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Community Engagement: Lessons Learned from the African-American Antiplatelet Stroke Prevention Study and Studies of Dementia in the Black Aged

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Abstract

Background and Purpose: Community engagement is a means to help overcome challenges to the delivery of health care and preventative services.

Methods: On the occasion of the 2021 International Stroke Conference Edgar J. Kenton III Lecture, I review community engagement strategies utilized in the African-American Antiplatelet Stroke Prevention Study (AAASPS) trial and Studies of Dementia in the Black Aged (SDBA) observational studies that I directed.

Results: The main community engagement strategies included use of home visits (bringing the study to the community), engagement of churches, community advisors, community physicians, other healthcare providers, and major African-American community organizations, and utilization of diversity training.

Conclusions: Community engagement strategies were a major component of AAASPS and SDBA that helped to ensure successful recruitment and retention of an underrepresented community in clinical trial and observational studies. Lessons learned from these studies largely carried out in the 1980s and 1990s helped to dispel myths that African Americans could not be recruited into large scale clinical trials, emphasized the importance of studying underrepresented groups with adequate statistical power to test primary study hypotheses, and provided foundational recruitment and retention methods for future consideration.

Keywords

African-American Antiplatelet Stroke Prevention Study (AAASPS); community engagement; community participatory research; underrepresented minorities

Introduction

On the occasion of the 2021 American Heart Association/American Stroke Association (AHA/ASA) Edgar J. Kenton III Lecture and lifetime achievement award for contributions

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to investigation, management, mentorship, and community service in the area of stroke inequities, I am substantially honored to be the recipient of the accolade. I will present key observations on community engagement from our previously funded National Institutes of Health (NIH) studies in Chicago and nationally. The NIH-funded research that I refer to in relation to the Kenton Award is Studies of Dementia in the Black Aged (SBDA) (RO1 AG10102) and the African-American Antiplatelet Stroke Prevention Study (AAASPS) (RO1 NS 33430).

Ed Kenton was a friend to many of us, colleague, scientific collaborator, and advocate for health equity. I met Ed through my committee work at AHA/ASA and the American Academy of Neurology, and we collaborated on the AAASPS trial [1] and other engagements. I published with Ed [2] and learned from him. He was loved by his family, adored by his patients, and highly respected by his colleagues as he set a high bar for clinical and academic quality and interpersonal interaction. He continues to be missed at the national stroke level where he was able to provide pithy and spot-on commentary on a divergence of stroke topics as they were newly released for publication and seeking interpretation for laypersons and the press. Ed is remembered as a powerful voice for stroke advocacy in the United States (US).

The African-American community has experienced a disproportionate burden of stroke for decades [3–5]. Even with the many advances in stroke prevention, treatment and care, African Americans generally continue to have a disadvantage in relation to stroke mortality and occurrence [6]. More recently the emphasis in public health has shifted to social determinants of health and health equity [7–10]. An AHA Presidential Advisory emphasizes the role of structural racism as a persistent and fundamental cause of health disparities for black and brown communities in the US [7]. This and other factors have been magnified during the COVID-19 pandemic as exemplified by higher rates of disease and death in black and brown communities [11], and now the challenge to treat and vaccinate persons from these underrepresented communities.

Community engagement is a means to help overcome challenges to the delivery of health care and preventative services in underserved communities. In this tribute to Edgar J. Kenton III MD, I share foundational work in the domain of community engagement that was carried out by our research group in the African-American community in the 1980s and 1990s, and that Ed contributed to, as well as select key results from the studies. Lessons learned from this body of work have application today as we attempt to close the health equity gap.

Community Engagement and Participatory Research

I begin with a definition of engagement in research. According to the Patient Centered Outcome Research Institute (PCORI) engagement is the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders during the entirety of the research process—that is from planning the study, to conducting it, and to dissemination of the results [12]. To create an effective engagement strategy, one must be aware that the strategy will vary (i.e., “one size does not fit all”) [12]. Thus, engagement approaches and practices will vary with condition, geography, the target population, and other factors, such as the type of healthcare setting, or possibly the social ecosystem. The same research principles may be

applied to the community public health domain or healthcare network system. Similarly, the level of community engagement in real-life situations will differ according to the complexity of the setting as there is no consensus on the methodology of community engagement for a given situation [13]. Finally, community engagement may serve to maintain and build trust within the community, facilitate ethical implementation, and improve overall health and healthcare.

By way of history, community-based participatory research (CBPR) originated in the 1940s as a means to use research for social action and change as a guide for decision making [14]. CBPR also has been used to research social injustices in relation to disadvantaged communities but did not become better recognized in the US until the 2000s. Core principles of CBPR include participation, cooperation, partnering in a collaborative and equitable manner, exchange of expertise, systems development, sustainability, building on the strengths of the community, empowerment (i.e., shared decision-making power) and ownership of all the phases of the research, implementation of an intervention, recognition of the community as a social entity with an identity, and long-term commitment by all of the partner groups [14]. Given the social injustices that black, brown and other underrepresented communities in the US have experienced [7], community engagement and participation methodologies are a means to attempt to overcome mistrust that may have beset these communities and encourage involvement in public health and other healthcare initiatives.

Simply put, CBPR may be thought of as a form of community engagement whereby there is collaborative participation, shared decision making, and mutual ownership of all aspects of the research process by the affected community being studied, researchers, and organizational representatives [15–18]. CBPR brings to the community a research topic of importance with the aim of combining knowledge with action to achieve social change to improve health outcomes and eliminate health disparities [16]. Successful CBPR may include establishment of relationships with community members at various levels, respect of diverse cultural perspectives, placement of equal emphasis on community knowledge and academic perspectives, and allowance for flexibility of research methodology [16]. As a ‘research plus’ type of activity, CBPR requires substantial planning and engagement [17]. Therefore, although there has been significant work around community level interventions, there are relatively few community-engaged or participatory clinical trials.

Lessons Learned from Stroke Studies in the African-American Community: SDBA and AAASPS

Study Designs

SDBA.: The AAASPS and SDBA research groups carried out a series of NIH-funded stroke-related studies in the African-American community of Chicago, Illinois and nationally. One series of studies, SDBA, focused on elucidation of cardiovascular and other risks in African Americans with Alzheimer’s disease (AD), stroke with cognitive impairment, and stroke with no cognitive impairment in a case-control study paradigm [19–22]. Participants were referral-based subjects from stroke inpatient admissions and AD centers [19, 21]. Pretested study questionnaires and other data collection metrics were utilized in the SDBA studies. Enrollees included 113 AD, 79 vascular dementia (VaD),

and 56 stroke without dementia participants. The SDBA studies were designed to compare demographic, medical and other epidemiologic factors among the 3 participant groups to search for distinct patterns or predictors of AD and VaD in African Americans. One of the foci of the studies was to better understand the possible association of cardiovascular risks with not only VaD, but also AD. In addition, long-term survival and cognitive and functional outcomes were studied [22, 23]. Finally, we established an end of life and autopsy recruitment program for study participants [24–26].

AAASPS.: The other major research initiative was AAASPS [1, 27]. AAASPS was a randomized, double-blind, investigator-initiated, multicenter trial of 1,809 African-American men and women with recent non-cardioembolic ischemic stroke who were recruited from over 60 academic or community centers in the US that served the black community. Participants were followed for up to 2 years and received either ticlopidine 500 mg/day or aspirin 650 mg/day. The main primary outcome composite was recurrent stroke, myocardial infarction or vascular death according to intention-to-treat analysis. The main secondary outcome was fatal or non-fatal stroke. The blinded phase of the trial was terminated after 6.5 years based on futility analysis which showed that there was less than a 1% probability that ticlopidine would be superior to aspirin. In fact, had the trial been continued, there was an estimated 40% to 50% likelihood of aspirin being superior to ticlopidine [1].

The decision to administer ticlopidine in AAASPS was based on a sub-analysis of non-white patients in the Ticlopidine Aspirin Stroke Study (TASS), a recurrent stroke prevention study, of which 495 of 603 participants were black [28]. The sub-group analysis results for non-white enrollees in TASS suggested a substantial reduction of non-fatal stroke or death and fatal or non-fatal stroke at 1 year, respectively, and there was a signal that cumulative event rates for both endpoints were lower after 2 and 3 years, respectively, favoring the ticlopidine-treated participants [28].

At the time that AAASPS was assembled, building a randomized controlled trial solely around African-American participants was a controversial matter [29]. One prevalent view was to recruit a sample of underrepresented participants that would reflect the approximate US population percentage of the subjects and was argued as a justifiable approach as a cost containment strategy [29]. The counter viewpoint was that a high percentage of underrepresented participants was needed to have adequate statistical power to analyze key study hypotheses in the underrepresented group [29]. At the time of the NIH review for AAASPS, a strong showing at the site visit review by the community advisors from the African-American community may have helped to sway the review group of the importance of funding a clinical trial of recurrent stroke prevention in the African-American community [1, 27]. The community advisors were engaged from the beginning of the development of the study, during the implementation phase, and in the after phase of AAASPS. They were passionate about the importance of prevention of stroke in the African-American community and articulated a substantial message to the NIH review group.

Community Engagement Strategies—Both SDBA and AAASPS were investigator-initiated studies that existed well before the concept of community engagement in research was popularized in the US. The SDBA series of studies began in the mid-1980s and

AAASPS was implemented in the mid-1990s. Each of the respective study series, however, provided important lessons in relation to community engagement in the African-American community.

SDBA.: The key lesson in relation to community engagement in SDBA was the principle of bringing the research to where the community resides (i.e., “seek and ye shall find”). Our research group made the initial misstep of scheduling stroke patients who were socioeconomically strapped or had other barriers to outpatient attendance, to travel to clinic office research visits. After several days of 100% “no show” rates (not one participant attended an office research visit), the study team made the adaptation to carry out home visits. Although such visits were more time consuming, they worked out very well for our study participants who in some cases were significantly physically impaired or disabled and thus difficult to transport from their home or long-term care facility, had lack of access to transportation, or when they did have access to family or friends for travel, they could only be transported after customary and usual daytime work hours. The home visit program proved advantageous as there was opportunity to examine study subjects in their natural environment and better understand their surroundings and what they faced in the way of barriers or challenges on a daily basis. The home visit research program led to a high follow-up rate on an annual basis over the up to 7 years of annual visits [22, 23].

AAASPS.: AAASPS was a national investigator-initiated randomized trial of recurrent stroke prevention [1]. The fact that it was associated with an interventional or “experimental” treatment created a barrier for some members in the African-American community. Our research group spent considerable preparatory time in the African-American community to better understand barriers to clinical trial participation, and how one might surmount the barriers. For example, study staff carried out a historical overview of abuses and injustices against African Americans in the research domain and a brief community survey to determine why African Americans might not wish to participate in clinical trials [30]. Four key barriers to participation in clinical trials emerged from the research: 1. Lack of awareness of trials; 2. Economic factors; 3. Communication challenges; and 4. Mistrust [30]. In a subsequent study, rationale for why African Americans enrolled, refused trial participation or voluntarily withdrew from study was elucidated [31]. Those who participated in the trial did so to help find a “cure” for stroke, and those who withdrew or refused to participate did so for fear of being used as “guinea pigs”.

The above findings led to the establishment of a “recruitment triangle” as an attempt to strengthen enrollment probability and maintain participants in the study [31]. The recruitment triangle had the following sides: 1. Participant; 2. Key family members and friends; and 3. Healthcare providers. It was hypothesized that by maintaining the integrity of the triangle through proper communication and education of the 3 key constituencies, participants would be more likely to enroll and remain in a clinical trial [31].

Finally, a community recruitment network was established in the Chicago area, a main hub of sites for AAASPS, to help overcome barriers to recruitment of African-American stroke patients [32]. An African-American community advisory board was developed to guide the effort and the overall study. The community advisory board had an essential

role, met regularly, and consisted of stroke patients, physicians, and key community supporters. The community advisory board made recommendations in relation to community education efforts and strategies to heighten awareness of the study in the African-American community, and also was consulted on scientific issues, especially those which might raise sensitivities in the community [32].

In addition, a community coordinator was hired to develop a community network consisting of local churches, black nurse, physician and other key community organizations, and a community volunteer corps, and for media and other efforts (e.g., use of internet, cable television) to raise visibility of AAASPS [32]. In addition, the coordinator was responsible for linking the study with key political organizations at the national, state and local levels [32]. A main goal at the community networking level was to work with major church and community organizations. For example, 200 Baptist churches were recruited to interact and support AAASPS recruitment efforts as was Operation People United to Save Humanity (Operation PUSH). AAASPS staff attended weekly church health fairs, appeared on Operation PUSH Saturday programs, and marched under the AAASPS banner in the annual Bud Billiken Parade in the Bronzeville area of Chicago. The Bud Billiken Parade is the largest African-American parade in the US, is sponsored by the Chicago Defender Charities, and signifies return to school. Billiken was a mythical character and angel who protected children.

There was great joy at AAASPS headquarters in Chicago in October 2001 when recruitment for the study was completed [1]. The Chicago sites contributed to over one third of the 1,809 participants. The 4 top recruitment sites (number of enrollees in parentheses) in the Chicago area were Cook County Hospital (252), RUSH University (153), Michael Reese Hospital (50), and Hines Veteran's Administration Hospital (49). AAASPS had made a substantial journey to complete recruitment beginning with a study kick-off meeting for the community at the Harold Washington Library in Chicago in November 1994, a local television and radio media blitz prior to the official opening of recruitment, and all of the community engagement activities enumerated above that occurred during the approximate 6–7 year enrollment period.

To better equip the Chicago and nationwide local AAASPS sites to be successful in the recruitment and retention of African-American stroke patients for the study, annually, all of the local site study staff was invited to Chicago for a study update meeting and review of AAASPS methods and progress. A portion of these meetings was devoted to recruitment and retention of study subjects, at which time AAASPS headquarters' staff conducted mock recruitment and retention sessions with African-American stroke patients. The sessions were designed to share best recruitment and retention methods, highlight issues which might be sensitive ones in the community and how to handle them, and emphasize the importance of a respectful approach to recruitment and retention and one providing adequate time for patients, family members and significant others involved at the patient level in making a final decision. The aforementioned features were considered important components for successful recruitment and retention. The enrollment time window was within 90 days of ischemic stroke onset [1].

Main Results of SDBA and AAASPS

SDBA.: During the 1980s and 1990s AD and VaD were largely viewed as separate and distinct entities—AD a neurodegenerative disorder and VaD a vascular-based disorder [21]. In studying solely African Americans in SDBA, a pattern emerged among the participants who were diagnosed with AD according to operational study criteria [21]. Specifically, there was a relatively high frequency of some cardiovascular risks. For example, 50% of participants had hypertension, 13% had diabetes mellitus, 15% had myocardial infarction or angina pectoris, and 2% had atrial fibrillation [21]. Although cardiovascular risks were present and were viewed by some as a possible “red flag” to question a diagnosis of AD, the supporting clinical, neuropsychological, and neuroimaging manifestations were consistent with AD [21, 33]. In fact, when a small subset (n=13) of the participants had brain necropsy, 2 had pure VaD, 5 had pure AD, and 6 had a mixture of AD and strokes [26]. Furthermore, and in general, among these study participants there was good agreement between the clinical and pathologic diagnoses [26]. These findings as well as others served to stimulate new thought about the possible role of cardiovascular risks in AD and the possibility of prevention or slowing of not only vascular causes of cognitive impairment, but also AD based on prevention or treatment of cardiovascular risks [34]. Over an approximate 20-year time period cardiovascular risks became accepted as possible modifiable factors for dementia and AD [35].

In addition to our descriptive observational contributions to the understanding of the possible role of cardiovascular risks on dementia, other key SDBA findings included those from longitudinal follow-up of up to 7 years in relation to cognitive and functional decline in African Americans and survival. For example, cognitive and functional decline over time was greatest for AD, followed by VaD, and then stroke with no dementia participants [23]. In relation to survival among African Americans, death was predicted by older age and lower Barthel activities of daily living scale scores in AD participants; by administration of antihypertensive medications but lower risk if antithrombotic medication was administered or one had higher diastolic blood pressure among VaD participants; and by older age and history of smoking or atrial fibrillation among those with stroke with no dementia [22]. Of interest, the issue of the proper blood pressure target for persons who already have cognitive impairment remains a controversy (i.e., should blood pressure be lowered or modestly allowed to be elevated) [36, 37]. SDBA showed that administration of blood pressure lowering medications was associated with raised risk of VaD, whereas higher diastolic blood pressure was associated with lower risk of VaD [22].

AAASPS.: The main phase results of AAASPS showed that there was no statistically significant difference between ticlopidine or aspirin in relation to the prevention of the composite primary outcome of recurrent stroke, myocardial infarction or vascular death (hazard ratio: 1.22 95% confidence interval, 0.94, 1.57) and by the log-rank test for time to event (p=0.12) [1]. For the secondary outcome of fatal and non-fatal stroke, the log-rank test favored and approached a statistically significant result for aspirin over ticlopidine (p=0.08). Had the trial not been stopped for reasons of futility and had gone to completion, it was estimated that there was a 40%–50% likelihood that aspirin would be better than ticlopidine in the reduction of risk of recurrent fatal or nonfatal stroke [1]. The latter finding helps to

emphasize a pitfall of application of non-primary analytic findings that are not adequately statistically powered in clinical decision making in practice. As one recalls, TASS found rather substantial subgroup results favoring use of ticlopidine over aspirin in non-whites [28]. AAASPS results, however, were not able to validate the subgroup finding [1].

In the safety analysis there was no statistically significant difference in laboratory-determined serious neutropenia (3.4% for ticlopidine, 2.2% for aspirin) or serious thrombocytopenia (0.3% for ticlopidine, 0.2% for aspirin), however, 1 ticlopidine-treated participant developed a case of possible thrombotic thrombocytopenia purpura (TTP) and recovered after receiving plasmapheresis [1].

One of the unique and interesting findings in AAASPS was the recruitment of more women than men [1]. Women have traditionally been under-enrolled in many clinical trials including stroke trials [38]. In AAASPS depending on the treatment assignment, of the 1,809 participants the percentage of women enrolled was 54.5% (ticlopidine) and 52.4% (aspirin), respectively [1]. I now review select findings among women participants in AAASPS.

In an interim report from AAASPS in 1999 of the first 574 women and 513 men participants, women had higher rates of hypertension (88% vs. 80%), diabetes mellitus (45% vs. 32%), family history of stroke (46% vs. 36%), and no reported leisure time exercise (69% vs. 52%), whereas men had higher rates of smoking (78% vs. 48%) and heavy alcohol use (5% vs. 1%) [39]. There were few differences in the proportions of baseline stroke subtypes or those receiving preventative treatments in women compared to men. In another AAASPS analysis of 1,711 participants to study the impact of obesity and the metabolic syndrome, 70% of men and 81% of women were categorized as being overweight or obese, and the combination of hypertension, diabetes mellitus and dyslipidemia were present among 43.3% of AAASPS men and 29.1% of women with class 3 obesity. Overall, the odds ratios for having metabolic syndrome increased steadily as one ascended from class 1 to class 3 obesity [40].

In another interim report of interest but that did not focus on differences between men and women, of the first 1,086 AAASPS enrollees, awareness, treatment and control of vascular risks were relatively low [41]. For example, at the baseline exam 48% of subjects had a blood pressure \geq 140/90 mm Hg, and of those with a history of hypertension, 73% were on blood pressure lowering medication, however, only 30% of those treated had a blood pressure $<$ 140/90 mm Hg [41].

Finally, an analysis was carried out to investigate the effect of sex on select main outcomes in AAASPS among the 1,809 study subjects [42]. Recurrent non-fatal stroke occurred in 186 participants (89 women, 97 men). At baseline there was no statistically significant difference in the National Institutes of Health Stroke Scale score (2.87 for women, 3.00 for men), the modified Barthel score (18.26 for women, 18.52 for men), and the Glasgow Outcome Scale score (1.49 for women, 1.51 for men) [42]. At the time of the stroke recurrence examination, there were no statistically significant differences in the aforementioned metrics with the exception of the modified Barthel score for which women had a lower score at a 6-month

follow-up exam (18.49 vs. 19.37; $p=0.02$). Furthermore, in the survival analysis AAASPS women and men had no significant statistical difference in the time to recurrent stroke [42]. Thus, although differences in risk profiles existed between AAASPS women and men participants as noted above, there was little evidence of differences in key stroke outcome metrics [42].

Discussion

AAASPS, although a neutral trial, helps to dispel myths that African Americans cannot be recruited into large scale clinical trials, emphasizes the importance of studying underrepresented groups with adequate statistical power to test primary study hypotheses, and provides foundational recruitment and retention methods for future consideration [43]. A unique feature of AAASPS was the enrollment of women who represented slightly over 50% of the participants. Central to the study was a community engagement strategy designed to be tailored to the African-American community [1, 32]. The Table summarizes key components of the community engagement strategy according to key personnel, community networking components, and mechanisms for community outreach. AAASPS success in recruiting all African-American clinical trial participants and a high relative percentage of women compared to other studies may be attributable largely to our community engagement strategy. Our heavy emphasis on African-American churches may have been responsible at least in part for our recruitment success. Both African-American men and women are known to be religious and to attend religious services [44]. This is especially true of African-American women [44]. Other stroke studies have had recruitment success by engaging churches in various communities [45]. Taken together, the findings suggest that over time there have been advances in recruitment and retention of subjects from underserved communities, especially if proper planning and recruitment and retention approaches are utilized.

Although not the case in AAASPS [1], women continue to be underrepresented in clinical trials of stroke [38]. This raises concern about generalizability of such studies, access issues, and efficacy and safety of new therapies in women [38]. Factors that may lead to underrepresentation of women in clinical trials may include trial eligibility (e.g., older age limits, exclusion of certain comorbidities), attitudes and beliefs of women which may select against their participation in studies, and potential biases amongst study personnel [38]. Many of these barriers may be overcome with proper pre-study planning and increasing the number of women who lead clinical trial studies [38].

The National Institutes of Health has funded 11 research centers at minority institutions to strengthen research infrastructure to conduct biomedical research and establish a next generation of researchers from underrepresented populations [46]. A focus of some of the centers is community engagement. For example, at the Morehouse School of Medicine site in Atlanta directed by Dr. Vincent Bond, there is a community engagement focus centered around facilitating the integration of basic research and community engagement [46]. We await reports from this study and others in the consortium on new and transformative community engagement strategies.

Another community-based research engagement strategy is the utilization of black beauty salons and barbershops to disseminate stroke knowledge. For example, in one study 30 black beauticians were educated about innovative ways to educate women about stroke during beauty shop visits in 2 large urban areas [47]. Overall, education in this venue was found to improve knowledge about stroke warning signs and utilization of 911 calls. One might envision the utilization of beauty salons and barbershops to assist in study recruitment efforts in the African-American community. In fact, in a cluster-randomized trial of 52 black-owned barbershops whereby study participants with uncontrolled blood pressure were assigned to either a pharmacist-led blood pressure intervention in barbershops or an active control whereby barbers encouraged lifestyle modification and doctor visits. In the study, systolic blood pressure was lowered by 27.0 mm Hg in the pharmacist-led study group compared to 9.3 mm Hg in the control arm ($P < 0.001$) [48]. In addition, a blood pressure level of $< 130/80$ mm Hg was achieved in 63.6% of those in the pharmacist-led intervention and in only 11.7% of those in the control group ($P < 0.001$) [48].

Recently, the US Department of Health and Human Services (HHS) announced funding of a collaborative research project with the American Heart Association to address hypertension in racial and ethnic minority populations [49, 50]. The collaborative with the HHS Office of Minority Health (OMH) and the Health Resources and Services Administration (HRSA) Bureau of Primary Health Care supports a \$32 million 3-year agreement for a national initiative to improve blood pressure control. The program is targeted to the most vulnerable populations including persons from racial and ethnic minorities with higher rates of high blood pressure and who are at increased risk of COVID-19 and other chronic conditions such as heart disease and stroke [49, 50]. Black, Hispanic and indigenous communities are the main focus of the initiative led by Dr. Eduardo Sanchez, Chief Medical Officer for AHA and principal investigator and Pamela Garmon Johnson, AHA Vice President of Health Equity and Executive Director of the National Hypertension Control Initiative (NHCI). The initiative will utilize a public service announcement campaign with an Ad Council, emphasize self-monitoring and the value of life-style changes for blood pressure control and overall health, and strives to influence patient knowledge, beliefs and attitudes towards blood pressure management. In addition, community engagement and integration will be affected by utilizing community-based institutions such as barbershops, beauty salons, recreational centers and community-based pharmacies [49, 50]. AHA already has in place a collaboration with Live Chair Health, an organization that trains barbers and hair stylists to be health advocates and supports the barbers and stylists and their customers through a Live Chair app to engage and screen clients for referral for treatment if they are at risk of heart disease and stroke [50].

The 2021 International Stroke Conference Health Equity and Actionable Disparities in Stroke: Understanding and Problem Solving (HEADS-UP) symposium is largely devoted to community engagement and participatory research, a partnership that equitably joins the community, organizational representatives and researchers throughout a research or clinical journey [51, 52]. As we strive to bring down racial/ethnic disparities in healthcare overall and in stroke prevention and treatment [9], the theme of the symposium is timely as we keep in mind the importance of community engagement and participation to ensure success of our clinical and research initiatives. AAASPS established a strong community engagement

and community participatory foundation during its inception approximately 25 years ago [30–32], and the same lessons still may be applied today [43].

As we move forward in the field, programs such as the National Institutes of Health minority research centers [46] and Training in Research for Academic Neurologists to Sustain Careers and Enhance the Numbers of Diverse Scholars (TRANSCENDS) program funded by the National Institutes of Health [53] will help propel us forward to new heights in our understanding of community engagement and participation. The approach to understanding racial/ethnic health disparities is evolving as we have entered the domain of now confronting structural factors such as structural racism, and social determinants of health [7]. With this comes a reframing of the research and new conceptual models [54]. Leaders at the American Heart Association journal, *Circulation: Cardiovascular Quality and Outcomes*, have seized the moment to facilitate best practices to beneficially impact racial/ethnic disparities by promoting a forward change with novel instructions for authors carrying out racial and ethnic disparities research and submitting articles to the journal [54]. By providing a new set of publishing guideposts a reframing of the research may lead to a greater likelihood of successfully reaching cardiovascular health equity [54]. The editors provide 5 overarching principles to achieve the goal [54]:

1. Develop questions and methodological strategies informed by conceptual frameworks (i.e., focus on mechanisms and interventions to overcome racial/ethnic disparities);
2. Explicitly describe rationale and classification for inclusion of racial and ethnic participant groups in the methods section (e.g., use of the 2020 US census self-identified classifications);
3. Form diverse and inclusive study teams familiar with the research domain of interest;
4. Contextualize discussion of results within conceptual frameworks and models (i.e., identify pathways to equity, contributing factors, and strategies to break down barriers such as structural or institutional ones); and
5. Avoid generalized genetic explanations for racial/ethnic disparities (e.g., keep in mind that correlations with genetic ancestry also may be linked to social determinants of health including environmental exposures, socioeconomic factors, racism and discrimination) [54].

Summary

Community engagement remains an important component of research and clinical healthcare especially in underrepresented communities where there may be mistrust of medical institutions and providers, lack of awareness of healthcare programs, economic barriers to participation in such programs, and needs for better communication of healthcare information [30–32]. Community engagement and participatory efforts serve as a means to help overcome challenges to the delivery of health care and preventative services. AAASPS and SDBA provide a rich experience about how to organize and implement community

engagement efforts. The foundational lessons from AAASPS and SDBA in this domain [1] and new ongoing initiatives and guideposts based on engagement and participatory or related efforts [7, 45–55] provide promise to help bridge gaps in stroke and other health disparities.

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Non-standard Abbreviations and Acronyms

AAASPS	African-American Antiplatelet Stroke Prevention Study
HEADS-UP	Health Equity and Actionable Disparities in Stroke: Understanding and Problem Solving
SDBA	Studies of Dementia in the Black Aged
TRANSCENDS	Training in Research for Academic Neurologists to Sustain Careers and Enhance the Numbers of Diverse Scholars

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Table:**Key Components of the African-American Antiplatelet Stroke Prevention Study Community Engagement Strategy [32]**

Key Personnel

1. Community Network Coordinator
2. Community Advisory Committee
3. AAASPS Leadership

Key Networking Components

1. African-American Physicians (Cook County Physicians Association)
2. African-American Nursing Associations and Allied Organizations
3. African-American Community Volunteer Corps
4. African-American Health Professionals and College Students
5. 200 African-American Churches from the Baptist Pastor's Conference of Chicago and Vicinity
6. Local Stroke Associations
7. Operation People United to Save Humanity (Operation PUSH)
8. Diversity Training

Mechanisms for Community Outreach

1. Speaker's Bureau
 2. Television, Radio and Newspaper Media
 3. Community Brochures, Mailings and Newsletters
 4. Internet Postings
 5. Church Health Fairs
 6. Saturday Programs at Operation PUSH
 7. Attendance at Annual Bud Billiken Parade in Bronzeville
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