

Community Engagement: Experience from the SIREN Study in Sub-Saharan Africa

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Abstract : Background: Stroke, the leading cause of adult-onset disability and the second leading cause of death, is a major public health concern particularly pertinent in Sub-Saharan Africa (SSA), where nearly 80% of all global stroke mortalities occur. The Stroke Investigative Research and Education Network (SIREN) 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 non communicable diseases in SSA. One of the first steps to address this goal was to effectively engage the communities that suffer the high burden of disease in SSA. This study describes how the SIREN project engaged six sites in Ghana and Nigeria over the past three years, describing the community engagement activities that have arisen since inception. Aim: The aim of community engagement (CE) within SIREN is to elucidate information about knowledge, attitudes, beliefs, and practices (KABP) about stroke and its risk factors from individuals of African ancestry in SSA, and to educate the community about stroke and ways to decrease disabilities and deaths from stroke using socioculturally appropriate messaging and messengers. Methods: Community Advisory Board (CABs), Focus Group Discussions (FGDs) and community outreach programs. Results: 27 FGDs with 168 participants including community heads, religious leaders, health professionals and individuals with stroke among others, were conducted, and over 60 CE outreaches have been conducted within the SIREN performance sites. Over 5,900 individuals have received education on cardiovascular risk factors and about 5,000 have been screened for cardiovascular risk factors during the outreaches. FGDs and outreach programs indicate that knowledge of stroke, as well as risk factors and follow-up evidence-based care is limited and often late. Other findings include: 1) Most recognize hypertension as a major risk factor for stroke. 2) About 50% report that stroke is hereditary and about 20% do not know organs affected by stroke. 3) More than 95% willing to participate in genetic testing research and about 85% willing to pay for testing and recommend the test to others. 4) Almost all indicated that genetic testing could help health providers better treat stroke and help scientists better understand the causes of stroke. The CABs provided stakeholder input into SIREN activities and facilitated collaborations among investigators, community members and stakeholders. Conclusion: The CE core within SIREN is 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 and has implications as a model for assessment in other high-stroke risk populations. SIREN's CE program uses best practices to build capacity for community-engaged research, accelerate integration of research findings into practice and strengthen dynamic community-academic partnerships within our communities. CE has had several major successes over the past three years including our multi-site collaboration examining the KABP about stroke (symptoms, risk factors, burden) and genetic testing across SSA.

Keywords : community advisory board, community engagement, focus groups, outreach, SSA, stroke

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