2CEERIAS:
Phase II of the Community Engagement for Early Recognition and Immediate Action in Stroke Initiative in the COVID Environment Final Project Report and Convening Summary

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KEEPING STROKE "CEERIAS" DURING THE PANDEMIC: LESSONS LEARNED FROM THE 2CEERIAS STUDY

Overview

The Coronavirus 2019 (COVID-19) pandemic has impacted public life and health care delivery, including utilization of stroke treatment. Stay-at-home orders and guidance to practice social distancing have imposed risks to accessing care and treatment for people with chronic and acute conditions, like stroke. COVID-19 has disproportionately affected Black and Hispanic communities, populations who are also at higher risk for stroke.

Phase II of the Community Engagement in Early Recognition and Immediate Action in Stroke (2CEERIAS) aims to address barriers to timely stroke care in Chicago's communities of color in the context of the COVID-19 pandemic. 2CEERIAS builds on the success of the CEERIAS study, funded by the Patient Centered Outcomes Research Institute (PCORI) in 2014. CEERIAS partnered with the community members in two predominantly Black and Hispanic Chicago neighborhoods at high-risk for stroke to develop an educational program to spread messaging about stroke warning signs and symptoms, promote trust, and communicate the importance of early arrival to the Emergency Department (ED) in improving stroke outcomes. CEERIAS trained influencers from the community ("Stroke Promoters") to encourage community members to complete the "Pact to Act FAST" pledge, attesting that they would call 911 if they witnessed someone having a stroke. Study findings demonstrated that following the CEERIAS program, there was an increase in younger people, men, and Black patients who arrived at the Emergency Department (ED) early in select Chicago hospitals, which increased their chances of receiving time-dependent treatment. Furthermore, the number of people who used an ambulance when they thought they were having a stroke also improved after the program began.

Photo Collage from CEERIAS Walk with a Doc (WWAD) Event

PCORI funded 2CEERIAS in 2020 to adapt the CEERIAS program to a virtual environment, as the COVID-19 pandemic has prompted changes to our social norms and moved many engagement activities online to reduce risk of infection. For the 2CEERIAS study, we recruited 20 Stroke Promoters to complete an interactive virtual training on stroke awareness and symptom identification, and participate in discussions on barriers to timely stroke care during COVID-19 and strategies for effective messaging to communities of color on the importance of acting "FAST" for stroke. The virtual training equipped Stroke Promoters to embark on a 90-day 2CEERIAS community engagement campaign with a virtual focus.

This paper examines our efforts to virtually train 20 Stroke Promoters in the context of the current stroke and COVID-19 landscape, including our approach to engagement, results from the virtual trainings, and lessons learned. This paper also recommends further research and action to improve stroke-related health outcomes for communities of color and address community needs during a pandemic that necessitates social distancing and remote engagement.

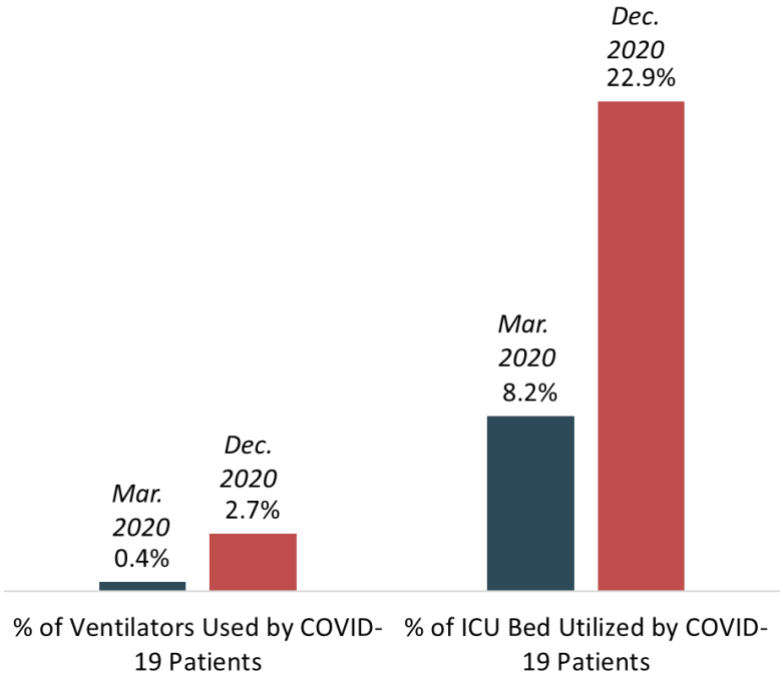
Unprecedented: Addressing Stroke During a Pandemic

The immediate need for comprehensive education and engagement on the importance of timely stroke care is even more urgent in the COVID-19 environment, where communities of color face additional challenges to accessing quality care and experience worse health care outcomes.

The rapid spread of the 2019 Coronavirus (COVID-19) has strained U.S. resources and placed pressure on the health care system to meet the needs of those most vulnerable.[1,2] The focus on COVID-19 prevention and treatment has made access to treatment for other acute health conditions like stroke more challenging. Among 2CEERIAS program community members, the knowledge that COVID-19 disproportionately affects communities of color added to preexisting mistrust of the health care system. This was further exacerbated by fears and anxieties about leaving homes and neighborhoods to seek care. Community members also expressed concern about being separated from their loved ones during an ED or clinic visit given COVID-19 protocols that restrict family members from coming to the hospital. Further, research indicates that COVID-19 is linked to more severe infections in stroke patients and in high-volume care settings, and as many as one-third of COVID-19 patients exhibit neurological symptoms such as headaches and dizziness.[3-6]

The COVID-19 pandemic continues to change how providers deliver stroke care. Hospitals have reorganized workflows, implemented more stringent sanitation protocols, and re-allocated personnel to different departments, which has led to delays in the timely administration of stroke treatment.[7-9] Acute care facilities have also been strained by the surge of COVID-19 patients as cases have risen across the U.S., as illustrated by changes in intensive care unit (ICU) utilization from the beginning of the pandemic in March to December 2020 (see Figure 1, next page). Higher acuity stroke patients may require more intensive care or ventilators. Accessing this equipment becomes more challenging when facilities must also meet the demands of treating COVID-19 patients.[10]

Figure 1. Chicago Ventilator and ICU Bed Utilization by COVID-19 Patients[I,II*]



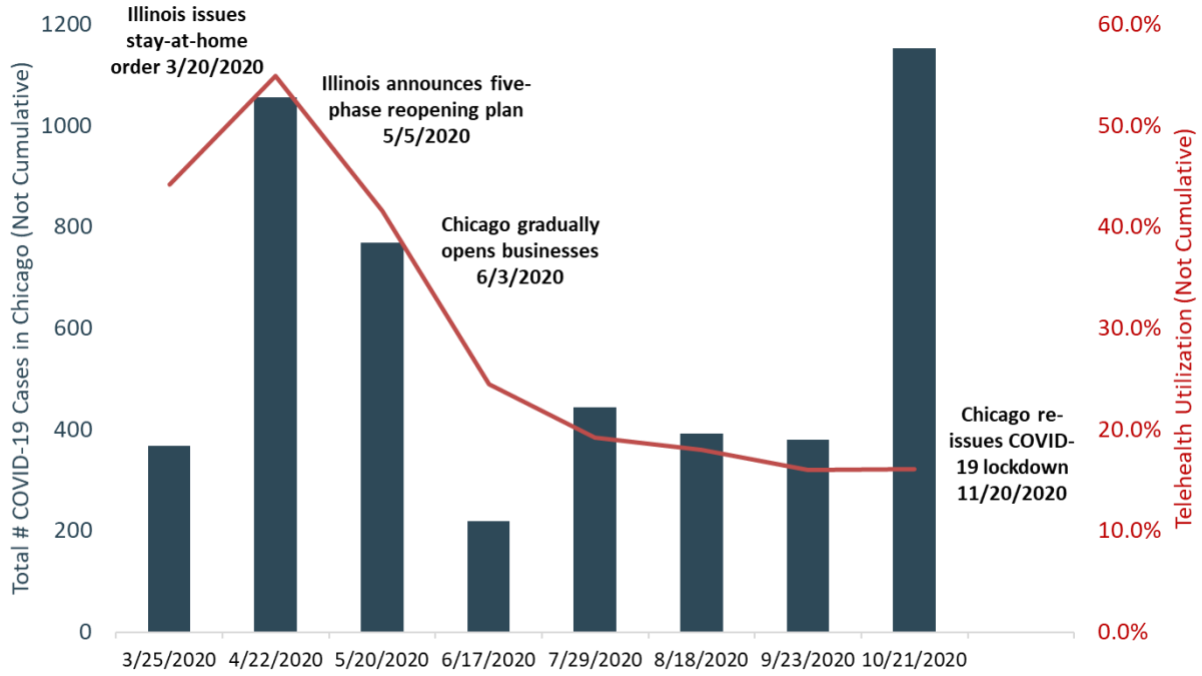
The pandemic has also influenced how people access treatment for many conditions, which may extend to stroke. Some preventive care services, like wellness visits, have been delayed or moved to a telehealth environment to accommodate guidance to remain socially distant and address changes in healthcare workforce capacity and the availability of personal protective equipment (PPE).[11-13]

Chicago's surge in telehealth services after the start of the pandemic underscored the opportunity to also leverage virtual platforms for enhanced community engagement in stroke education and awareness, such as the 2CEERIAS initiative. Figure 2 (next page) shows telehealth utilization patterns in Chicago over the course of the pandemic. Telehealth utilization has increased since March 2020, spiking after Illinois Governor Pritzker issued a stay-at-home order.[14] Telehealth utilization decreased since March, but has remained about 15% higher than before the COVID-19 public health emergency. The ways in which patients and providers will continue to use virtual solutions to manage their conditions, such as post-stroke recovery, will continue to evolve.[15]

Of note, there are racial, ethnic, geographic, and socioeconomic disparities in telehealth access and literacy.[16] Not everyone is able to access telehealth services or use them effectively. Though in-person strategies for community engagement are useful, there is a need to ensure that there is equitable access to effective use of virtual platforms to improve outcomes and eliminate health disparities.

[*] March 2020 data reflect ventilator and ICU utilization on March 19, 2020. December 2020 data reflect ventilator and ICU utilization on December 3, 2020. Data are not cumulative.

Figure 2. Chicago Telehealth Utilization and Total COVID-19 Cases Over Time[III-V,IX†‡]



While some people are seeking preventive and rehabilitative care virtually via telehealth, others are delaying care due to concerns about contracting COVID-19.[17] Major stroke centers have reported decreases in patient contacts, likely due to social distancing orders and fear of infection.[18] As of August 2020, 4 in every 10 adults in the U.S. reported delaying or avoiding medical care because of concerns related to COVID-19. Almost one-third of U.S. adults delayed or avoided routine medical care, and 12% avoided emergency care.[17] For stroke patients, delaying care can have serious long-term or fatal consequences.

The pandemic has also intensified disparities in stroke care and outcomes during the pandemic due to social determinants of health (e.g., race/ethnicity, socioeconomic status, health literacy, etc.).

Early studies on COVID-19 have shown that racial and ethnic minority groups have been disproportionately affected by the virus.[19] Even before the pandemic, research found that stroke has a greater impact on racial and ethnic minorities. Black and Hispanic populations are almost twice as likely to have a stroke as Whites and are more likely to die as a result of stroke.[20-22] Black stroke survivors are more likely to be disabled, and their range of activity tends to be much more limited than stroke survivors of other races.[23,24] The financial burden of stroke is also significantly greater in minority communities because strokes tend to occur at an earlier age in Black and Hispanic populations.[25,26]

Figure 3 (next page) shows that prior to the COVID-19 pandemic, women and racial minorities were less likely to receive tissue plasminogen activator (tPA), a medication used to treat acute ischemic stroke, than White

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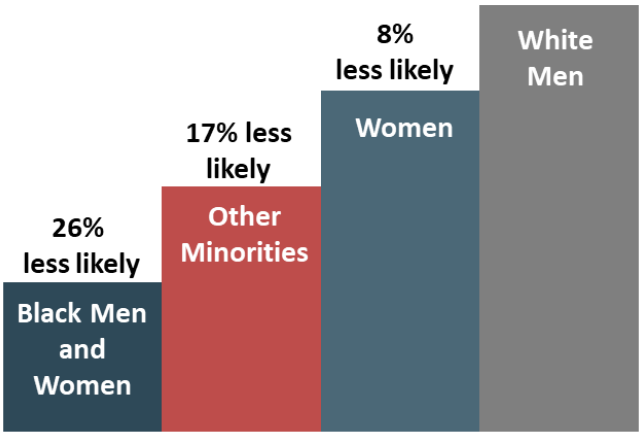
† Telehealth utilization data are sourced from the Chartis Group and Kythera Labs Telehealth Adoption Tracker, which uses telehealth medical claims from "self-insured and fully insured health plans across most major commercial payors and Medicare Advantage." Data reflect the percent of medical services provided via telehealth in that week.
‡ COVID-19 data reflect the total number of positive COVID-19 cases reported on a particular date. Data are not cumulative.

Figure 3. Racial Disparities in Stroke Treatments: tPA Utilization



men.[27] People experiencing acute ischemic strokes who receive timely tPA are more likely to successfully recover post-stroke.[28] These disparities in tPA administration may worsen as a result of COVID-19, given that racial and ethnic health disparities have grown more broadly.[46]

Stroke and COVID-19 in Chicago Communities of Color

National trends in stroke disparities are reflected at the community level in Chicago. A 2013 Chicago study found that on average, White stroke patients arrived at a hospital 85 minutes after stroke symptoms started, whereas the time to arrival for Black stroke victims was 152.5 minutes on average. For Black stroke victims who called 911, the time from when stroke symptoms started until the stroke victim arrived at the hospital was 34 minutes longer than White stroke victims.[29]

Chicago's South Side, which has a mostly Black and Hispanic population, is the area of the city most impacted by stroke. High rates of COVID-19 deaths are also observed in this area of Chicago.[30,31] Figure 4 and Figure 5 below show Chicago regions with more stroke-related deaths per 100,000 (by neighborhood) and COVID-19 deaths per 100,000 (by zip code), respectively.

Figure 4. Chicago Stroke Deaths per 100,000[VI §]

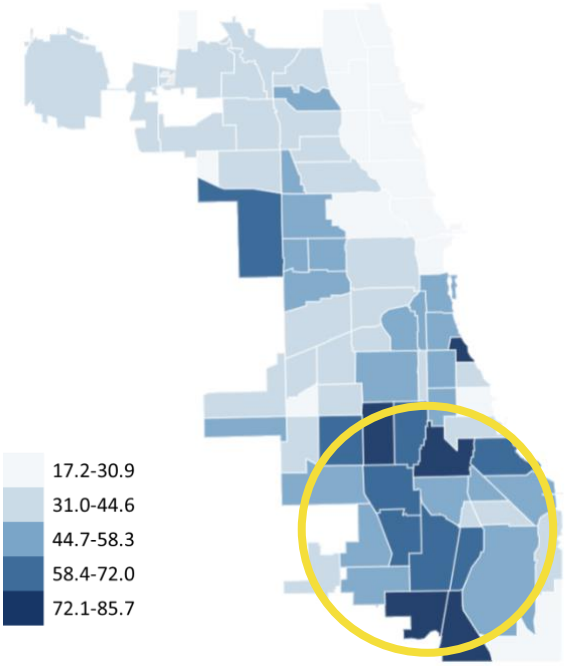
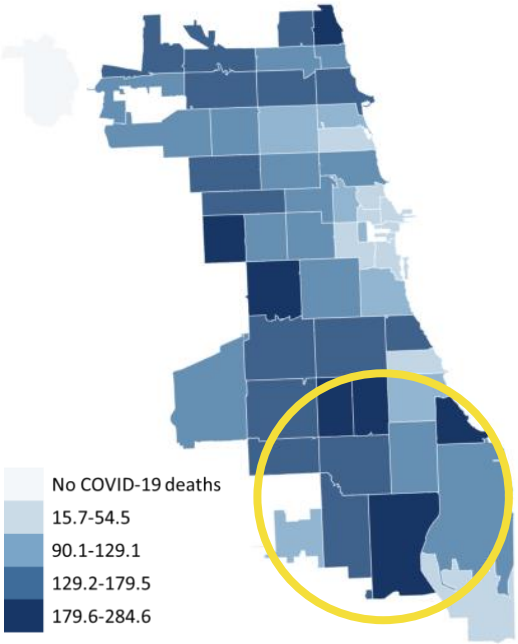


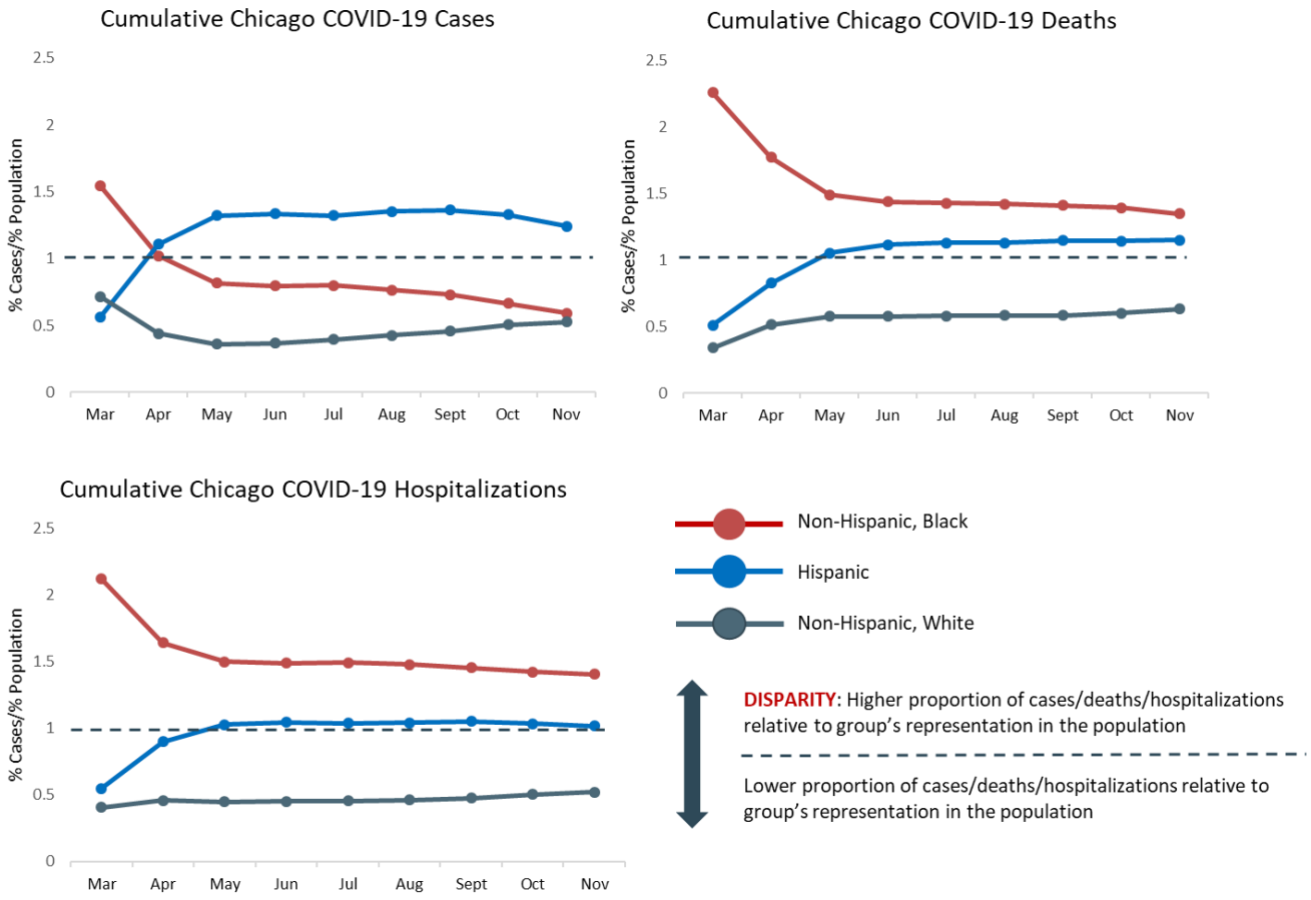
Figure 5. Chicago COVID-19 Deaths per 100,000[VII **]



§ Adapted from Chicago Health Atlas; data last updated April 9, 2019.
** Adapted from Chicago.gov; data last updated December 3, 2020.

Figure 6 below further demonstrates that COVID-19 has had a disproportionate impact on communities of color in Chicago. It breaks down the percentage of COVID-19 cases, deaths, and hospitalizations for non-Hispanic Black, Hispanic, and non-Hispanic White groups relative to these groups' representation in Chicago's population.[32,33] Non-Hispanic Black and Hispanic Chicagoans have a higher proportion of COVID-19 cases, deaths, and hospitalizations in comparison to White Chicagoans.

Figure 6. Percentage of 2020 Chicago COVID-19 Cases, Deaths, and Hospitalizations by Racial/Ethnic Group Relative to Racial/Ethnic Group Population Shares[††IX,X]



These data highlight racial and ethnic health care disparities among Black and Hispanic Chicagoans, which may be affected by different social and environmental factors.[34] For instance, Black and Hispanic groups have higher incidences of other underlying conditions, like hypertension, that can increase the risk of stroke and the severity of COVID-19 symptoms.[35,47] This may lead to increased hospitalizations and worse COVID-19 mortality. Further, Blacks disproportionately work in essential occupations (e.g., health care and transportation) that place them at higher risk of COVID-19 infection.[36]

[††] Chicago population estimates use 2019 Census data.

About 2CEERIAS

PCORI has funded 2CEERIAS to build on previous efforts to improve early treatment of stroke and stroke outcomes in predominantly Black and Hispanic Chicago communities by creating a program that addresses needs brought on by the COVID-19 pandemic.

In 2014, PCORI funded the Community Engagement in Early Recognition and Immediate Action in Stroke (CEERIAS) study to improve stroke-related health outcomes and reduce racial disparities in Chicago. CEERIAS researchers conducted the observational study in a predominantly Black community in the South Side of Chicago. Researchers selected this community because of its high stroke incidence and low Emergency Medical Service (EMS) usage- EMS is critical for mitigating the adverse effects of stroke.[37] The CEERIAS team implemented an in-person stroke preparedness program that equipped community influencers, or "Stroke Promoters," to spread messaging that emphasized early recognition of stroke symptoms and tools to overcome barriers to seeking treatment for stroke.

The key message of the program, "Act FAST for Stroke," encouraged participants to recognize signs of stroke (e.g., [f]ace drooping on one side, [a]rm weakness on one side of the body, [s]peech slurring or difficulty, and expedite care given to stroke patients - [t]ime to call 911). Results of the CEERIAS study indicated that successful implementation of the stroke preparedness program can improve stroke-related health outcomes in vulnerable communities. Positive returns also suggested a need to build upon the CEERIAS approach to educate additional community members on the risk of stroke and how to "Act FAST" in Chicago.

Building on a "CEERIAS" Success: Phase II

Phase II of the CEERIAS study (2CEERIAS) launched in 2020 to bring the campaign to a virtual platform in response to new environmental conditions brought on by the COVID-19 pandemic. Like in the CEERIAS study, Stroke Promoters complete stroke identification and preparedness training and spread "Act FAST" messaging. In 2CEERIAS, we delivered the training via web meetings, social media, and other forms of remote communication. Figure 7 (right) highlights the 2CEERIAS study principles for community engagement. These principles continue to guide our team interactions with advisors, stroke promoters, and the broader community.

Figure 7. 2CEERIAS Community Engagement Principles

- Community Ownership
- Agile, Flexible Approach
- Experiential Learning Model
- Inclusive, Open Dialogue
- New Learning

In October 2020, 2CEERIAS trained 20 Stroke Promoters through 2-hour interactive online trainings, which included education and discussion on the risk of stroke, its prevalence in Chicago's communities of color, and the skills needed to identify stroke symptoms quickly and act. The meetings also emphasized the impact of COVID-19 on care delivery. Two neurologists, Dr. Neelum Aggarwal and Dr. Shyam Prabhakaran, delivered the educational and training material. Dr. Aggarwal and Dr. Prabhakaran served as co-Principal Investigators for the CEERIAS study and provide clinical expertise for 2CEERIAS.

Stroke Promoters were required to attend at least one of four online trainings, but had the opportunity to join for more than one session. All four trainings covered the same material. To promote both experiential learning and open dialogue, participants were encouraged to share their experiences with the healthcare system, before and during the COVID-19 pandemic, and co-design approaches to adapting 2CEERIAS messaging and delivery to be effective in a virtual environment. Likewise, we co-developed all training materials with the

2CEERIAS Community Advisory Board (CAB), a committee of patients, families, community members, and former CEERIAS Stroke Promoters that provided oversight on all study activities. CAB members also attended the virtual training.

At the conclusion of the virtual trainings, we provided Stroke Promoters with a 90-day action plan to promote the 2CEERIAS "Pact to Act FAST" pledge. 2CEERIAS Stroke Promoters will be engaging in a social media campaign to educate Chicago's South Side and grow the 2CEERIAS community through messaging on Facebook, Instagram, Twitter, TikTok, and other sites.

Approach to Virtual Engagement: Training for Stroke Promoters

We used an agile methodology to facilitate continuous process improvement in the development of educational materials and other supporting materials to prepare Stroke Promoters for successful participation in the virtual training.

Pre- and Post-Survey Design

2CEERIAS Stroke Promoters completed an online pre-survey administered before the training and an online post-survey administered after the training to assess changes in Promoter knowledge about stroke, perceptions of self-efficacy with addressing stroke, and experience with the health care system and COVID-19. Some of the survey content was drawn from the CEERIAS project and adapted to be more appropriate for the current environment. We also modified the surveys in response to CAB feedback:

- **Streamlined Survey:** We removed survey items that were redundant and prioritized those items most pertinent to assessing training effectiveness, Stroke Promoter experience with the health care system, and Stroke Promoter experience during COVID-19.
- **Flexible Response Options:** For sensitive topics (e.g., trust in the health care system), we included an option for Stroke Promoters to defer a response and follow up over the phone. One Stroke Promoter selected this option, which prompted follow-up and further discussion beyond the survey and virtual training sessions.

Table 1 below summarizes the concepts captured in the pre- and post-surveys. Results from the pre- and post-survey are summarized in Appendix A.

Table 1. Summary of Concepts Captured Across the Pre- and Post-Surveys

Survey Concept	Pre-Survey (Up to 33 questions)	Post-Survey (13 questions)
Demographics	✓	X
Experience with Stroke	✓	X
Stroke Knowledge	✓	✓
Stroke Knowledge Attitudes and Self-Efficacy	✓	X
Experience with the Health Care System	✓	X
Impact of COVID-19 Pandemic	✓	✓
Feedback on Convening Experience	X	✓

Training Design and Scheduling

We designed the trainings to meet the objectives summarized in Figure 8 below.

Figure 8. 2CEERIAS Virtual Training Objectives

We solicited input from the CAB and the Stroke Promoters to design the virtual training and make continuous process improvements:

- **Streamlined Training**: While the initial plan for the virtual training was to conduct a one-day remote session, we 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, we condensed the training from a four-hour session to a two-hour session.
- **Stroke Promoter- and CAB-Centric Scheduling:** We 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, we 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.
- **Office Hours**: Prior to the training sessions, we 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, we shifted the order of the training agenda to encourage increased engagement and discussion among the Stroke Promoters earlier in the program.

Engagement in the Virtual Environment

We leveraged virtual meeting tools to encourage Stroke Promoter engagement and discussion during the training, including the chat function, video and screen-sharing, and unmuted phone lines. Stroke Promoters used the chat to share comments and questions throughout the presentation.

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Stroke Promoter Virtual Training Discussion

Stroke Promoters shared insights in the pre- and post-training surveys and during the virtual training. We identified key themes around community member experiences with and perceptions of the health care system, as well as opportunities for health care 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% of Stroke Promoters reported difficulty reaching the doctor's office or clinic by phone, and over 75% of Stroke Promoters feel they have to wait too many days for an appointment.

> "When you talk about health care, when you access places within our neighborhoods, what does that look like? It looks like long waits. It looks like people that, when they're working with us, they don't talk to us, they talk at us.
>
> That shouldn't be what our people face but that's what we're faced with at even the hospitals or facilities that are within the communities. If you make patients your priority, then they'll make health theirs."

Stroke Promoters and CAB members shared that when they can access health care 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% 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 will 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 health care providers. Over 80% 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 health care 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.

> "Black people really don't feel that the doctors are actually listening to them as they express certain symptoms, like a headache. They'll quickly give us an aspirin instead of further assessing for stroke, or a clot."

> "It may take ten or 15 minutes to get an ambulance to you, whereas in a White community they are there within five minutes."

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, co-workers, 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 health care system**. In the pre-survey, over 80% 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% 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 health care system. Such messaging should include information about Chicago Primary Stroke Centers, which are required to meet certain quality

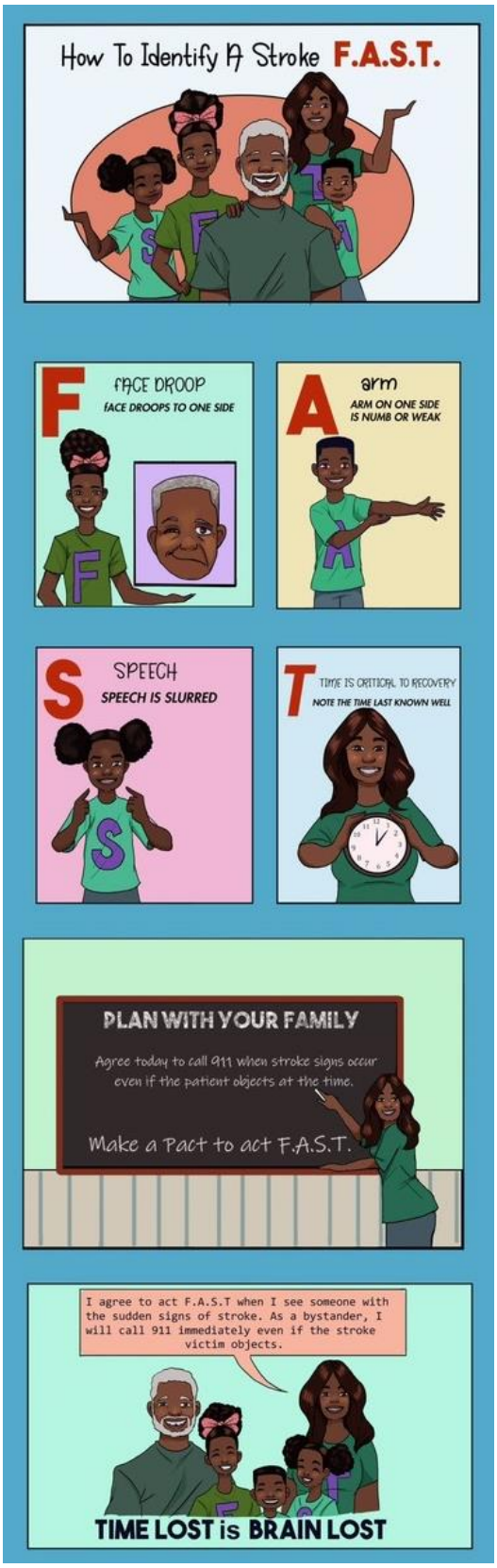
standards and are trusted to treat stroke patients. Appendix B includes a list of Chicago's Primary Stroke Centers.

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.



Stroke-Promoter Adapted Pledge Graphic

90-Day Social Media Campaign

Completion of the 90-Day Social Media Campaign was a Project Milestone designed to test the revised messaging summarized from the Virtual Convening in the using virtual and non-traditional engagement platforms. The Campaign began late October and continued through the end of January 2021. Promoters used the project website, Facebook, Twitter, Instagram, Tik Tok, and LinkedIn to spread the 2CEERIAS message. Other methods of dissemination included phone banking and community events.

Website Analytics

- New Visitors to site 49.3%/50.7% Returning Visitors
- 80 Users (72 New Users)
- Device most used: Mobile (63.7%), Desktop (35%), Tablet (1.3%)
  - 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%), Twitter (+1190%).
- Impression began to precipitously decline after November 2020.
- Exhibit 1. Shows that Facebook and Instagram yielded the most followers. LinkedIn having the least value.

Exhibit 2. Shows that Facebook and Twitter yielded the most overall impressions. LinkedIn having the least value.

	Percent Change			
	FaceBook	Twitter	Instagram	LinkedIn
Month 2				
	▲ 572.73%	▲ 11.11%	▲ 46.15%	▲ 0.00%
	▲ 39.53%	▲ 81.82%	▼ -83.33%	▲ 87.50%
	▼ -34.69%	▲ 275.00%	▼ -92.00%	▼ -100.00%
	▲ 157.69%	▼ -33.33%	-	-
	▲ 0.00%	-	-	-
	▲ 23.08%	▲ 1714.29%	▲ 23.08%	▼ -100.00%
	▲ 366.67%	-	-	-
	▲ 63.79%	▲ 1190.48%	▼ -50.00%	▼ -100.00%
Month 3				
	▲ 5.41%	▲ 0.00%	▲ 5.26%	▲ 25.00%
	▼ -20.00%	▼ -38.33%	▼ -100.00%	▼ -40.00%
	▲ 0.00%	▼ -20.00%	▼ -100.00%	-
	▼ -10.45%	▲ 100.00%	▼ -100.00%	-
	▼ -33.33%	-	-	-
	▼ -96.88%	▼ -90.94%	▼ -96.88%	-
	▼ -80.36%	-	-	-
	▼ -44.21%	▼ -83.39%	▼ -94.74%	-
Month 4				
	▲ 1.28%	▲ 0.00%	▼ -5.00%	▲ 0.00%
	▼ -6.25%	▲ 2.70%	-	▲ 5.56%
	▼ -84.38%	▼ -25.00%	-	▼ -100.00%
	▼ -35.00%	▼ -100.00%	-	-
	▼ -50.00%	-	-	-
	▼ -100.00%	▼ -100.00%	▼ -100.00%	▼ -100.00%
	▼ -100.00%	▼ -100.00%	▼ -100.00%	-
	▼ -57.55%	▼ -80.00%	▼ -100.00%	▼ -100.00%

Additional insight from Stroke Promoters yielded was the way in which Social Media was used for engagement. For example, by using Facebook Stories feature, Promoters were able to see the names of their contacts that looked at the 2CEERIAS content. Promoters used this opportunity to engage in one-on-one discussions with those targeted individuals; resulting in more 2CEERIAS pledges completed. We also learned that platforms such as Microsoft Team were leveraged to broadcast the 2CEERIAS message to colleagues and other constituents. This engagement strategy also helped to more broadly share the 2CEERIAS message and from early responses yielded imply that further dissemination beyond our targeted reach of Chicagoland is desired.

Lessons Learned

Overall, Stroke Promoters responded positively to the training. A total of 3,679 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 our project end meeting has been compiled to understand the project learnings relative to our objectives. A restatement of those objectives include:

- 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. Figure 9 below captures the most prominent themes that Stroke Promoters shared throughout the project.

The use of virtual platforms is a form of dissemination that worked for the 2CEERIAS engagement strategy. Accordingly, further dissemination of the critical messages could adopt a similar learning platform as used for

the virtual training and in particular the spread of the 2CEERIAS message. When asked how the virtual training could be improved, Stroke Promoters provided the following feedback:

- "Shorter time frame"
- "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."

Figure 9. Word Cloud Summarizing Positive Stroke Promoter Feedback on Virtual Trainings

Based on Stroke Promoter feedback and additional input from the CAB, 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 felts 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. We used different strategies to communicate with Stroke Promoters based on their stated individual preferences. We also engaged with the Stroke Promoters frequently. In addition to personal phone calls and text messaging, based on the Stroke Promoters' stated preference, we held bi-weekly office hours meetings to troubleshoot issues encountered during the 90-day campaign and share information about stroke and COVID-19.

We were able to quickly build strong relationships with the Promoters as evidenced by our frequent communication and interactive discussions through the engagement principle of Inclusive, Open Dialogue. We believe 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 us 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, we 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, we 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, we 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 notice. 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 summer and fall 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 co-workers, who can accelerate spread. 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.

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.

Recommendations

Funders and health care researchers should scale the 2CEERIAS intervention and conduct additional studies to learn more about effective community engagement strategies and improve health outcomes for communities of color, particularly for stroke and COVID-19.

Building a Force for Change

The 2CEERIAS study is piloting an approach to adapt the successful CEERIAS training and engagement strategies to the virtual environment. The learnings from the 2CEERIAS study can be further adapted to reach other communities of color throughout the U.S. While the 2CEERIAS study benefited from leveraging the strong CEERIAS network established during the first phase of this work, "social media listening" can also be leveraged to identify Key Online Influencers in Chicago and other regions. These influencers could be recruited to expand the reach of the program. Recruiting people "on-the-ground" who live in and understand the needs of communities at a national scale will build a force for serious change in health care. A future study could establish a nationwide virtual Stroke Promoter learning community to enhance communication, expand the spread of best practices, and accelerate change.

Funders and researchers should also explore how people access information, particularly in communities of color. While 2CEERIAS leverages the social networks of the Stroke Promoters to tailor and share messaging, funders and researchers could consider launching a comprehensive multichannel communications strategy to amplify the voices of the Stroke Promoters and expand reach. In Chicago, researchers could build on 2CEERIAS lessons learned regarding in-person and virtual community engagement to establish a multi-stakeholder consortium with other health care stakeholders like health plans, accountable care organizations, community-based organizations, and local businesses to spread consistent messaging. If successful, such a program could be piloted in other regions.

Moving from Reach to Behavior Change

The 2CEERIAS study examines community reach via virtual engagement strategies (i.e., social media and other forms of virtual communities), adapting in-person engagement strategies used in the CEERIAS study. Funders and researchers should evaluate the success of 2CEERIAS using real world evidence (RWE) to understand the effect of the campaign on changes in care-seeking behavior. The current measure of success for the 2CEERIAS study is the number of people who have signed the "Pact to Act FAST" pledge. Results can be further evaluated to see how signing the pledge has translated to behavioral change and subsequent health outcomes.

The 2CEERIAS study uncovered barriers to care and identified promising tactics to overcome those barriers in predominantly Black and Hispanic Chicago neighborhoods. More broadly, funders and researchers should conduct studies to better understand motivators of behavior change as they relate to the care seeking behaviors of communities of color.

Eliminating COVID-19 Racial and Ethnic Health Disparities

The CEERIAS and 2CEERIAS projects were designed, in part, to address racial and ethnic disparities in stroke outcomes. The lessons learned from these projects could also be applied to other conditions, such as COVID-19.

The long-term impacts of COVID-19 are yet to be known. As the Stroke Promoters discussed during the virtual training sessions, COVID-19 long-haulers combat the effects of COVID-19 long after they test negative for the

virus. About 10% of COVID-19 patients become long-haulers, many of whom are essential workers who were exposed to COVID-19 earlier in the pandemic.[42] A recent study found that Black Americans were more likely to have pandemic-essential jobs, such as those in the personal care industry.[36]

As of December 2020, several life sciences organizations have announced the successful development of COVID-19 vaccinations.[43] However, a survey released in November 2020 found that fewer than 50% of Black people and 66% of Hispanic people said that they would take the COVID-19 vaccine free of charge. The survey found that only 14% of Black people trust that a COVID-19 vaccine will be safe.[44,45] This aligns with findings from the post-training survey to Stroke Promoters, in which only 40% of Stroke Promoters said they would take the COVID-19 vaccine.

As such, racial and ethnic disparities in COVID-19 health outcomes will likely worsen, and research should be conducted to understand these disparities in order to identify strategies to eliminate them and improve outcomes for all. Similar methods and tactics from 2CEERIAS could be applied to engage Chicago communities of color on these topics.

The connection between the 2CEERIAS message and COVID-19 generated discussions about primary care services for at-risk populations. Many promoters cited that the lack of primary care utilization and connections to primary doctors is also a barrier to successful outcomes among Black and brown communities throughout the Chicagoland area.

Next Steps for 2CEERIAS

In 2021, Stroke Promoters will continue to reach out to their friends, family, neighbors, and broader community using tactics that have worked well in 2020 and identifying new tactics to overcome the challenges of virtual engagement. To better understand what drives behavior change in the virtual environment, we are fielding a brief survey to people who sign the pledge to gather data on what motivated them to complete the pledge. These learnings can be used to shape engagement strategies.

We are also going to expand outreach to the community through Chicago health disparities organizations, such as the Center for Health Innovation. We also plan to develop podcast episodes for the Diversity Dialogues AMWA Podcast series.

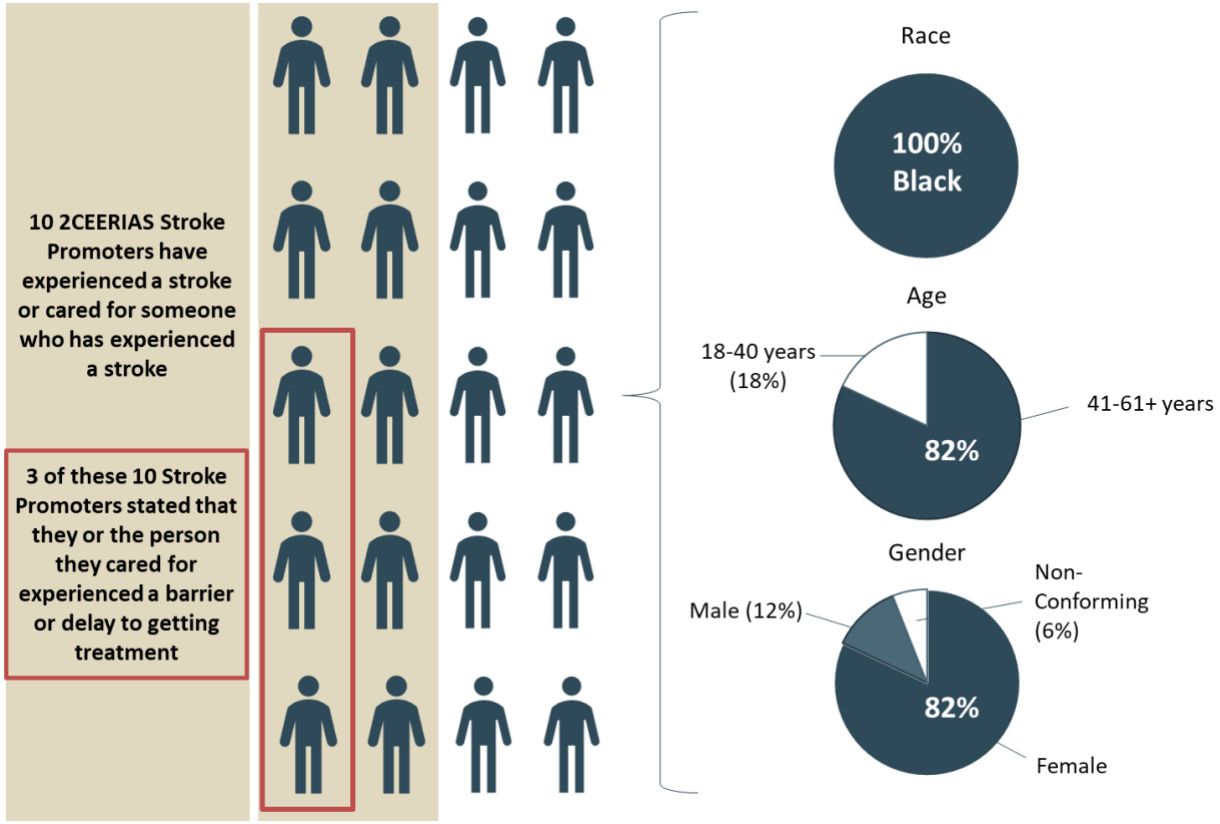
Finally, we plan to seek funding to pursue some of the research projects described above. Specifically, the Stroke Promoters felt strong about the need to use the 2CEERIAS learning model to further disseminate and promote the for early arrival to care as well as the need for patient partners within the community identifying and utilizing a primary care services. By further building the evidence base in this area, we can better demonstrate and increase the effectiveness of these initiatives. The agile nature of the 2CEERIAS program is such that the more we learn, the better we can adapt to the changing environment to empower the community and drive meaningful change.

Appendix A: Summary of Pre- and Post-Survey to Stroke Promoters Results

Demographics and Experience with Stroke

17 out of 20 Stroke Promoters completed the pre-survey and all 20 Stroke Promoters completed the post-survey. Figure A1 includes demographic information about the 2CEERIAS Stroke Promoters who completed the pre-survey, as well as their prior experiences with stroke.

Figure A1. 2CEERIAS Stroke Promoter Experience with Stroke and Demographics (N=17)



10 out of 17 Stroke Promoters have experienced a stroke or cared for someone who has experienced a stroke. Half of these respondents (5 out of 10) stated that they cared for a family member who either was deceased or who survived a stroke. Stroke symptoms experienced included facial drooping (9 out of 10), arm weakness (7 out of 10), and speech difficulties (8 out of 10). Stroke Promoters shared that other symptoms included "confusion," "short loss of memory," "hearing difficulties," "eyes rolling in opposite directions," "terrible headache," "unable to move limbs," and "very lethargic and vision problems."

3 of the respondents stated that they or the person they cared for experienced a barrier or delay to getting treatment. Delays in treatment were due to a lack of familiarity with stroke and being unable to describe what they were experiencing. Another respondent stated that their loved one was misdiagnosed with chronic fatigue. 6 out of the 10 respondents stated that they did call 911. Of the 6 respondents who called 911, 3 patients received treatment at a Primary Stroke Center.

Stroke Knowledge

FAST Acronym

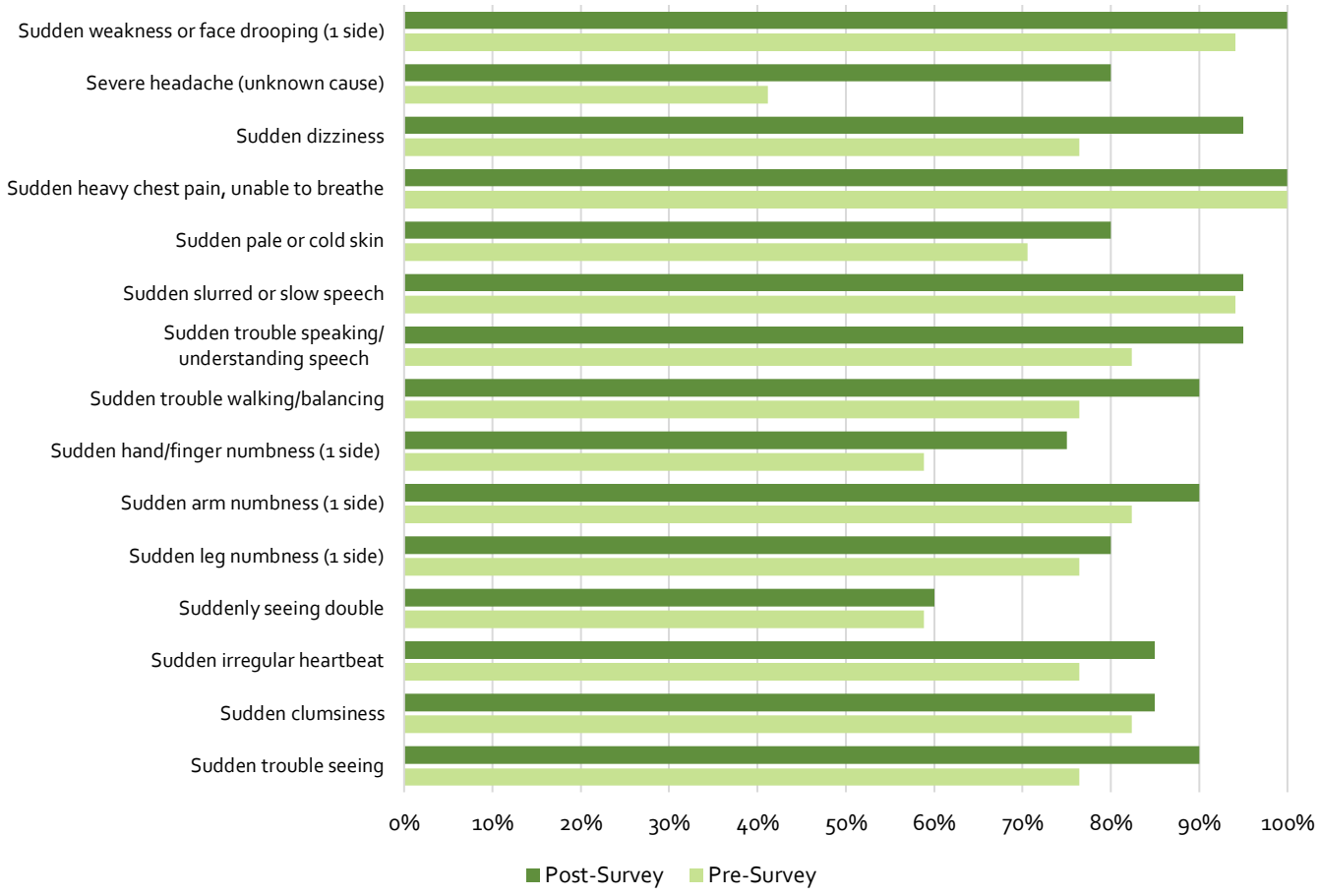
15 out of 17 pre-survey respondents correctly described the meaning of the acronym FAST (face drooping, arm weakness, speech difficulty, time to call 911). 16 out of 17 respondents stated it was very important if they saw someone having a stroke for that person to get to the hospital quickly and 16 out of 17 respondents stated they would know to call 911 immediately.

In the post-survey, 18 out of 20 Stroke Promoters correctly described the meaning of the acronym FAST, Face drooping, arm weakness, speech difficulty, time to call 911. All respondents stated that they would not delay seeing their doctor or going to the emergency room or urgent care during the COVID-19 pandemic after completing the Stroke Promoter Convening.

Identifying Stroke Symptoms and Calling 911

Figure A2 below compares the response to the Stroke Knowledge assessment items in the pre- and post-survey. The post-survey results indicate that following the training, more Stroke Promoters said they would "call 911 immediately" in the event of a observing a stroke warning sign.

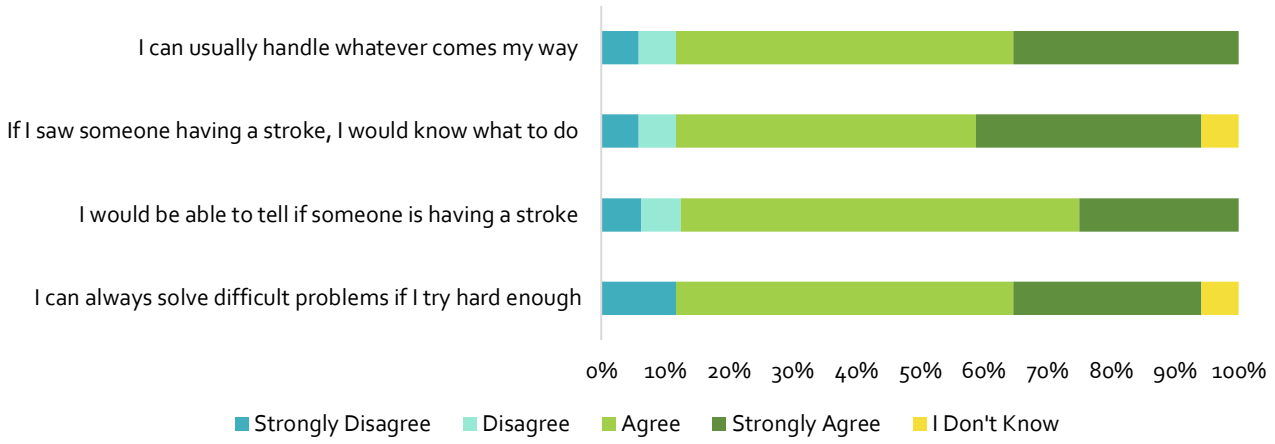
Figure A2.
Change in Stroke Knowledge After Completing 2CEERIAS Stroke Promoter Virtual Training (N=17, 20)



Stroke Knowledge Attitudes and Self-Efficacy

Figure A3 summarizes the Stroke Promoters' responses in the pre-survey regarding their attitudes toward their stroke knowledge and their perception of self-efficacy. Most Stroke Promoters agreed or strongly agreed that they would be able to identify stroke symptoms, know what to do, and would be able to handle the situation.

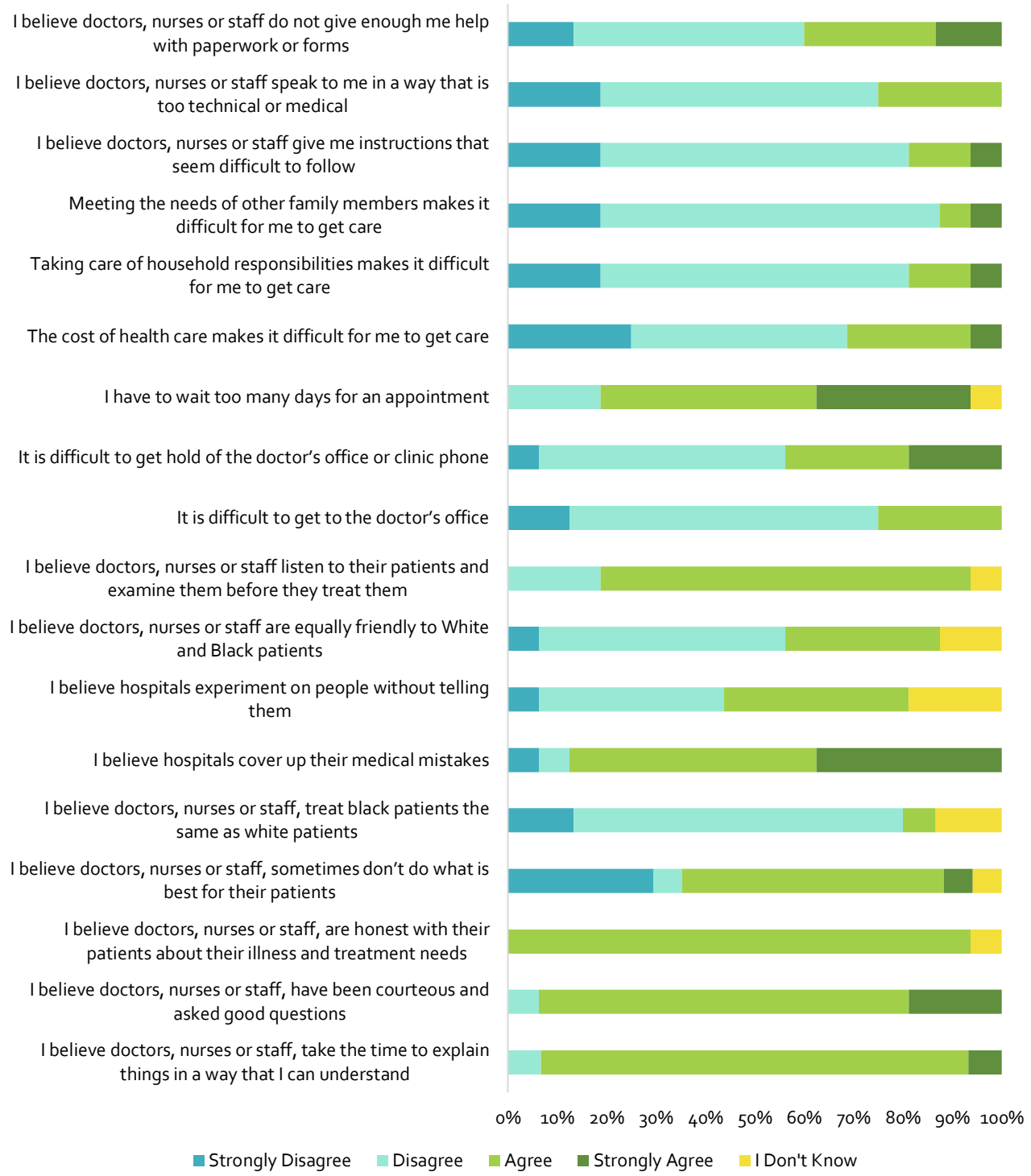
Figure A3. Summary of Stroke Promoter Responses to Stroke Knowledge Attitudes and Self-Efficacy Pre-Survey Items (N=17)



Experience with and Trust in the Health Care System

Figure A4 (next page) summarizes Stroke Promoters' responses in the pre-survey regarding their experiences with and trust in the health care system. About 70% of the participants feel they have to wait too many days to get an appointment with the doctor, that doctors do not treat black patients the same way as White patients, and that hospitals cover up the medical negligence.

Figure A4. Summary of Stroke Promoter Responses to Stroke Knowledge Attitudes and Self-Efficacy Pre-Survey Items (N=17)[‡‡]



[‡‡] Some Stroke Promoters opted to not answer some of these survey items. Responses are shown as percents.

Impact of the COVID-19 Pandemic

In the pre- and post-surveys, Stroke Promoters responded to survey items intended to capture their experiences during the COVID-19 pandemic and their attitudes toward health care considering the COVID-19 pandemic. About 50% of the participants have acknowledged that they have delayed visiting their doctor or seeking emergency care due to the fear of exposing themselves to COVID-19. In the post-survey, all Stroke Promoters said that they would not delay seeing their doctor during the COVID-19 pandemic after completing the 2CEERIAS virtual training and that they would not delay visiting the emergency room or urgent care clinic during the COVID-19 pandemic.

Additionally, 60% of the participants indicated that they are willing to take vaccine or treatment for COVID-19.

Table A1 below indicates Stroke Promoter attitudes about mask-wearing in different situations. The majority of Stroke Promoters support mask-wearing in public.

Table A1. Summary of Concepts Captured Across the Pre- and Post-Surveys (N=19)[§§]

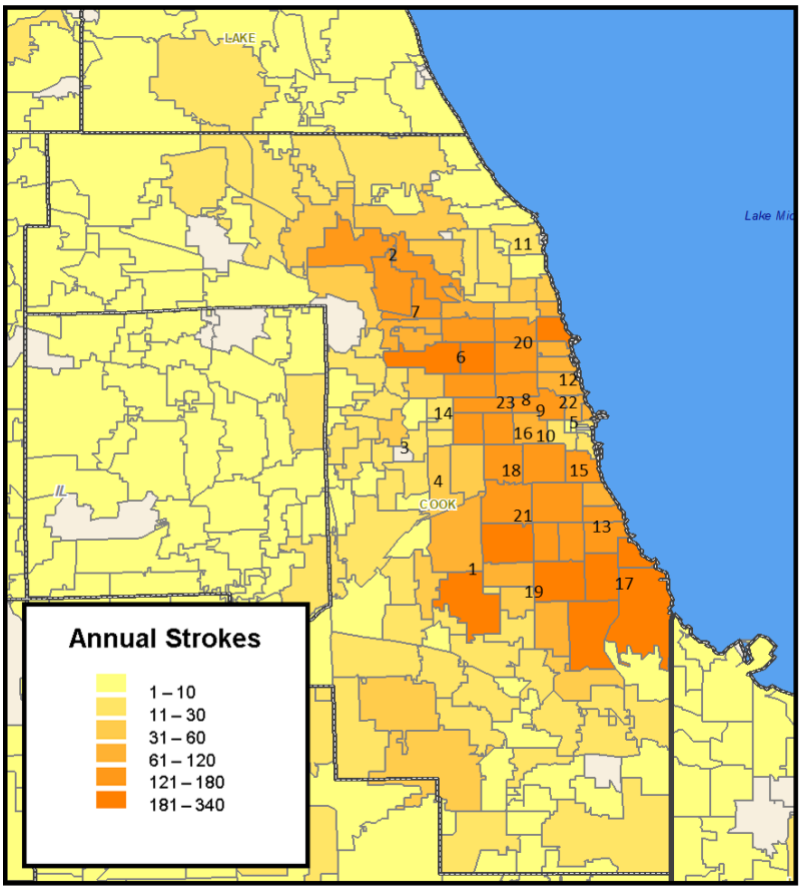
Situation	Strongly Disagree or Disagree	Strongly Agree or Agree
It is important for me to wear a cloth face covering when I am out in public	21%	79%
It is important for everyone to wear a cloth face covering when they are out in public	21%	79%
Wearing a cloth face covering while I am out in public is easy for me	21%	79%
Everyone wearing cloth face coverings while out in public would prevent the spread of coronavirus in our community	26%	68%
	(1 respondent selected "I don't know")	
People who are important to me want me to wear a cloth face covering when I am out in public	26%	74%

[§§] 1 out of 20 Stroke Promoters opted not to answer post-survey questions related to the COVID-19 pandemic.

Appendix B: Chicago Primary Stroke Centers

Figure B1 below identifies Chicago's Certified Primary Stroke Centers on a heat map showing areas with higher numbers of annual strokes.

Figure B1. Certified Primary Stroke Centers in Chicago[VIII]



Certified Primary Stroke Centers

1. Advocate Christ Medical Center
2. Advocate Lutheran General Hospital
3. Loyola University Medical Center
4. MacNeal Hospital
5. Northwestern Memorial Hospital
6. Our Lady of Resurrection Medical Center
7. Resurrection Medical Center
8. St. Mary of Nazareth Hospital
9. Rush University Medical Center
10. University of Illinois Medical Center
11. St. Francis Hospital
12. St. Joseph Hospital
13. University of Chicago Medical Center
14. West Suburban Hospital
15. Mercy Hospital
16. Stroger Hospital of Cook County
17. Advocate Trinity Hospital
18. Mount Sinai Hospital
19. Little Company of Mary Hospital
20. Swedish Covenant Hospital
21. Holy Cross Hospital
22. Advocate Illinois Masonic Hospital
23. Norwegian American Hospital

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