community-based intervention to reduce noncommunicable disease risk in a low-resource urban setting in Malaysia: a research protocol. *Implem Sci Commun*. 2020;1:87.
52. LaMorte WW. *The Health Belief Model*. Boston University School of Public Health; 2019.
53. Norman P, Conner M. Health behavior. In: Stein J, ed. *Reference Module in Neuroscience and Biobehavioral Psychology*. Elsevier; 2017:1–27. Editor.
54. Taylor D, et al. *A Review of the use of the Health Belief Model (HBM), the Theory of Reasoned Action (TRA), the Theory of Planned Behaviour (TPB) and the Trans-Theoretical Model (TTM) to Study And Predict Health Related Behaviour Change*. The National Institute for Health and Clinical Excellence (NIHCE): The School of Pharmacy, University of London; 2007:3–19. D.o. Health, Editor.
55. Abraham C, Sheeran P. The health belief model. In: Conner M, Norman P, eds. *Predicting and Changing Health Behaviour: Research and Practice with Social Cognition Models*. Open University Press: McGraw-Hill; 2015. Editors.
56. Champion VL, Skinner CS. The health belief model. In: Glanz K, Rimer BK, Viswanath K, eds. *Health Behavior and Health Education: Theories, Research, and Practice*. San Francisco, CA: Jossey Bass; 2008. Editors.
57. Yadeta TA, Bedane HK, Tura AK. Factors affecting parent-adolescent discussion on reproductive health issues in Harar, Eastern Ethiopia: A cross-sectional study. *J Env Public Health*. 2014;2014:1–7.
58. Brewer NT, Rimer BK. Perspectives on health behaviour theories that focus on individuals. In: Glanz K, Rimer BK, Viswanath K, eds. *Health Behavior and Health Education: Theories, Research, and Practice*. San Francisco, CA: Jossey Bass; 2008. Editors.
59. Petty RE, Cacioppo JT. Source factors and the elaboration likelihood model of persuasion. *Adv Consum Res*. 1984;11:668–672.
60. Petty RE, Cacioppo JT. The elaboration likelihood model of persuasion. *Adv Exp Soc Psychol*. 1986;19:123–205.
61. Angst CM, Agarwal R. Adoption of electronic health records in the presence of privacy concerns: the elaboration likelihood model and individual persuasion. *MIS Q*. 2009;33(2):339–370.
62. Braten I, Strømsø HI, Salmeron L. Trust and mistrust when students read multiple information sources about climate change. *Learn Instr*. 2011;21(2):180–192.
63. Uvere EO, et al. Capacity-building for Stroke genomic Research data collection: the African Neurobiobank ethical, legal, and social implications Project experience. *Biopreservat Biobank*. 2022.
64. Parlina A, Ramli K, Murfi H. Theme mapping and bibliometrics analysis of one decade of big data research in the Scopus database. *Information*. 2020;11(2):69.
65. Caulfield, J., How to do thematic analysis | step-by-step guide & examples, in Scribbr. 2022.
66. Nordquist, R., Definition and examples of vignettes in Prose, in ThoughtCo. 2018.
67. Barter C, Renold E. *The Use of Vignettes in Qualitative Research*. Social Research Update; 1999.
68. Singh A, et al. Biological sample donation and informed consent for neurobiobanking: evidence from a community survey in Ghana and Nigeria. *PLOS ONE*. 2022;17(8), e0267705.
69. Doak C, et al. *Suitability Assessment Of Materials (SAM)*. American Public Health Association; 1994.
70. Weintraub D, et al. Suitability of prostate cancer education materials: applying a standardized assessment tool to currently available materials. *Patient Educ Couns*. 2004;55(2):275–280.
71. Shoemaker SJ, Wolf MS, Brach C. *The patient education materials assessment tool (PEMAT) and user's guide. Agency for Healthcare Research and Quality*. U.S. Department of Health and Human Services; 2020.
72. Willis GB, et al. Cognitive interviewing revisited: A useful technique, in theory? In: Presser S, et al., eds. *Methods For Testing And Evaluating Survey Questionnaires*. New Jersey: John Wiley & Sons; 2004. Editors.
73. Willis GB, Miller K. Cross-cultural cognitive interviewing: seeking comparability and enhancing understanding. *Field Methods*. 2011;23(4):331–341.