Community engagement for early recognition and immediate action in stroke (CEERIAS): Pre and post COVID-19

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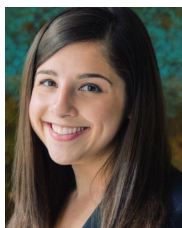
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Abstract   Engagement science can help healthcare providers understand promising practices that address health disparities. The Community Engagement in Early Recognition and Immediate Action in Stroke (CEERIAS) study began in 2014 with the aim of improving health outcomes related to stroke and addressing racial inequities among at-risk South Side Chicago neighbourhoods by engaging community members called 'Stroke Promoters' in designing and implementing a stroke preparedness programme. Launched in 2020, Phase II (2CEERIAS) furthered this aim by developing a replicable virtual platform for the programme in response to challenges prompted by the COVID-19 pandemic. The CEERIAS community engagement programme results provided meaningful data to South Side Chicago communities; nearly 40,000 'Pact to Act FAST' pledges were collected over 11 months, and although early hospital arrival and emergency medical services (EMS) usage for confirmed stroke did not increase overall, early arrivals for suspected stroke increased significantly for men, younger people and black community members along with EMS usage for suspected stroke. The 2CEERIAS virtual programme collected nearly 3,800 new pledges in a 90-day window during the onset of the COVID-19 pandemic. The engagement of trusted nonclinical laypeople during both phases of the CEERIAS study demonstrates that community engagement can positively influence clinical outcomes and increase reach and sustainability for such efforts. The use of engagement science can also generate a deep sense of co-creation

among community members, and the 'social contract' approach can effect behavioural change. The virtual adaption reinforced important engagement science principles for interventions aimed at eliminating stroke disparities. To this day, eight years after research support ended for the CEERIAS programme, community members trained as 'Stroke Promoters' remain connected to the researchers and continue to educate family and neighbours about stroke preparedness.

INTRODUCTION

Both prior to and at the height of the COVID-19 pandemic, stroke remained among the top five leading causes of death and disability in the United States.[1] Approximately 795,000 people have a stroke annually in the United States, where one in every six deaths are stroke related. Stroke-related costs in the United States totalled nearly US$53bn between 2017 and 2018, including the cost of health-care services, medicines to treat stroke and missed days of work.[2] Black and Hispanic populations are nearly twice as likely to experience stroke and are at higher risk of death by stroke than those in the white population.[3] Owing to an earlier age onset of stroke, their financial burden is also significantly higher.[4,5] Black stroke survivors are more likely to be disabled, and their ranges of activity tend to be more limited than those of stroke survivors of other races.[6] In cases of acute stroke, black and Hispanic patients are less likely to use EMS than non-Hispanic, white patients.[7] Thus, delay in hospital arrival may be an important driver of disparities in tPA use and post-stroke outcomes among minority groups.[8] As demonstrated in the Community Engagement in Early Recognition and Immediate Action in Stroke (CEERIAS) study, targeted educational intervention disseminated via a semi-structured community engagement model can positively influence outcomes for hard-to-reach, at-risk populations where known disparities are prevalent.[9]

The rapid spread of COVID-19 and the subsequent stay-at-home orders and guidance to practise social distancing limited access to care and treatment for those with chronic and acute conditions. Concurrently, changes in capability to manage risk factors of stroke (ie lack of exercise, poor diet and increased stress, etc) adversely affected prevention efforts.[10] Furthermore, research indicates that COVID-19 is linked to more severe infections in stroke patients.[11] As many as one-third of patients with COVID-19 exhibit neurological symptoms, such as headaches and dizziness, complicating the diagnostic process.[12]

Given the burden of stroke and poor outcomes among minority populations, effective interventions that emphasise immediate activation of EMS and early arrival at the hospital are needed. Modifying layperson behaviour (eg calling 911 at the first signs of stroke), however, is complex and challenging. Poor public awareness about stroke warning signs is a significant barrier to appropriate early action and is low among minority groups at highest risk.[13–16] They may be less likely to receive information about stroke owing to literacy, education and language barriers and are thus less likely to recognise stroke warning signs.[17,18] Furthermore, knowledge of stroke warning signs had not improved in the past decade despite broad educational campaigns, especially among minority groups.[19,20] Although up to 53 per cent of Americans are familiar with stroke through personal, family or friend experience, only 7 per cent worry about stroke, and nearly 60 per cent

do not know if they are at risk.[21] Other barriers include perceived lack of severity,[22–24] misperceptions about treatment (eg tPA) risks and benefits, reluctance to call 911 due to poor knowledge of tPA,[25] mistrust of healthcare[26–28] and low self-efficacy.[29,30]

Stroke educational campaigns focus largely on improving public knowledge via the Face, Arm, Speech, Time (FAST) message, which emphasises three common signs of stroke (ie facial droop, arm weakness and speech change) and the importance of 'time to call 911'.[31–33] Although poor public awareness of stroke warning signs is a barrier to appropriate early action,[34,35] mass-media public education campaigns improve knowledge only temporarily and, in some instances, only improve the intention to call 911.[36–39] They have not, however, delivered meaningful changes in EMS use for stroke.[40–42]

Lastly, in alignment with the historical lack of minority participation in clinical trials, efforts to develop health-care interventions have not been sufficiently inclusive. The people and processes have not reflected or addressed the needs and experiences of all patients, specifically communities of colour. Typically, healthcare researchers determine study questions, develop and deliver interventions, collect data, aggregate and report results all without input from or participation of the communities and people for whom they seek to make improvements. Perspectives and priorities of these stakeholders differ from — and are often more comprehensive than those of healthcare researchers. Over-reliance on professional expertise, without regard for the experiences or knowledge of diverse communities, may lead to lapses in addressing disparities in stroke, improved outcomes and sustaining measurable change.

METHOD

A preliminary data analysis identified important Chicago neighbourhoods where stroke incidence and mortality were high and EMS utilisation was low. These neighbourhoods served as sites for our community-partnered intervention and evaluations. Stroke-related mortality rates vary at the local community level, as illustrated in Figure 1. The stark differences across community areas suggest the need to understand the behavioural influences that drive healthcare decision-making and outcomes from one territory to another.

The CEERIAS study, funded by the Patient-Centered Outcomes Research Institute (PCORI), used mixed methods and qualitative and quantitative approaches and followed a formal study protocol (ClinicalTrials.gov Registry No. NCT02301299). CEERIAS researchers leveraged community engagement by activating laypersons from at-risk populations at crucial levels of the research infrastructure, including governance/policy, organisational/ health system and operations/community levels. At the governance/policy level, a Community Advisory Board (CAB) was created as an equal partner with researchers to implement a stroke preparedness programme that equipped community influencers called 'Stroke Promoters' to spread messaging about early recognition of stroke signs/symptoms and overcoming barriers to seeking treatment. Working in partnership with the principal investigator were co-investigators (co-PIs) representing the community/health system level (ie a clinical education expert and an engagement science expert). Stroke Promoters, laypeople from the community, were important project team members activated at the operations/ community level and received financial compensation for their contributions.

The co-PIs identified more than 350 people as potential Stroke Promoters from local churches, schools and businesses using an algorithm of selection criteria from previously hosted community-based focus groups. An 8-hour training session was held in-person, in which 242 individuals
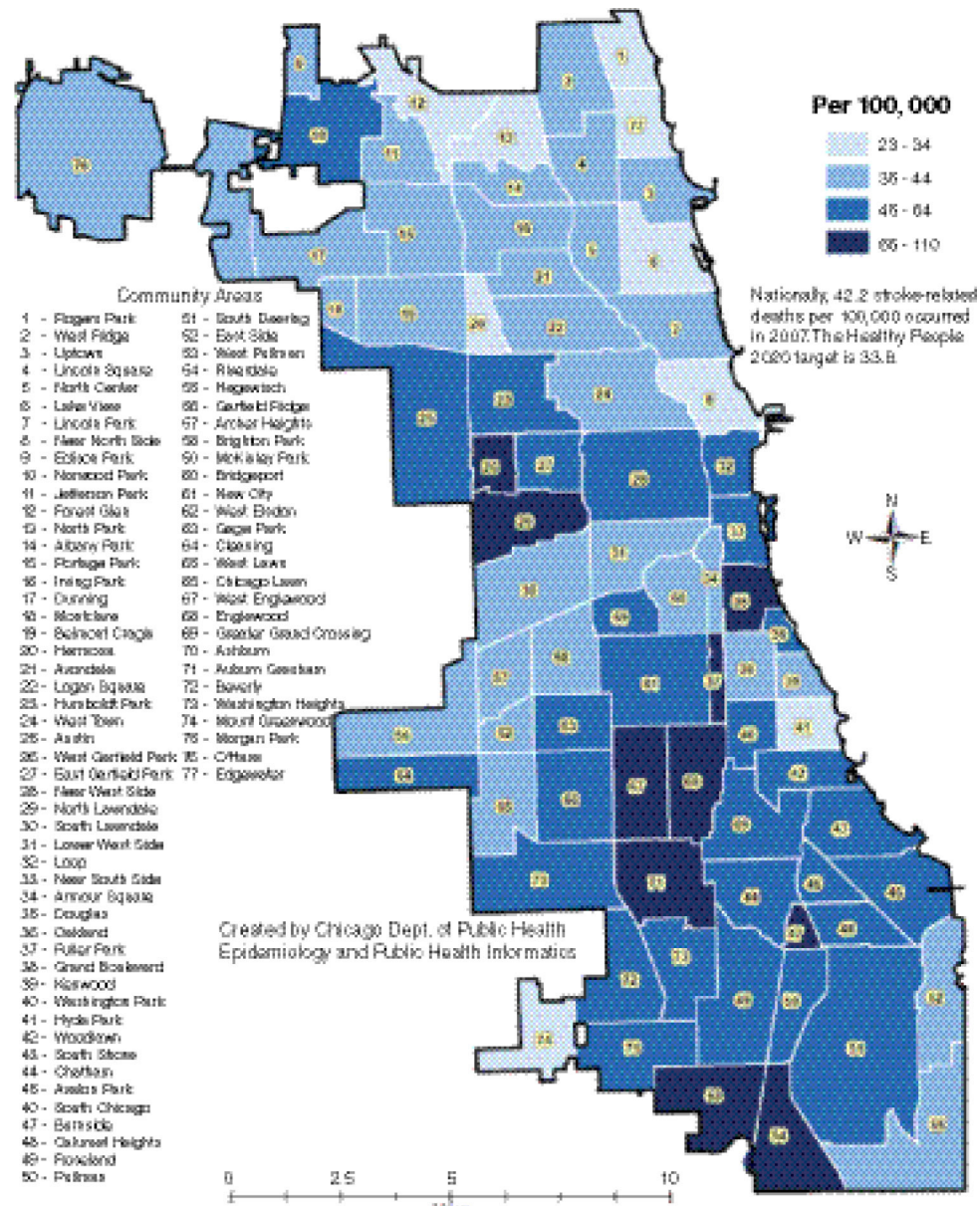
Figure 1 Chicagoland community stroke-related death rates by area

were taught about the characteristics (ie age, sex and race) of a typical stroke patient, signs and symptoms of stroke, cost of an ambulance and benefits of early treatment. Training included a mix of didactic material on local stroke statistics and experiential learning, including storytelling of shared experiences to enhance the learning process. Training manuals were distributed, and information about stroke demographics, disparities and local data on EMS usage, arrival times, treatment rates and outcomes was presented to enhance transparency of neighbourhood-level findings.[43]

Following didactic training, hospital-based tours were conducted from the emergency department (ED) to the stroke unit. Promoters were encouraged to ask questions about stroke patients, required tests in the ED and physician–patient discussions of

the risks and benefits of administering tPA. The tour was followed by a discussion of barriers to early hospital arrival and EMS usage, which solicited questions and provided solutions using role-playing.

The CEERIAS engagement model centred on bidirectional learning and co-created products and materials. In accordance with the theory of planned behaviour,[44] Bandura's theoretical self-efficacy model was used as a framework to promote decision-making capacity in stroke bystanders. Kolb's experiential learning theory was used as the framework that guided CAB discussions and the interactive Stroke Promoter training.[45,46] Educational materials and messaging were developed from recommendations received by Stroke Promoters and approved by the CAB. Co-created, culturally sensitive materials, including flyers and pamphlets, with information about stroke were distributed to the community. The important message of the programme, 'Act FAST for Stroke', encouraged participants to recognise signs of stroke and promote EMS usage.[47]

Launched in 2020 with additional funding from PCORI, 2CEERIAS aimed to bring the community-led education campaign virtual and test web-based tools, platforms and social media sources for dissemination of educational interventions. A CAB of selected Stroke Promoters from the CEERIAS study guided all aspects of 2CEERIAS, including research design and data collection. Study questions posed to the CAB included those used previously plus additional questions focused on COVID-19 — their values and beliefs related to recommended protocols, its effect on stroke in their neighbourhoods, how the pandemic overall was affecting them, their friends and families.

2CEERIAS sought to train approximately 10 per cent of CEERIAS Stroke Promoters with an emphasis on recruiting black Promoters since public health reports of COVID-19 cases, hospitalisations and deaths demonstrated greater disparities among

the black community. Using a convenience sampling method, potential participants were initially identified based on a quantitative review of top promoters from CEERIAS. Recruitment invitations were e-mailed, and selections were made based on willingness to participate and access to virtual or remote dissemination sources such as established social media accounts, extensive phone records and familiarity with virtual platforms. New participants were identified based on recommendations from previous Stroke Promoters and were evaluated based on similar criteria.

Promoters completed stroke identification and preparedness training adapted from CEERIAS that was intentionally interactive and used a variety of virtual training methods. Content included a review of CEERIAS study findings; discussions of stroke disparities; didactic lectures on stroke signs/symptoms and acute care activation; engagement science and strategy; and a review of COVID-19 cases, hospitalisations and deaths. Facilitated break-out sessions captured reaction to the content and gathered new knowledge and perspectives of how to best reach and activate members of at-risk communities.

FAST message was promoted in 2CEERIAS using modified messaging. This message was thought to be effective, easy to remember and readily adopted by the community in ways that aligned with the respective cultures, including messaging via varying genres of music, dance and art. Unlike CEERIAS, the messaging campaign was short and occurred over a 90-day period via virtual meetings, social media posts and other forms of remote communication, including phone banking.

Promoters tracked their activity and self-reported their performance weekly using two methods: (1) an online form embedded within the 2CEERIAS webpage and (2) e-mailed research team weekly summaries of engagement activities. They were also encouraged to attend 30-minute weekly

office hours virtual meetings to share their engagement experiences and any supporting educational materials they customised for broader dissemination among the entire cast of Promoters.

RESULTS

For the CEERIAS engagement approach, a total of 242 community Stroke Promoters (81 black men, 133 black women, four Hispanic men, five Hispanic women, three non-Hispanic white men and 16 non-Hispanic white women) were trained between October 2015 and May 2016.[48] Of these Stroke Promoters, 40 per cent were self-employed, 26.0 per cent from faith-based organisations, 11.6 per cent from healthcare organisations, 9.9 per cent from schools and 16.5 per cent from other community advocacy groups and local businesses.

A total of 39,795 'Pact to Act FAST' pledges were registered between December 2015 and November 2016, 80.3 per cent of which were registered at South Side ZIP codes.[49] Dissemination methods for CEERIAS were contained to all in-person activities in the community. Study participants attended community-sponsored events and shared messaging in their classrooms, businesses and homes. Although early hospital arrival and EMS usage for confirmed ischaemic stroke did not increase overall, positive trends were noted in the following subgroups: (1) men, younger people (all races under the age of 66) and black people who arrived at the ED early in select Chicago hospitals increased significantly, and (2) the number of people who used an ambulance when they thought they were having a stroke increased after the programme started.[50] The 2CEERIAS campaign ran from October 2020 to January 2021 and was planned entirely virtually in response to COVID-19. Of the 20 Promoters, there were three black men and 17 black women; 20 per cent were self-employed, 10 per cent were from faith-based organisations, 20 per cent were from healthcare organisations and 50 per cent were from community advocacy groups and local businesses; 11 of the 20 were previous CEERIAS Stroke Promoters.

Stroke Promoters used the project website 2CEERIAS.com, Facebook, Twitter, Instagram, TikTok and LinkedIn to spread 'Act FAST for Stroke' messages. Promoters were trained to use specific hashtags (ie #2CEERIAS, #stroke, #enddisparities, #atwhealth, #discernhealth, #rushmedicine, #universityofchicago and #endstrokedisparities) and to tag other study participants in their social media messaging. The first 30 days of the campaign were 100 per cent virtual, and Stroke Promoters engaged mostly via their e-mail, phone and social media contacts. During the remaining 60 days, however, Stroke Promoters began to align their messaging with community-based events that provided other social support such as food and face-mask giveaways, mass COVID-19 vaccination drives, walks in the park or while attending events supported by social distancing protocols. The use of video messaging through Facebook Live, Instagram and TikTok increased over time. Phone banking (eg calls and text messaging) and the 2CEERIAS website were the most used methods for dissemination.

Results of the 90-day virtual campaign demonstrated that

1. 3,786 'Pact to Act FAST' new pledges were signed by community members,
2. Phone banking, Facebook and Instagram yielded the most followers and
3. Overall impressions showed the highest increase from October to November 2020 (Facebook +64 per cent, Twitter +1,190 per cent).

When comparing both campaigns, CEERIAS rendered on average twice the number of pledges monthly. While intended to be solely virtual, 2CEERIAS engagement was modified by Stroke Promoters to

include in-person engagement because participants deemed social media platforms to be less effective for health campaigns than in-person activities and that the targeted population engaged social media mostly for entertainment purposes. When comparing both studies, similar improvement trends were demonstrated for pre and post-testing results. 2CEERIAS post-survey participants' response to calling 911 improved by 20 per cent than the pre-survey responses (see Figure 2).

The overall success of both campaigns sparked interest in Stroke Promoters and the community at large to continue on their own using both platforms (ie in-person and virtual). As a result, the website www.2ceerias.com remains active post study.

DISCUSSION

CEERIAS and 2CEERIAS developed a successful framework for community engagement that can be replicated in future healthcare improvement efforts led by hospitals and health systems. The framework includes the following four distinct facets (Figure 3):

- **Agile, Flexible Approach**: Community partnerships to promote equal voices that determine the path for success.
- **Experiential Learning Model**: Patient, family and community-driven research that surfaces recommendations from lived experiences.
- **Community Ownership**: Structured and deep learning interventions endorse culturally and linguistically appropriate applications.
- **Inclusive, Open Dialogue**: Targeted all teach, all learn activities.

The use of engagement science as a means of activating community participants throughout this project generated a deep sense of co-creation. Researchers listened to lived experiences of community members to understand their obstacles and built trusting relationships to implement effective, co-developed strategies and tactics tailored to their needs. This powerful balance of co-creation where community input and messaging were equal to that of the researchers incited the development of products such as music, online bible study lessons, line dancing, cultural art and graphics. Additionally, the person delivering the message is just as important as the message itself. Messages should be shared via a source that community members trust. Trust for study participants meant that messengers had proven experiences, backgrounds that were like persons in the community.

When developing messaging materials for distribution, Stroke Promoters and CAB members recommended using 'real people's faces, not just stock photos'. The message will resonate more when community members see their friends, family and neighbours expressing support. One Stroke Promoter acted on this recommendation and adapted the pledge to the likeness of their family in a shareable graphic (Figure 4). The use of 'real people' was also seen in the development and dissemination of videos.

Patient and community member engagement is crucial for creating a culturally and linguistically relevant health education campaign. Likewise, Stroke Promoters and CAB members engaged everyone, not just older adults who may be at higher risk of stroke. Specifically, the engagement of public schools and historically black colleges and universities (HBCUs) offer crucial outreach to children and young adults. Many of those raised in multigenerational households have witnessed cardiovascular events (eg heart attack and stroke) and have initiated the 911 call. According to Promoter Sandra Franklin, we do better when we know better, and to address the stroke epidemic in the black community, it is incumbent to raise

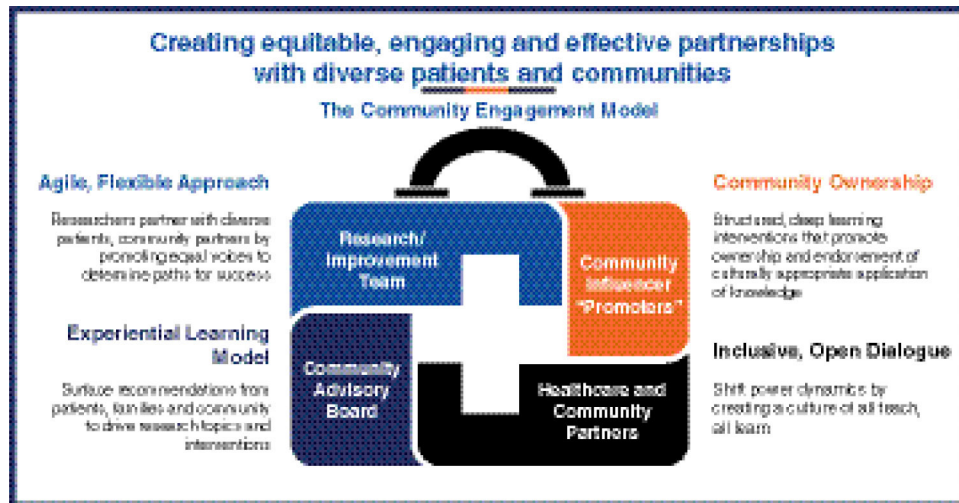Figure 2   2CEERIAS pre and post-testing survey response to calling 911
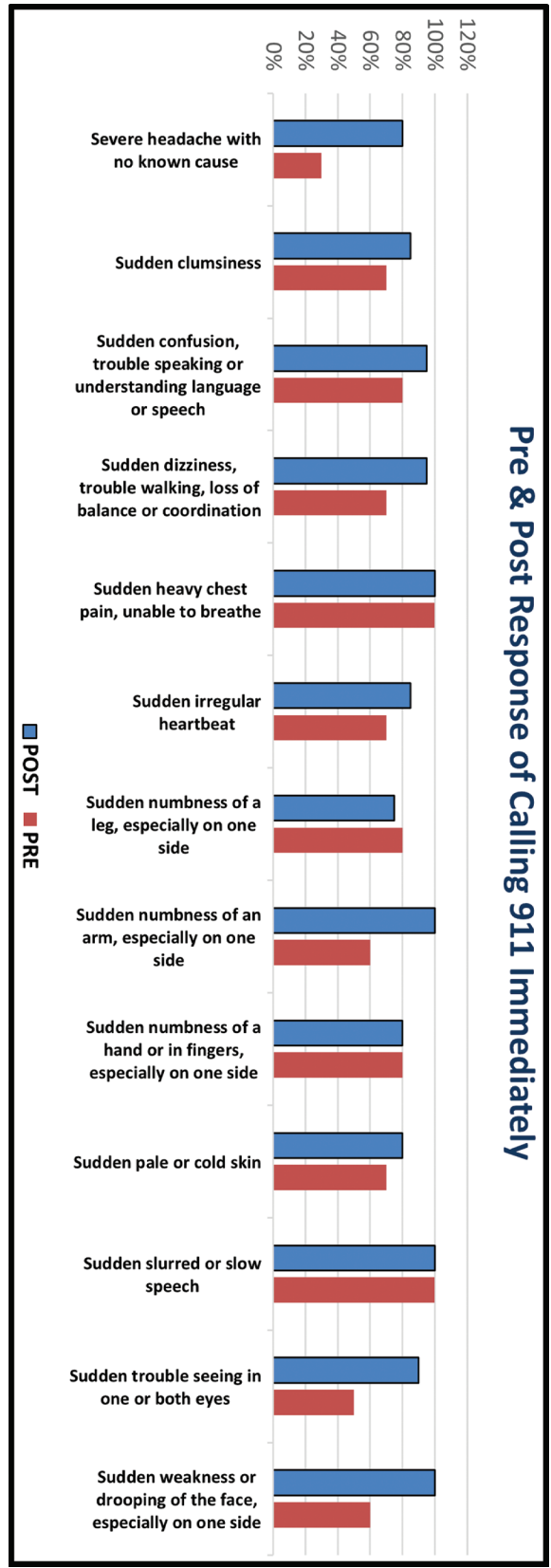
Figure 3   Framework for community engagement

awareness using all available avenues. While Ms Franklin was engaged in the CEERIAS initiative, she taught her family about the signs and symptoms of stroke, and her cousin was able to get herself to the hospital quicker when she was experiencing her second stroke and had a better clinical outcome because of it.[51]

Furthermore, engaging patients and community members in healthcare builds sustainability from the outset. The CEERIAS study sustained itself through two phases, and collaboration between researchers and selected Stroke Promoters has continued through local engagement campaigns. Additionally, many of the top Stroke Promoters remained active on their own in spreading the message of stroke early intervention since 2015 as trusted educators in the community. Lastly, Stroke Promoters have participated in other studies focusing on cardiovascular disease and risk reduction (U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (POINTER NCT03688126) and studies preventing recurrent stroke through lifestyle (diet) changes (Mediterranean-DASH Intervention for Neurodegenerative Delay [MIND] Diet in Stroke Patients NCT04337255).

CONCLUSION

Community engagement in CEERIAS and 2CEERIAS prompted new knowledge on barriers that impede black and brown community members' use of the healthcare system. These are not simply the traditional and well-studied socio–economic or psychosocial barriers (eg cost, access, history of injustices); they are rooted in truth and lived experiences that intensified during COVID-19 and the murder of George Floyd. For example, hesitancy to call 911 in an emergency out of fear of interaction with police is based on the real experiences of black and brown people. Additionally, learnings about COVID-19 vaccination hesitancy underscored the need to understand values, beliefs and perspectives of people representing different races and ethnicities.

Study findings contribute to existing evidence and reveal new innovations, including (1) advancement of a community–partnered intervention strategy using nonmedical laypeople and demonstration of its feasibility, (2) development of a 'social contract' approach (eg obtaining 'Pact to Act FAST' pledges) to effect behavioural change and (3) focused educational interventions addressing knowledge

Figure 4 Shareable graphic for identifying symptoms of stroke

deficits and other barriers (eg mistrust, low self-efficacy).[52]

While the community engagement strategy for CEERIAS rendered notable results, sustainability in the COVID-19 environment was questionable. Adopting engagement strategies for at-risk black and brown populations to virtual platforms during a pandemic offers several lessons. The adaption of social media and other virtual mechanisms for health message dissemination among hard-to-reach populations is most effective when combined with in-person and traditional engagement methods. Accordingly, when using virtual platforms, identifying study participants representing the community who have large networks in the form of social media and text messaging, as well as relationships with other ongoing programmes with similar missions (eg cardiac emergencies) is crucial for widespread dissemination and sustainability.

As reflected here, community engagement should be modelled in a way that shifts the power structure towards and balances the influence of the community for which the research seeks to make improvements (eg use of community co-PI, CAB and laypeople as Stroke Promoters from the targeted community). Both CEERIAS and 2CEERIAS were driven by large health systems that made the investment to partner in a meaningfully structured way that fostered leadership partnerships and further developed trust and promoted the sustainability of the model. Results of the studies demonstrate the opportunity for this approach to benefit targeted populations, but the engagement techniques could be applied more broadly across a range of communities or medical events. Community engagement should also be a prerequisite for designing future educational interventions, irrespective of the health topic, as the likelihood of success and sustainability is lower when this step is cursory or skipped altogether. Funding to

sustain similar programmes can be supported by hospital community benefits programmes and built into the wellness strategies used with systems that have community health workers. With the appropriate framework and context, trusted nonclinical laypeople can be recruited into health initiatives that seek to positively influence clinical outcomes. Lastly, programmes that support a community-led approach, such as CEERIAS and 2CEERIAS, build capacity and promote sustainability for long-term success.

DISCLAIMER

The views presented herein do not represent the views of the Federal Government.

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