
2CEERIAS - Phase II of Community Engagement for Early Stroke Recognition and Immediate Action in Stroke (CEERIAS) in the COVID-19 Environment

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Project Methods and Key Findings

Methods

The primary methods used within the 2CEERIAS research project included:

- Pre and post surveying
- Virtual educational convening session
- Message dissemination via social media
- Office hours (data capture and project feedback loop for study participants), stakeholder evaluation survey, and patient focus groups

Key Findings

Overall, Stroke Promoters responded positively to the training. A total of 3,786 2CEERIAS PACT to ACT FAST Pledges were completed resulting from the 90-day campaign. Data collected from the virtual convening, 90-day campaign office hours, and the team's project end meeting has been compiled to understand the project learnings relative to the objectives. A restatement of those objectives includes:

- Produce recommendations for future patient-, family-, and community-driven research focused on stroke education and early treatment
- Address barriers to community stroke activation and assess the impact of neighborhood-level factors on stroke-related disability in the COVID-19 environment
- Disseminate and track a modified educational intervention response among Chicagoland Stroke Promoters using online, social, and broadcast media

In conclusion, the 2CEERIAS project demonstrates an evidence-based method for effective engagement strategies for at-risk acute stroke communities. It is also believed the 2CEERIAS

model could potentially be tested and adopted to eliminate disparities among other chronic and acute conditions.

Although a virtual approach was adopted due to the COVID-19 pandemic, this form of dissemination worked well for the 2CEERIAS engagement strategy. Accordingly, the critical messages, including the 2CEERIAS message, could be disseminated via a similar learning platform as used for the virtual training. When asked how the virtual training could be improved, Stroke Promoters provided the following feedback:

- “Shorter timeframe.”
- “Perhaps providing the slides in advance would be helpful.”
- “More time or maybe even Zoom breakout sessions with other [Stroke] Promoters to hear their promotion ideas/plans/strategies.”

Based on Stroke Promoter feedback and additional input from the CAB, the 2CEERIAS team identified lessons learned for training community influencers (i.e., 2CEERIAS Stroke Promoters) in a virtual environment on stroke treatment and community engagement strategies. It is recommended that platforms such as YouTube be activated within another dissemination effort to address the further spread of the 2CEERIAS message. Also, by shortening the learning session and providing these learnings via YouTube, study participants felt 2CEERIAS could address stroke disparities in the COVID-19 environment and beyond, across other regions and territories.

Build Trust

Relationship building during a pandemic was challenging. The team used different strategies to communicate with Stroke Promoters based on their stated individual preferences. The team also engaged with the Stroke Promoters frequently. In addition to personal phone calls and text messaging, based on the Stroke Promoters’ stated preference, the team held biweekly office hours meetings to troubleshoot issues encountered during the 90-day

campaign and share information about stroke and COVID-19.

The team was able to quickly build strong relationships with the Promoters as evidenced by the frequent communication and interactive discussions through the engagement principle of inclusive, open dialogue. The team believes there was already a strong foundation of trust with the experienced Stroke Promoters who had participated in the original CEERIAS study and rejoined 2CEERIAS prepared to resume their work where the campaign previously left off. Many of the Stroke Promoters new to 2CEERIAS were recommended by experienced CEERIAS Stroke Promoters; these existing relationships helped to integrate new participants.

Further, open conversations between Stroke Promoters and the 2CEERIAS physicians allowed for a bidirectional discussion of challenges in the community and in the hospital setting, with honest discourse on how both groups would need to continue to partner to improve health outcomes for communities of color.

Be Flexible

Adopting an Agile approach (another principle) allowed the team to be flexible, pivoting quickly to address challenges as they arose, without derailing the overall goals and objectives of the initiative. After the first of four virtual training sessions, the team switched the order of the presented material to ensure adequate time for discussion and encourage Stroke Promoters to interact. During the first virtual training, the Stroke Promoters spent less time sharing their perspectives on barriers to care during COVID-19 and strategies for improving messaging and dissemination. After this training, the team moved some of the presented material after an initial discussion on barriers to care, which established a more open and expressive environment earlier in the training session. This fostered more participation from more Stroke Promoters, both using the chat function and audio. This new format was used in the third and fourth training sessions, as well.

As discussed above, the team was flexible in scheduling the trainings to maximize Stroke Promoter participation and engagement. Trainings were held on different days of the week,

including a Saturday, and at different times of the day to accommodate Stroke Promoter work schedules and caregiving needs.

Listen, Act, and Empower

The first core principle of 2CEERIAS community engagement is Community Ownership. To help foster this principle, the team listened to the insights and perspectives from Stroke Promoters and the CAB and acted on their recommendations to improve messaging and dissemination strategies and shape the 90-day campaign. For instance, the team modified the 2CEERIAS “Pact to Act FAST” pledge to include information about stroke prevention and COVID-19 and stroke risk factors.

In spite of the positive responses to the virtual training from Stroke Promoters, Stroke Promoters have reported that converting social media messaging and virtual dissemination efforts to action in the form of signed “Pact to Act FAST” pledges has been challenging. They indicated that community members often “like” and share online messages, but do not complete the pledge. Several Promoters explained that people in their networks use social media for entertainment, and for this reason, educational messages, like from the 2CEERIAS program, may not be getting as much attention. These challenges mirror trends in telehealth utilization. While use of virtual platforms to engage in health care spiked after the start of the pandemic, telehealth usage leveled off during the summer and fall of 2020. This aligns with what Stroke Promoters have experienced in conducting community outreach: virtual strategies were more of a focus in spring 2020, whereas there has been a recent shift to more traditional in-person tactics. Most of the pledges that have been signed to date were garnered from in-person community engagement rather than social media.

To overcome the challenges of virtual engagement, Stroke Promoters have been empowered to take ownership of the 90-day campaign, taking the 2CEERIAS message and transforming it into something meaningful for their families, friends, neighbors, and coworkers, who can accelerate dissemination. Stroke Promoters are infusing 2CEERIAS messaging across their

social interactions, and have developed original materials, like the graphic that one Stroke Promoter created to reflect the likeness of her family.

Interpretation of Relevance of Findings

Stroke Promoters are identifying ways to further adapt engagement strategies based on their personal relationships with the community. For instance, one Promoter distributes 2CEERIAS printed materials any time she interacts with people during “essential” activities, such as trips to the grocery store or doctor’s office. She stressed the importance of maintaining a safe social distance and adhering to COVID-19 safety guidelines while seeking to make a personal connection when explaining the 2CEERIAS program. As virtual social activities have become more common, other Promoters emphasized that video calls with friends and family create an ideal environment to share videos and online materials. Stroke Promoters have attributed their success in generating pledges to opportunities for deep personal connections. Phone and video calls allow Promoters to engage in more intimate conversations, thereby establishing connections that lead to greater community engagement.

Project Impacts on Patients and Other Stakeholders

The use of patient advisors throughout the project created a deep sense of co-creation and built a strong partnership among the entire research team. Stroke Promoters and members of the community advisory board contributed significantly to the design of the research, data collections processes, and finalizing the final report with activities that included:

- **Streamlined Training:** While the initial plan for the virtual training was to conduct a one-day remote session, the team pivoted to accommodate Stroke Promoter needs. The Stroke Promoters and the CAB shared that they were experiencing “Zoom fatigue” from overusing virtual communication platforms. As such, the team condensed the training from a four-hour session to a two-hour session. This was inspired by patient advisor and Stroke Promoter participation.

- **Stroke Promoter- and CAB-Centric Scheduling:** The team scheduled four training sessions during different days of the week and times of the day to align with Stroke Promoter and CAB availability. Many of the Stroke Promoters have jobs and commitments (e.g., barber, community health worker, faith leader, caregiver, etc.) that necessitated flexible scheduling. Stroke Promoters were required to attend at least one session but had the option to attend more than one training to engage more deeply with other Stroke Promoters in discussions around stroke and COVID-19.
- **Pre-Training Materials:** To ensure that Stroke Promoters received the full scope of the 2CEERIAS educational materials after moving to an accelerated session format, the team developed a pre-training video for Stroke Promoters to watch in advance of the virtual training. Stroke Promoters also received a virtual training one-pager that provided information about training logistics, an agenda for the session, and tips for online participation. This collateral was inspired by patient advisor participation.
- **Office Hours:** Prior to the training sessions, the team held two optional office hours meetings for Stroke Promoters to meet the team, test the virtual platform (Zoom meeting) technology, and ask questions.
- **Adjustments and Modifications:** At the end of each training, the 2CEERIAS project team debriefed and identified opportunities for continuous improvement. During the second, third, and fourth training sessions, the team shifted the order of the training agenda to encourage increased engagement and discussion among the Stroke Promoters earlier in the program.

Project Accomplishments and Challenges

Accomplishments

There were several major accomplishments achieved as a result of the 2CEERIAS project. Completion of the virtual convening assisted in educating Stroke Promoters, CAB members,

and patient advisors about the relationship between stroke and COVID-19, and provided updated data and information about early access to care when signs and symptoms of stroke are present.

This 2CEERIAS Stroke Promoter Campaign yielded 3,786 total 2CEERIAS Pledges completed. Other methods of dissemination for the 2CEERIAS message besides the website included phone banking and community events.

Additional accomplishments include the use of social media as a source for dissemination of the 2CEERIAS educational intervention.

Website Analytics

- New Visitors to site 49.3 percent/50.7 percent Returning Visitors
- 80 Users (72 New Users)
- Device most used: Mobile (63.7 percent), Desktop (35 percent), Tablet (1.3 percent)
 - Users: 51 (mobile), 28 (desktop), 1 (tablet)
 - New Users: 49 (mobile), 23 (desktop), 0 (tablet)

Social Media Overview

- Total Overall Impressions
 - Facebook (n=457)
 - Twitter (n=346)
 - Instagram (n=116)
 - LinkedIn (n=42)

- October to November had the greatest increase in overall impressions. Facebook (+64 percent), Twitter (+1190 percent).
- Impressions began to precipitously decline after November 2020.
- Exhibit 1. Shows that Facebook and Instagram yielded the most followers, LinkedIn having the least value.

Challenges

There were no challenges faced during the 2CEERIAS project. There was a strong sense of community developed among the members of the research team as well as a high rate of participation from community members. The fact that the teams and the co-PI's had worked together before helped maintain a strong sense of teamwork. The team also believes the strong collaboration was related to the media exposure of COVID-19 disparities and the quest for minority communities to become more engaged in solutions that produce more equitable outcomes.

Project Stakeholders/Collaborators

As mentioned, the engagement of patients and stakeholders helped the research team to understand the lived experiences of at-risk stroke populations as they relate to the impact of COVID-19. Patient and stakeholder participants helped researchers to validate community priorities and to better understand strategies that worked and those that required further improvements. Mostly, patient and stakeholder participants helped to improve communications and engagement strategies by providing the team meaningful examples of the cultural adaption of the team's engagement activities.

Stroke Promoters shared insights in the pre- and post-training surveys and during the virtual training. The team identified key themes around community member experiences with and perceptions of the healthcare system, as well as opportunities for healthcare providers and

researchers to improve community engagement around stroke and COVID-19.

Barriers to Safe and Timely Care

Effective treatment for stroke is timely treatment—barriers to critical care for people experiencing a stroke result in poor health outcomes. Some Stroke Promoters and CAB members shared that community members may be reluctant to call 911 out of fear of negative police interactions. Others noted that some community members may be at-risk for stroke but are unable to take preventive measures to reduce stroke risk (e.g., exercise, diet, etc.) due to challenges with accessing primary care, healthy food, and transportation in their neighborhoods. In the pre-survey (N=17), almost 45 percent of Stroke Promoters reported difficulty reaching the doctor's office or clinic by phone, and over 75 percent of Stroke Promoters feel they have to wait too many days for an appointment.

Stroke Promoters and CAB members shared that when they can access healthcare services, poor provider-patient communication makes interactions difficult. During the virtual training, Stroke Promoters noted that healthcare providers lack transparency and are unwilling to listen to patients' concerns. In the pre-survey, over 75 percent of Stroke Promoters (N=17) said that providers often speak in a way that is too technical or medical and give instructions that are difficult to follow. Views on providers were not all negative, however. Other Stroke Promoters indicated during the training sessions and in the pre-survey that their own providers take time to explain things in an understandable way and are generally honest about illness and treatment needs.

Favorable interactions do outweigh Stroke Promoters' and CAB members' concerns with equitable treatment of Black patients by healthcare providers. Over 80 percent of Stroke Promoters in the pre-survey shared that they believe providers do not treat Black patients the same as White patients. Prior to the spread of COVID-19, disparities in care delivery influenced Stroke Promoters' decisions to seek medical care in Chicago's South Side. Stroke Promoters shared that they are hearing that community members feel that, regardless of

social status, Black people receive less treatment from healthcare providers. Stroke Promoters and CAB members also discussed that high-profile influencers in their communities have experienced serious challenges with the healthcare system and described how these examples can make people of color skeptical of seeking care. Stroke Promoters and CAB members discussed negative experiences at hospitals and other places of care in their neighborhoods, like waiting a long time to get the care they needed or receiving low-quality care. They noted that people in the Black community cannot rely on EMS in the way that non-minorities can, referencing disparities in EMS arrival times.

The COVID-19 pandemic has intensified barriers to care for communities of color in Chicago. Fear of contracting COVID-19 has deepened Stroke Promoter and CAB member concerns about stroke preparedness and response. Stroke Promoters and CAB members shared that they are hearing from friends, family, coworkers, and neighbors that they are worried about going to the doctor's office or hospital out of fear that it will increase their risk of COVID-19 infection.

This fear is mixed with general uncertainty around the virus and confusion on how to safely access care while still maintaining proper protective measures. Stroke Promoters shared concerns about the uncertain, long-lasting effects of COVID-19 infection. Stroke Promoters and CAB members expressed concerns that COVID-19 "long haulers," people who have recovered from COVID-19 (tested negative) but still experience symptoms are at greater risk for stroke and other conditions.³⁸⁻⁴⁰

Promoters have expressed distrust in the healthcare system. In the pre-survey, over 80 percent of Stroke Promoters said that they believed that hospitals "cover up" their medical mistakes and that hospitals experiment on people without telling them. Once a vaccine or treatment becomes available for COVID-19, 40 percent of Stroke Promoters (N=19) said that they would not be willing to take it in the post-survey. Similar to results from a national survey about attitudes toward COVID-19,⁴¹ Stroke Promoters were concerned that the COVID-19 vaccine would not be thoroughly tested due to a "rushed" review and/or approval by the

Food and Drug Administration (FDA).

Empowering the Community to Take Ownership of Their Care

Stroke Promoters and CAB members discussed ways that the 2CEERIAS team can improve messaging (e.g., social media posts, 2CEERIAS talking points, etc.) to and engagement of Chicago's Black and Hispanic communities on stroke care.

Messaging should include information and evidence that addresses COVID-19-related concerns. Messaging should cover topics such as the ways in which hospitals and EMS have changed their procedures to reduce the risk of COVID-19 transmission by using appropriate PPE and cleaning protocols. This messaging can help alleviate community members' reluctance to seek care during the pandemic and equip them with the tools and resources to do so safely. Messaging should also include information to help people when they are communicating with their providers, such as examples of questions to ask during doctor visits. Materials should be available in multiple languages.

Stroke Promoters and CAB members recommended that stroke messaging should address prevention and stroke care quality. The 2CEERIAS campaign should include educational materials that discuss the linkages among obesity, cardiovascular disease, and COVID-19, and stress the importance of eating well, exercising, and taking other measures to reduce stroke risk. Additionally, people of color in Chicago may not be as confident in seeking stroke care due to previous negative experiences with the healthcare system. Such messaging should include information about Chicago Primary Stroke Centers, which are required to meet certain quality standards and are trusted to treat stroke patients. Appendix B includes a list of Chicago's Primary Stroke Centers.

The person delivering the message is just as important as the message itself. Messages should be shared via a source that people in the community trust. When developing messaging materials for distribution, Stroke Promoters and CAB members recommended that 2CEERIAS use "real people's faces, not just stock photos." The message will resonate more when

community members see the faces of their friends, family, and neighbors expressing support. One Stroke Promoter acted on this recommendation and adapted the pledge to the likeness of her family in a shareable graphic (see right).

The 2CEERIAS campaign should engage everyone, not just older adults who may be at higher risk for stroke. The 2CEERIAS team should engage public schools and historically Black colleges and universities (HBCUs) to reach children and young adults. As noted in the CEERIAS study, many young adults, who have lived in multigenerational households, have witnessed cardiovascular events (e.g., heart attack and stroke) and have been responsible for initiating the 911 call for assistance.³⁷ Knowing the warning signs and symptoms of stroke will enable people to help others experiencing a stroke get timely treatment.

While 2CEERIAS has a virtual component, the campaign should not be restricted to virtual outreach. Stroke Promoters and CAB members who can safely engage with community members in person can spread the 2CEERIAS message. One Stroke Promoter suggested creating a Quick Response (QR) code, a barcode that smartphones can read, to share 2CEERIAS materials while maintaining social distance. 2CEERIAS can be combined with other initiatives and essential services, like voter registration or food deliveries. Stroke Promoters and CAB members also discussed creating a 2CEERIAS-branded face mask.

Some of these suggested ways to improve messaging have already been implemented. Others are opportunities for improvement in a future phase of this work.

Plans to Disseminate Findings from the Project

ATW Health Solutions will continue its efforts to share and disseminate findings from the 2CEERIAS project through various virtual platforms. In March, the team presented study findings to the Centers for Disease Control and Prevention (CDC) Heart and Stroke Division. Members of the Heart and Stroke Division attended this lunch and learning session to become educated on the methods of community and patient engagement used within 2CEERIAS. The

team will continue this type of dissemination as well as pursue publication opportunities. Finally, the team will post the final report narrative to its website for easy access and sharing.

COVID-19 Pandemic Impacts on Project

The only change to the engagement strategy was the addition of more community events than anticipated when the research project was designed. During the holiday season, the Stroke Promoters were highly active with community events, although the state of Illinois and the city of Chicago continued to have restrictions on types of events, engagement levels, and capacity. As more data and information was shared publicly about the safety protocols for activities outside the home, the team was able to increase the number of in-person events such as food drives, COVID testing, and the like.