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Stroke Investigative Research and Education Network: Community Engagement and Outreach Within Phenomics Core

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Abstract

Stroke is the leading cause of neurological hospital admissions in sub-Saharan Africa (SSA) and the second leading cause of death globally. The Stroke Investigative Research and Education Network seeks to comprehensively characterize the genomic, sociocultural, economic, and behavioral risk factors for stroke and to build effective teams for research to address and decrease the burden of stroke and other noncommunicable diseases in SSA. One of the first steps to address this goal is to effectively engage the communities that suffer the high burden of disease. The purpose of this article is to describe plans to elucidate information about knowledge, attitudes, beliefs, and practices about stroke and genomics from patients, caregivers, and local leaders, to

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recruit participation in research activities and dissemination of ongoing results, as well as to facilitate research uptake and impact within the broader communities of scientists, health professionals, policy makers, and others. We describe the (a) study sites and their communities; (b) plans for community advisory boards, focus groups, and surveys; (c) methods for data management in REDCap database; (d) analyses of qualitative data; (e) evaluation of community and public engagement across multiple sites and research teams in SSA and the United States; (f) use of RE-AIM for presentation of evaluation data; and (g) community indicators of success. This is the first of its kind public outreach engagement initiative to evaluate stroke and genomics in SSA, and has implications as a model for assessment in other high-stroke risk populations.

Keywords

community advisory boards; community engagement; focus groups; genomics; REDCap database; SSA; stroke; sub-Saharan Africa

Stroke is becoming a leading cause of disability and death, and a major public health concern in Africa. Every minute, approximately six Africans experience a stroke (Owolabi et al., 2015; Owolabi & Ovbiagele, 2013). Although the age-standardized incidence of stroke has decreased by about 12% between 1990 and 2010 in high-income countries (Hall, Levant, & DeFrances, 2012; Ovbiagele, 2011; Rosengren et al., 2013; Wang, Rudd, & Wolfe, 2013), in Africa the burden of stroke is increasing, disproportionately afflicting young and middle-aged adults (H3 Africa Consortium, 2014; Owolabi, 2011). Stroke is the leading cause of neurological hospital admissions (Ekenze, Onwuekwe, & Ezeala Adikaibe, 2010; Obiako, Oparah, & Ogunniyi, 2011) and the second leading cause of death globally (O'Donnell, Xavier, Liu, & INTERSTROKE investigators, 2010). The Cardiovascular Working Group of the Human Heredity and Health in Africa Initiative (H3Africa) and especially the Stroke Investigative Research and Education Network (SIREN) seek to comprehensively characterize the genomic, sociocultural, economic, and behavioral risk factors leading to the development of clinical risk factors for stroke and subclinical disease that over time may result in clinically apparent stroke (Kernan et al., 2014).

Overall Goals of SIREN

The overall goal of SIREN is to evaluate the premier genetic and environmental risk factors for stroke in SSA, while simultaneously training professionals and building sustainable capacities in phenomics, biobanking, genomics, biostatistics, and bioinformatics for the high-level investigation of stroke (and other noncommunicable diseases) in sub-Saharan Africa (SSA). SIREN comprises two major study cores: Systematic Investigation of Blacks With Stroke (SIBS)–Phenomics and SIBS–Genomics, along with SIBS–Biostatistics and Bioinformatics. As a member of the H3Africa Initiative, we believe and adhere to the principles of High-Level Principles on Ethics, Governance and Resource Sharing, which states,

Research networks and programs should incorporate appropriate engagement with the communities participating in the research as an integral element—this should be an ongoing activity throughout the program which extends beyond the original

consent and ... includes communication of results and their healthcare implications.
(Retrieved from <http://h3africa.org/about/ethics-and-governance>)

Community and public engagement actions are essential for the success of SIREN. We define community engagement as a multifaceted process of working collaboratively with people with stroke and members of the broader community. The community engagement facet has been integrated into SIBS-Phenomics to facilitate community-based recruitment of almost all of the 3,000 controls (others may be recruited directly from hospitals in the community) as well as community sensitization to facilitate early presentation of stroke cases in SIBS hospitals, thereby greatly minimizing referral bias. This community engagement core within SIBS-Phenomics will be a first-of-its kind public outreach engagement initiative to evaluate and address perceptions about stroke and genomics by patients, caregivers, and local leaders in SSA. Doing this will help promote better uptake of medical regimen adherence, behavioral modification, and participation in research studies by at-risk persons and the communities at large. We will also involve “public engagement” to facilitate dissemination of results, as well as research uptake and impact, within the broader communities of scientists, health professionals, policy makers, and others within the broader cultural landscape.

Theoretical frameworks guiding our community engaged research are the social ecological model (Institute of Medicine, 2001) and the explanatory model of illness (Kleinman, Eisenberg, & Good, 1978). The constructs of the social ecological model are used to explore individual and population health related to stroke, including individual factors (e.g., genetics, pathophysiologic pathways, individual knowledge, beliefs, behaviors), interpersonal factors (e.g., family, friends, peers, and other social relationships), institutional processes (e.g., social networks, social support systems), community factors (e.g., relationships among networks, health care access, living conditions), and public policy (e.g., local, state, and national laws/policies). Kleinman et al.'s (1978) model provides the framework for further exploring beliefs and attitudes related to stroke and stroke research.

Purpose of This Article

The purpose of this article is to share a brief description of the six SIREN communities, the research approach, plans, and strategies for community engagement and community input across SIREN communities. The aim of community engagement is to elucidate information about knowledge, attitudes, beliefs, and practices about stroke and its risk factors from individuals of African ancestry in SSA, and to facilitate participation in genetic testing and other participation in research studies, as well as to help disseminate the results of SIREN. The hypothesis is the following: Systematic community engagement using established qualitative research methodologies will result in information that can be used to educate and mobilize the community regarding the nature of stroke, role of genetic testing, and benefits of involvement in research studies. Although this genomic research does not involve an intervention that focuses on immediate improvement of stroke outcomes, the goal is to identify particular genetic and genomic factors related to causation or prevention of stroke. Additionally, training of researchers in SSA and collaboration across continents are essential for improving ongoing research. If we are to reduce deaths and disabilities from stroke, we

must educate the community about stroke and ways to decrease disabilities and deaths from stroke. And the education must be done using socioculturally appropriate messaging and messengers so that community members will seek health care for stroke and stroke prevention. This process, combined with ongoing research and translation of research findings into clinical and community behaviors and practices, will ultimately lead to improvements in stroke prevention and treatment.

SIREN Study Sites and Their Communities

There are eight study sites located in six cities, with six study sites in Nigeria and two in Ghana. Nigeria is the most populous nation of individuals of African descent with over 177 million people in 2011 (Index Mundi, 2015b). Based on 2010 gross national income per capita, the World Bank classified Nigeria as a “Lower Middle Income Economy,” that is, gross national income ranging from \$1,006 to \$3,975. Nigeria is peopled by over 250 ethnic groups that are categorized into three major tribes: the Hausa/Fulani (North), Yoruba (Southwest), and Igbo (Southeast). Nigeria, thus, provides an ideal setting for this study. There are four study sites in Southern Nigeria (two in Ibadan and two in Abeokuta), two in Northern Nigeria (Kano and Zaria), and two in Ghana (Accra in Southern Ghana and Kumasi in middle Ghana). To provide the context for the research and community engagement, a brief overview of each of the sites is presented in Table 1.

Overview of the SIREN Research Team

The SIREN team consists of members who are researchers and clinicians, nurses, health educators, public health professionals, epidemiologists, and statisticians. Most have earned doctorates and are active researchers. The principal investigators at the sites are neurologists/medical doctors/researchers who provide clinical care to stroke patients. The team for community engagement includes investigators and staff with expertise in both qualitative and quantitative research and community engagement. Each is knowledgeable about the community culture in their respective communities. Members from the community participate and guide the team through input from the community advisory board (CAB) and linkages to the broader community. All have a personal interest in stroke and genomics.

Methodology (Protocol) for Community Engagement and Outreach, and Planned Results

Community Engagement Framework Design

Our framework for community and public engagement across the communities is built on the Principles of Community Engagement (National Institutes of Health, 2011) and review of available literature and focuses on both qualitative and quantitative processes. We use the following methods for engaging the community and for accomplishment of aims:

- Development and implementation of ongoing CABs within each site to guide the ongoing research activities and research dissemination within the communities and possibly across SSA

- Exploration of the knowledge, attitudes, and practices related to stroke, stroke risk factors, genetic testing, and exploring the genomics of stroke with patients, community and faith-based leaders, and health care providers and researchers; this will be accomplished through surveys and focus group qualitative research.
- Public outreach and engagement is focused on the following:
 - Community-based recruitment of almost all control participants ($n = 3,000$)
 - Community sensitization to facilitate early prevention of stroke and earlier entry into care and recruitment into SIREN for persons with stroke ($n = 3,000$)
 - Evaluation of perceptions of stroke and related genomics, particularly in patients, caregivers, and local leaders
 - Improved uptake of medical regime, adherence, behavior modification to prevent and manage stroke and improved participation in research study
 - Outreach to relevant authorities, staff, key opinion leaders, professional organizations, community organizations, and faith-based organizations to introduce SIREN, its objectives, and expectations and to invite active participation and input into SIREN
- Dissemination of results to the following:
 - Relevant authorities, staff, key opinion leaders, professional organizations, community organizations, and faith-based organizations
 - Scientific communities through presentations and manuscript submission
- Evaluation of community outreach:
 - The RE-AIM framework will guide the evaluation of community engagement activities (Jilcott, Ammerman, Sommers, & Glasgow, 2007)
- Participation in H3Africa Consortium of researchers to facilitate ongoing work related to ethics and community engagement in genomic research across all H3Africa communities

One of the challenges of working with diverse communities is the multiple languages and dialects spoken across and within the SIREN communities. To meet this challenge requires the translation of all SIREN materials from English into the appropriate languages or dialects spoken in the communities, and both trained staff and funding are needed to meet these requirements. Translation of SIREN materials into local dialects involves a minimum of two independent forward- translations by bilingual translators, who then compare their

versions to identify discrepancies pointing out use of ambiguous or vague wording. During synthesis a third bilingual person leads a discussion between the two original translators to develop one final version of the document that is pretested prior to use. A fourth person, blinded to the original documents, then back-translates the information into English and compares it with the original document to check the validity of the translation (Beaton, Bombardier, Guillemin, & Ferraz, 2000, 2002).

Each of the above approaches, their anticipated contributions to the success of SIREN, and the methods for planning, implementation, evaluation, and reporting the community and public engagement activities are reviewed below.

Community Advisory Boards

The CAB in each of the communities provides a systems-level infrastructure for academic–community partnerships and promotes institutionalization and sustainability of these partnerships and their products (Newman et al., 2011).

CAB Membership—SIREN specifies that each of the site’s CAB membership include the following: (a) stroke survivor(s), (b) faith-based leader(s), (c) community leader(s), (d) public health leader(s), (e) media representative(s), and (f) professional based organizations leader(s). Other potential members could include representatives from community systems shown in Figure 1.

Most communities find it helpful to specifically add representatives from faith-based groups to CABs. However, it is important to consider the linkages to the community as well as the representation, cultural insight, technical expertise, and leadership that each member brings to the CAB and to assure that most segments of the population are represented. Another framework that could provide suggestions for CAB membership is the 7Ps (patients and public, providers, purchasers, payers, policy makers, product makers, and principal investigators; Concannon et al., 2012). It is important that members demonstrate a commitment to the mission of the research, work to advance the research, attend CAB meetings, and work effectively with the team. Overall, for the CAB to be successful, the members will have connections to the local context and have broad representation and diversity.

CAB Roles and Responsibilities—The roles of the CAB are to increase community awareness, and to guide and provide feedback to the research team. The roles and potential roles for each site are shown in Figure 2. Each of the local CABs and the site principal investigator determine CAB governance, terms of service, compensation/honoraria (based on community engagement budget), leadership responsibilities, decision making, frequency of meetings, and other potential roles, as described in Figure 2.

Role of the SIREN Leadership Team With CAB Activities—The SIREN community engagement coinvestigators have developed standard operating procedures and are providing training for each site related to CAB development and reporting activities. Each site will provide a member of their research team as a liaison for their CAB and will provide

orientation, training, and ongoing updates for the CAB as well as manage communications with CAB members.

To support local CAB activities and to standardize record keeping across sites, the following forms were developed: (a) budget worksheets for allocation of staff time and expenditures for community engagement activities (see Figure 3 for examples), (b) SIREN CAB Membership List (with name, preferred phone numbers for communications, mailing address, and notes including availability, interests, agency/profession, etc.), (c) CAB Calendar of Meeting (with date, time, location, goals, and listing of administrative tasks including dates for meeting reminders, and minutes), and (d) a combined agenda and minutes record (including site, location, date and time of meeting, attendees and documentation of recorder and approval of minutes followed by columns for documenting topic, discussion leader, time allocation for agenda and discussion, action needed, and person responsible for minutes). Figure 3 Planning for SIREN CAB provides an example of one of several worksheets for internal budgeting and training provided for community engagement investigators and site principal investigators.

All forms are available from the authors. Additional information for establishing and developing CABs can be found in Guidance Tools for CABs (Menezes, Hannah, & Yassky, 2012).

Planned Data Management and Analysis of CAB Activities—The community engagement team will record, analyze, and report the following data for the CAB: (a) description of CAB membership; (b) meetings and meeting attendance; (c) qualitative analysis of meeting agendas, minutes, and community linkages; (d) community and public outreach; and (e) contributions to individual sites and overall SIREN successes.

Focus Groups

The purpose of the focus groups is to document knowledge, attitudes, and perceptions of risk factors for developing stroke, health-seeking behaviors, community attitudes, and willingness to be part of the genomic study. The focus group questions, shown in Figure 4, were developed based on the theoretical framework of Arthur Kleinman's explanatory model of illness (Kleinman et al., 1978).

The questions for the patients with stroke focus groups are also adapted to focus groups with (a) community and faith-based leaders and control volunteers and (b) health care providers and/or researchers at each of the community sites. To maximize input across each of the SIREN communities, a purposive sample of 6 to 12 participants representing the diversity of the communities will be recruited for each of the groups.

To standardize the focus group process, materials and training are provided for focus group discussions, in-depth interview guides, and forms for informed consents, demographics, and note-taking. Skype training is provided to all focus group leaders. All focus groups are conducted by trained interviewers. Focus group methods are based on methodology developed by Kruger and Casey (2000) and in-depth interview methodology developed by

Tremblay (1957). All materials and questions are translated into the appropriate language or dialect, cognitively pretested (Willis, 2005), and refined prior to use.

Focus Group Participant Demographic Information and Short Survey—To avoid bias from the information shared in the focus groups, prior to participating in the focus group discussion, each focus group participant is asked to complete/verify a demographics form and a short survey related to individual and perceived community beliefs and attitudes toward genetics and genomics.

Focus Group Processes and Analysis—Interviews and discussions are digitally recorded with participant consent to ensure that the details of the conversations are adequately captured. Additionally, the interviewer and note-taker for the groups write down detailed notes during the interviews and these notes are integrated into the transcripts. More extensive transcripts are developed following the interviews, and once the interviewer has had the opportunity to review the audio or video recording to ensure that the entire conversation is represented in the transcripts, the recordings are downloaded to a secure system, transcribed word for word, and reviewed for accuracy and completeness. After removal of personal identifiers, the data are analyzed using the NVivo 10 (QRS International, 2012), a software program for analyzing qualitative data. All final transcript data are analyzed using a constructivist variant of the widely used grounded theory methodology (Charmaz, 2006; Glaser & Strauss, 1967). The “Framework Analysis” approach includes five key stages: familiarization, identifying a thematic framework, indexing, charting, mapping, and interpretation (Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). Designated research staff assist in carrying out an initial reading of approximately 10% of the transcripts to establish interrater reliability for the final coding hierarchy that is used to analyze the text. Disagreements in description or assignment of attribute codes are resolved through discussion to achieve mutual consensus. Qualitative descriptive methods described by Sandelowski (2000), Pope, Ziebland, and Mays (2000), and Elo and Kyngas (2008) are used to inductively analyze the data. The inductive approach is used since the current information is fragmented and there is not enough evidence about knowledge, attitudes, and perceptions of risk factors for developing stroke, health-seeking behaviors, community attitudes, and willingness to be part of the genomics study. The Consolidated Criteria for Reporting Qualitative Research will be used for synthesizing and reporting results (Tong, Sainsbury, & Craig, 2007).

Data Management for CAB, Focus Groups, and Surveys

All data received from SIREN sites are transmitted to a secure data management and storage system at the Medical University of South Carolina, and the data are password-protected. One of the infrastructure innovations is the use of the REDCap (Research Electronic Data Capture: project-redcap.org) system that serves as the data repository for community engagement data from all sites. REDCap is a secure Web application designed to support data capture and storage for both quantitative and qualitative research studies, providing user-friendly Web-based case report forms, real-time data entry validation (e.g., for data types and range checks), audit trails, and a de-identified data export mechanism to common analytical packages. The REDCap system was initiated at Vanderbilt University and further

developed by a multiinstitutional consortium that includes the Medical University of South Carolina.

Evaluation of Community and Public Engagement

We will collect key lessons and recommendations throughout the SIREN research project. Our CABs, focus groups, and surveys, as well as each site's investigators will provide data related to key lessons and recommendations. We will also discuss key lessons and recommendations for community engagement and public outreach during the monthly investigators phone conferences. The evaluation of the Community Engagement for SIREN will be focused on the Indicators of Success as stated in the Research Plan.

Community Indicators of Success

The community indicators of success for our SIREN Community Engagement and Outreach include the following:

- Coverage (number of members reached)
- Perception of stroke (avoiding stigmatization)
- Knowledge of preventive measures
- Perception on health-seeking practices for stroke
- Willingness to be part of the genomic study
- Ability to support the stroke study and encourage uptake of preventive measures
- Community-based, faith-based, and professional organizations' willingness and ability to disseminate the information among their members

These indicators will be tracked through both qualitative and quantitative evaluations, reported quarterly, and synthesized to further explicate ways to effectively work with communities to facilitate research and improve stroke awareness and reduction of risks.

Additionally, RE-AIM will provide the evaluation framework (Jilcott et al., 2007). The five steps of RE-AIM to translate SIREN research into action are the following:

- *Reach* or coverage in the target population: The absolute number, proportion, and representativeness of individuals who are willing to participate (after being invited) in the research activities including (a) CABs, (b) focus groups, (c) surveys, (d) research study, and (e) estimated public outreach and engagement activities and attendance
- *Effectiveness* or efficacy of outreach efforts: The impact of an intervention on important outcomes, including potential negative effects, as well as willingness and participation in genomic research related to stroke
- *Adoption* and incorporation by target staff, settings, or institutions: The absolute number, proportion, and representativeness of settings and intervention agents (people who deliver the program) who are willing to initiate a program

- *Implementation* consistency, costs, and adaptations made during delivery: At the setting level, implementation refers to the intervention agents' fidelity to the various elements of an intervention's protocol, including consistency of delivery as intended and the time and cost of the intervention; at the individual level, implementation refers to clients' use of the intervention strategies
- *Maintenance* of intervention effects in individuals and settings over time: The extent to which a program or policy becomes institutionalized or part of the routine organizational practices and policies; within the RE-AIM framework, maintenance also applies at the individual level; at the individual level, maintenance has been defined as the long-term effects of a program on outcomes after 6 or more months after the most recent intervention contact.

Discussion and Conclusions

Community engagement and community-engaged research, particularly community-based participatory research, are increasingly viewed as the keystone to translational research and improving health across populations. Community-based participatory research has been shown to (a) develop and sustain trusting community-researcher relationships; (b) build community capacity for participation in research as well as expanding local resources for research; (c) spark novel approaches, facilitate intervention development, and recruit and retain participants; (d) assess barriers to participating in research; and (e) guide the researcher and team in disseminating findings and translating research into practice and policy. From our own experiences and that of others, community-engaged research, as compared to traditional research paradigms, facilitates culturally situated and contextually sound interventions that have high potential to influence policy.

As stated in the introductions, the overall goal of SIREN is to evaluate the premier genetic and environmental risk factors for stroke in SSA, while simultaneously training professionals and building sustainable capacities in phenomics, biobanking, genomics, biostatistics, and bioinformatics for the high-level investigation of stroke (and other noncommunicable diseases) in SSA. Some might ask, "Why is community engagement essential for SIREN?" Community engagement can influence both the researchers and the groups affected by or influenced by the research. The reciprocal relationships with communities can guide the researcher in the discovery process and guide the community in ownership and integration of research into improving health. However, genomic research may not include an intervention with tangible rewards, and in SIREN we are recruiting both participants with stroke and healthy controls. Both need to understand the research and the implications of the use of genetic samples for research. Engaging the community shows signs of respect for values, culture and traditions of those involved in research, and this may be very important for communities that are unfamiliar with phenomic and genomic studies, especially those involving biobanking (informal communication with H3Africa Working Group on Ethics and Regulatory Issues for the Human Heredity and Health Consortium).

At the conclusion of this phase of the study, there will be documentation of the knowledge, attitude, perception of risk factors for developing stroke, health-seeking behavior, and

willingness to be part of the genomic study. Strategies for utilization and dissemination of findings are built in from the beginning: (a) involvement of relevant authorities, staff, and key opinion leaders and (b) identification of communication channels that are already in place that can be used in dissemination of results and community actions.

This research will develop and present a grounded theory related to knowledge, attitude, perception of risk factors for developing stroke, health-seeking behaviors, and willingness to be part of the genomic study for residents of SSA. When the qualitative data from community engagement and outreach are triangulated with phenomics data (defined as the measurement of phenomes—the physical and biochemical traits of participants with stroke and community controls—as they change in response to genetic mutation and environment influences), SIREN will be able to compare community knowledge, attitudes, and perceptions related to stroke to actual biological information. The development of this approach provides a model for other high-stroke risk populations around the world. These comparisons have the potential for changing both policy and practice related to stroke prevention, management, and recovery, not only in SSA but also across the world.

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Figure 1.

Community Systems Wheel

Note. SIREN = Stroke Investigative Research and Education Network. The Community Systems Wheel portrays the many community systems that could contribute to the success of SIREN. Each community will determine the membership for their community advisory board and can use the Wheel to discuss which systems need representatives on the local community advisory boards.

Source. Adapted from Anderson and McFarlane (2006, p. 218).

Roles of CAB as Defined by SIREN

- Create community awareness related to stroke, stroke prevention and participation in SIREN by linking the team with opportunities for community and public outreach
- Guide the research team in building and expanding trust and relationships with the surrounding communities, as well as the broader African communities
- Provide the research team with any feedback and suggestions

Potential Roles of CAB in each of SIREN Sites

- Inform research priorities based on local needs
- Advise researchers on community norms and expectations
- Contribute to an effective informed consent process by providing input and reviewing forms and questionnaires
- Engage in protocol development and review
- Help build trust with the local community
- Create a supportive environment for trials by raising awareness and dispelling myths
- Facilitate recruitment by identifying contacts to relevant target groups
- Follow up closely on the research process
- Convey information about the research to the community and field questions
- Analyze findings from particular stakeholder perspectives
- Assist in the dissemination of results to appropriate audiences
- Advise trial site on ways in which research practice can contribute to improvement in local life

Figure 2.

Roles and potential roles for SIREN CAB and CAB members.

Note. SIREN = Stroke Investigative Research and Education Network; CAB = community advisory board.

A. Planning the Community Advisory Board (CAB)
 Conceptualizing the CAB (1-5 researcher hours)
 Development of membership list for CAB (1-4 researcher hours)
 Logistical arrangements for CAB (1-2 researcher hours)
 Planning for meetings (agenda, minutes, other, food) (2 researcher hours)

Researcher Planning Time _____ hours

B. Recruiting Members for the CAB
 1. Recruiting (Consider these choices)
 a. By the team:
 - Development of telephone script (1-2 researcher hours)
 - Phone recruiting (estimate about 10-15 calls per hour)
 - "Willing" prospects (2-4 calls for each confirmation)
 - "Hesitant" prospects (3-6 calls for each confirmation)
 - "Difficult" prospects (3 calls and then stop)
 b. By volunteers
 - Researcher prepares criteria and trains volunteer on how to recruit CAB members (1-2 researcher hours)
 c. By a group or agency
 - Researcher prepares criteria and specifications (2 researcher hours)
 2. Follow-up letters (if needed) for all who expressed interest (1-2 administrative hours per group)
 3. Follow-up phone reminders for first meeting (1 clerical hour per group)
 4. Thank you notes for those participating in CAB (1 clerical hour per group)

Phone Recruiter or Administrative Time _____ hours
Researcher Recruiting Time _____ hours

C. Convening and Overseeing Meeting Activities (meetings)
 1. Travel time for researcher
 2. Meeting time (3 hours per meeting—1 hour to set up, 1 hour for meeting,
 1 hour for breakdown and de-compressing activities)

Researcher Time _____ hours

D. Add Other Costs:

Travel expenses for team	\$ _____
Travel expenses for CAB members	\$ _____
Handouts---Minutes from last meeting,	
Agenda, examples of accomplishments)	\$ _____
Honoraria	\$ _____
Food	\$ _____
Room charge	\$ _____
Equipment rental or purchase	\$ _____
Tapes/batteries/name tents/handouts	\$ _____
Transcription costs for minutes	\$ _____
Phone costs (if needed, for call-in)	\$ _____
Office supplies, duplication, postage	\$ _____
Total Other Costs	\$ _____

E. Final Calculations

Total Other Costs		\$ _____
Total Administrative Time _____ Hours X Hourly Rate of \$ _____		\$ _____
Total Researcher Time _____ Hours X Hourly Rate of \$ _____		\$ _____
Grand Total Cost		\$ _____

Figure 3.

Planning for SIREN community advisory board (staffing and budget).

Note. SIREN = Stroke Investigative Research and Education Network.

- What do you think caused your stroke?
- What in your genes or genetic background or family history may have contributed to your stroke?
- What in your environment or health habits may have contributed to your stroke? (If not mentioned, please probe or ask question related to: smoking, stress, diet, alcohol, exercise, high blood pressure, high blood cholesterol)
- Why do you think the stroke started when it did?
- What were the signs of your stroke prior to diagnosis?
- Where did you seek help for your stroke or what did you do prior to coming to hospital and getting your diagnosis?
- How severe is your stroke? Will it have or has it has a long or short course?
- What kind of treatment do you think you should have received for your stroke?
- What are the most important results you hope or hoped to receive from this treatment?
- What are the chief problems your stroke has caused for you and your family?
- What do you fear most about your stroke?
- Our Research Team is exploring the link between our heritability, our environment, and stroke by doing some genetic testing of those who have had a stroke and others who have not had a stroke. What concerns and advice would you share to guide us in collecting a blood sample and information for the genetic testing?
- What suggestions do you have that will guide us in working with your community to increase participation in donating a blood sample and providing information for genetic testing for stroke?

Figure 4.
Focus group questions for patients with stroke.

Table 1

Overview of the SIREN Communities.

SIREN site	Population (in 2011)	Tribes/ethnic groups	Hospital/university coordination site	Other
Nigeria ^a	177,155,754 ^a	Nigeria, Africa's most populous country, is composed of more than 250 ethnic groups; the following are the most populous and politically influential: Hausa and Fulani 29%, Yoruba 21%, Igbo (Ibo) 18%, Ijaw 10%, Kanuri 4%, Ibibio 3.5%, Tiv 2.5% ^a	0.53 beds/1,000 population (2004) ^a	About 50% urban (2011) ^a Life expectancy at birth: 52.6 years ^a Languages: English (official), Hausa, Yoruba, Igbo (Ibo), Fulani, over 500 additional indigenous languages ^a Religion: Muslim 50%, Christian 40%, indigenous beliefs 10% ^a Literacy: 61.3% ^a
Southern Nigeria Sites				
Ibadan	2.949 million ^a		University College Hospital Ibadan: first teaching hospital in Nigeria with 850 beds tertiary center with several community care centers and Blossom Center for Neuro Rehabilitation: first neurorehabilitation hospital in East, West, and Central Africa	Capital of Oyo State and third largest city in Nigeria
Abeokuta	593,100 ^b		Federal Medical Center: 400-bed tertiary center with strong relationships to community care centers within and outside Abeokuta and Sacred Heart Hospital: 300 beds and the oldest existing medical hospital in Nigeria	Capital of Ogun State
Northern Nigeria Sites				
Kano	3.375 million ^a	Hausa and Fulani tribes are dominant	Aminu Kano Teaching Hospital and tertiary referral center with 78 beds	Largest commercial center in northern Nigeria with fertile plains for agriculture
Zaria		Hausa and Fulani tribes are dominant	Ahmadu Bello University Teaching Hospital with 768 beds	The city of Zaria hosts many unique institutions of learning and is referred to as the Center of Learning in Nigeria
Ghana ^c	25,758,108	Akan 47.5%, Mole-Dagbon 16.6%, Ewe 13.9%, Ga-Dangme 7.4%, Gurma 5.7%, Guan 3.7%, Grusi 2.5%, Mande-Busanga 1.1%, other 1.6% (2010 census) ^c	0.9 beds/1,000 population (2011) ^c	Low middle-income economy About 52% urban (2011) ^c Life expectancy: 65.75 years ^c Languages: English (official), Asante 14.8%, Ewe 12.7%, Fante 9.9%, Boron (Brong) 4.6%, Dagomba 4.3%, Dangme 4.3%, Dagarte (Dagaba) 3.7%, Akyem 3.4%, Ga 3.4%, Akuapem 2.9%, other includes English 36.1% (2000 census) ^c

SIREN site	Population (in 2011)	Tribes/ethnic groups	Hospital/university coordination site	Other
				Religion: Christian 71.2% (Pentecostal/Charismatic 28.3%, Protestant 18.4%, Catholic 13.1%, other 11.4%), Muslim 17.6%, traditional 5.2%, other 0.8%, none 5.2% (2010 census) ^c Literacy: 71.5% ^c
Southern Ghana Site				
Accra	2.573 million (2011) ^c	Akan, Ga-Dangme and Ewe are dominant	Korle Bu Teaching Hospital, a tertiary referral center with 1,500 beds	Accra is the capital and largest city of Ghana; the city was originally built as a port along the Atlantic coast and is now recognized for the fishing, financial, and agricultural sectors
Northern Ghana Site				
Kumasi	2.019 million (2011) ^c	Akan subgroup of Ashanti are dominant	KomfoAnokye Teaching Hospital, a tertiary referral center with 1,000 beds	Kumasi, a city in Ashanti Region, South Ghana, is among the largest metropolitan areas of Ghana; it is located near Lake Bosomtwi, in a rainforest region, and is the commercial, industrial and cultural capital of Asanteman, and is called the "Garden City" because of the many beautiful plants and flowers

^aIndex Mundi (2015b).

^bPopulation of Abeokuta, Nigeria (<http://population.mongabay.com/population/nigeria/2352947/abeokuta>).

^cIndex Mundi (2015a).