Coverdell Stroke Analysis Report

Fall 2022/Spring 2023
Focus Group and Survey Report
Pender and Brunswick Counties, North Carolina

Prepared for Novant-New Hanover Regional Medical Center

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Executive Summary

Stroke is the fifth leading cause of death in the United States (*About stroke*, 2022) and the risk of having a stroke is nearly twice as high for African Americans as it is for Whites (*Stroke facts*, 2022). There are several risk factors that increase the likelihood of having a stroke, including high blood pressure, high cholesterol, smoking, obesity, and diabetes (*Stroke facts*, 2022). Additionally, people that live in rural areas have an increased stroke incidence and mortality rate compared to those that live in urban areas (Georgakakos et al., 2020). This disparity is multi-factorial, but one of the most notable factors is that rural areas have limited access to care and stroke services. This includes access to health education, support for caregivers, and access to healthcare, especially hospital care (Georgakakos et al., 2020). People living in rural areas are more likely to be low-income, less educated, medically underserved, often lack health insurance and have lower socioeconomic status, which all contribute to the disparate stroke rates (Georgakakos et al., 2020).

In North Carolina, stroke is also the fifth leading cause of death (*Stats of the State of North Carolina*, 2018) and 70 of the 100 North Carolina counties are rural, which may contribute to the increased risk for stroke and barriers to accessing healthcare (*North Carolina Rural and Urban counties*, 2019). Due to these disparities, Novant – New Hanover Regional Medical Center initiated this project focused on Brunswick and Pender counties, two rural counties in North Carolina with limited access and several barriers to healthcare. Stroke is the fourth leading cause of death in Brunswick County (*Brunswick County CHA*, 2019) and the third leading cause of death in Pender County (*Pender County CHA*, 2018). In Brunswick County, 10% of the population is African American (*Brunswick County CHA*, 2019) and in Pender County, 16.4% of the population is African American (*Pender County CHA*, 2018). Therefore, the high rate of stroke may be disproportionately impacting segments of the population.

To better understand the disparities in these counties, a survey and focus groups were conducted in faith communities. The purpose of the survey was to understand community knowledge of stroke risk factors, stroke signs and symptoms, and stroke prevention measures. The focus groups targeted faith community members who had some type of experience with stroke to better understand their experiences with stroke, the impact stroke had on their lives or the life of loved ones, and what services could be offered for prevention and post stroke care. The results of this mixed-methods study will be used to inform Novant on tailoring stroke health education and identify and address disparities in access to and quality of care for populations at highest risk for stroke events.

There were several similarities and common themes related to stroke and stroke care across Brunswick and Pender counties, including lifestyle, access, advocacy, mental health, and health education. Many people reported the struggle to live a healthy lifestyle due to several barriers and health inequities related to living in a rural area and more specifically being a minority living in a rural area. Health education and resources are limited in these areas and many people felt that they do not know how to advocate for themselves and their families. Education

was discussed several times as one solution to positively impact the health of the community. Additionally, limited access to care and transportation were listed as barriers, and the solutions discussed were local community and/or wellness centers for programs, support groups, classes, resources, and wellness visits to create more accessible care and to help build trust. Based on the community feedback, health education and advocacy will be incredibly impactful in these areas. Especially, if offered in the community, such as at the faith communities.

Coverdell Stroke Analysis Report

Background

Stroke is the fifth leading cause of death in the United States and is a leading cause of disability due to the long-term health effects (*About stroke*, 2022). Every year, more than 795,000 people in the United States have a stroke (*Stroke facts*, 2022). While this is a leading cause of death for all Americans, the risk of having a stroke varies with race and ethnicity. The risk of having a stroke is nearly twice as high for African Americans as it is for Whites and African Americans have the highest rate of death due to stroke (*Stroke facts*, 2022). There are several risk factors that increase the likelihood of having a stroke including high blood pressure, high cholesterol, smoking, obesity, and diabetes. These have been identified as leading causes of stroke and one in three American adults has a least one of these conditions or habits (*Stroke facts*, 2022).

People that live in rural areas have an increased stroke incidence and mortality compared to those that live in urban areas (Georgakakos et al., 2020). This disparity is multi-factorial, but one of the most notable factors is that rural areas have limited access to care and thus stroke services. This includes access to health education, support for caregivers, and access to healthcare, especially hospital care (Georgakakos et al., 2020). Additionally, there are increased stroke risk factors in rural patients. People living in rural areas are more likely to be low income, less educated, medically underserved, often lack health insurance, and have lower socioeconomic status, which all contribute to the disparate stroke rates (Georgakakos et al., 2020). 19.3% of Americans live in rural areas, which makes addressing these rural-urban disparities an important part of improving stroke outcomes in the United States (Georgakakos et al., 2020).

Seventy of the 100 counties in North Carolina are rural, increasing the state's risk for stroke and barriers to accessing healthcare (*North Carolina Rural and Urban counties*, 2019). Stroke is the fifth leading cause of death in North Carolina and has a stroke rate higher than the national average. The stroke rate in 2017 in North Carolina was 43.0 per 100,000 people compared to the United States National rate of 37.6 per 100,000 people (*Stats of the state of North Carolina*, 2018). Lack of access to healthcare and health insurance is a large part of this disparity; 11.4% of people are uninsured in North Carolina and 17.9% have Medicaid and 15.3% have Medicare (*Health insurance coverage of the total population*, 2021).

This project focuses on Brunswick and Pender counties, two rural counties in North Carolina with limited access and several barriers to healthcare. In Brunswick County, 15% of residents do not have health insurance (*Brunswick County CHA*, 2019). Some of the barriers to access to healthcare identified as concerns by the community are high cost of health services, unaffordable health insurance, lack of knowledge of resources, and lack of transportation to health care (*Brunswick County CHA*, 2019). Of the ten top causes of death, seven are chronic diseases including cancer, heart disease, lung disease, stroke, Alzheimer's disease, diabetes, and kidney disease. Stroke is the fourth leading cause of death in Brunswick County with a rate

of 40.4 deaths per 100,000 people (*Brunswick County CHA*, 2019). Brunswick County has vulnerable populations, including 65.9% over the age of 60, 14.1% living in poverty, and 29% of adults are obese (*Brunswick County CHA*, 2019). These factors may contribute to the high rates of stroke in this area. Other contributing factors may include access to exercise opportunities, access to healthy food, education level, socioeconomic status, and substance misuse.

In Pender County, 15.2% of residents do not have health insurance, 18.7% of the population lives in poverty, and 31% of the population is obese (*Pender County CHA*, 2018). Most of the leading causes of death in Pender County are chronic conditions including cancer, heart disease, stroke, chronic lower respiratory disease, and diabetes. Stroke is the third leading cause of death with a rate of 53.3 per 100,000 people (*Pender County CHA*, 2018). The community identified lack of health insurance, access to healthcare, access to exercise opportunities, substance misuse, social and economic factors, service availability, and food insecurity as barriers to healthcare and factors that contribute to the overall health of the population and to the high stroke rates.

As previously discussed, the risk of having a stroke varies with race and ethnicity with the risk nearly twice as high for African Americans as it is for Whites (*Stroke facts*, 2022). In Brunswick County, 82.1% of the population is White and 10% is African American (*Brunswick CHA*, 2019). In Pender County, 76.6% of the population is White and 16.4% of the population is African American (*Pender County CHA*, 2018). Therefore, the high rate of stroke may be disproportionately impacting segments of the population.

Purpose

In order to better understand the disparities in Brunswick and Pender counties, a survey and focus groups were conducted in faith communities. The purpose of the survey was to understand community knowledge of stroke risk factors, stroke signs and symptoms, and stroke prevention measures. The focus groups targeted faith community members who had some type of experience with stroke to better understand their experiences with stroke, the impact stroke had on their lives or the life of loved ones, and what services could be offered for prevention and post stroke care. The results of this mixed-methods study will be used to inform Novant on tailoring stroke health education and identify and address disparities in access to and quality of care for populations at highest risk for stroke events. Novant's Paul Coverdell Stroke Grant project will support implementing a team-based approach to enhance quality of care for those at highest risk for stroke events and for stroke patients across systems of care and to link community resources and clinical services to provide support for stroke care.

Methods

Selected faith communities in Pender and Brunswick counties were asked to participate in a survey and focus group to help learn about the community's experience with stroke and understanding of stroke related health care. These communities were identified based on the

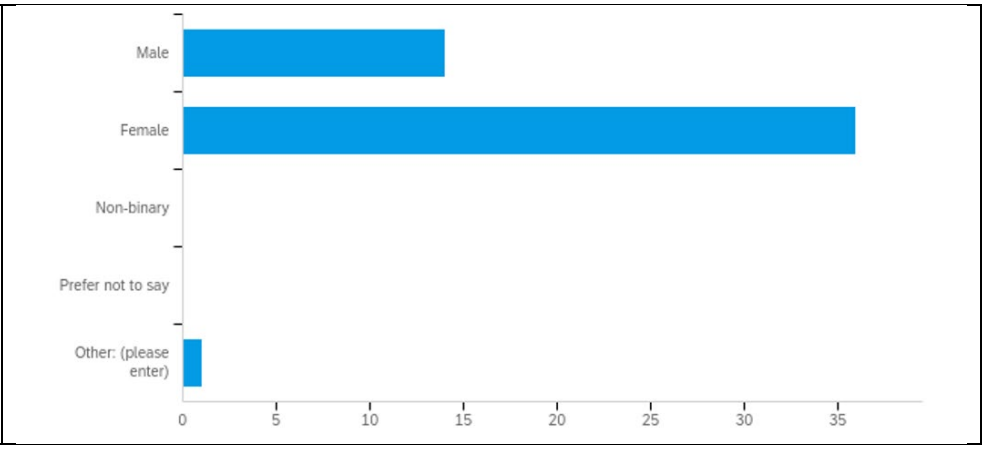
stroke risk map created by Cape Fear Collective as being areas at higher risk for stroke in North Carolina and the faith communities were selected based on Novant's existing relationships. The survey was distributed at four faith communities as both a paper version and an electronic version: *church names*. The paper version was delivered to the faith communities along with flyers (see appendix 1) containing a QR code to access the electronic version. Three hundred and fifty paper surveys were distributed across the four faith communities and were placed in a location accessible to the whole community along with the associated flyer. They were left with the faith community representative to distribute over 2-3 weeks. Of the total 350 surveys distributed, only 54 were completed and returned.

Focus groups were conducted in person at three of the faith communities; one in Pender County and two in Brunswick County. Fifteen people participated in the *a.x church* focus group, 13 people participated in the *b.x church* focus group, and 12 people participated in the *c.x church* focus group. Participants were required to have some type of experience with or connection to stroke and were recruited by the faith community representative. Each focus group lasted about an hour. The questions were broken up into three sections: barriers, impact, and solutions. Introductions were done in a round robin manner, but the rest of the questions were voluntary. Participants were not required to answer every question but encouraged to contribute as much or as little as they wanted to. The sessions were recorded, transcribed, and notes were taken in order to analyze and identify commonalities and themes.

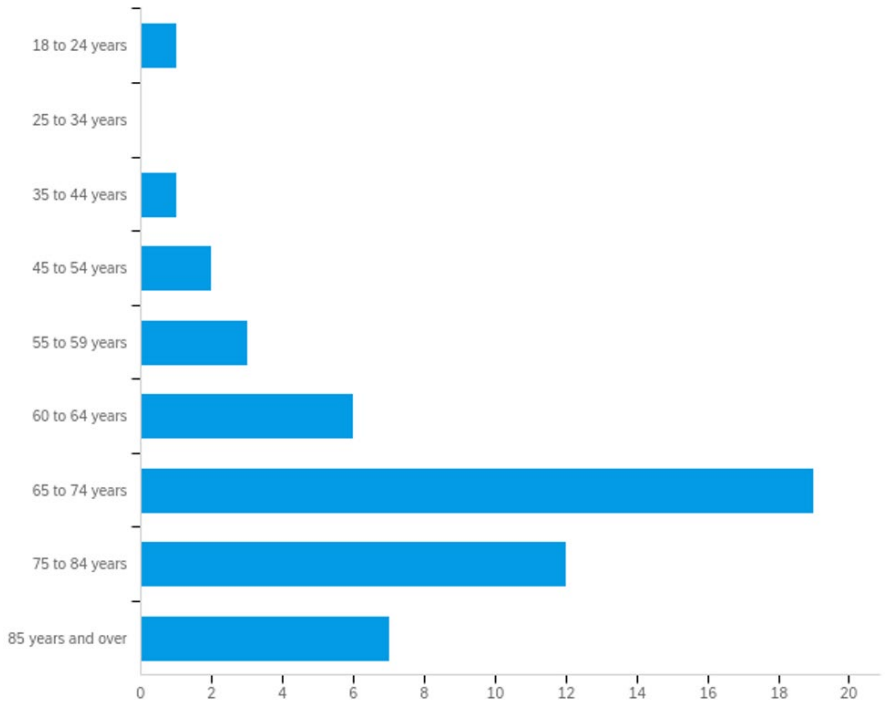
Results and Analysis

Survey Results

Survey Demographics (n=54)

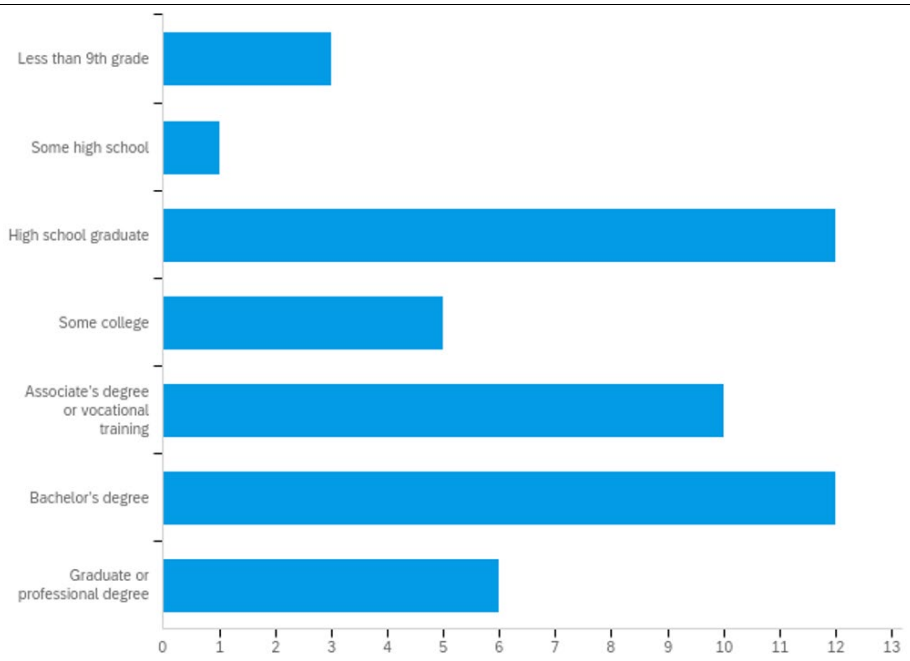
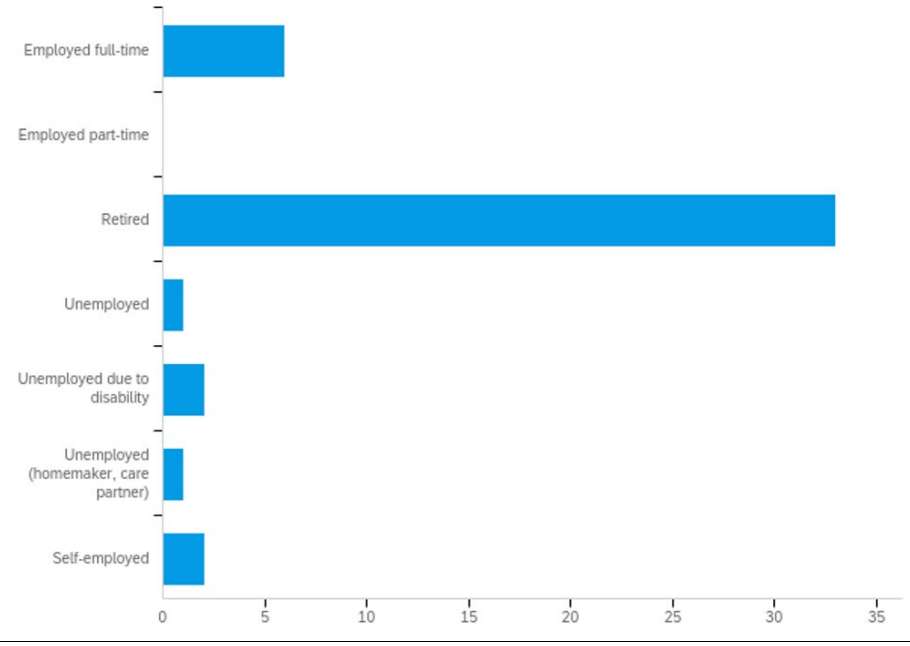
Gender	

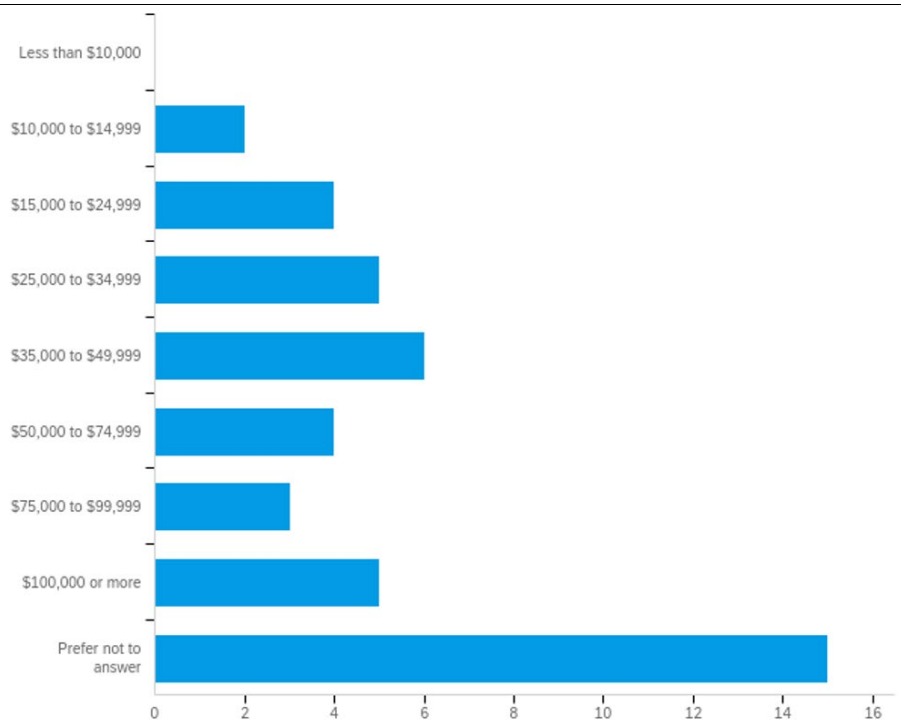
Age



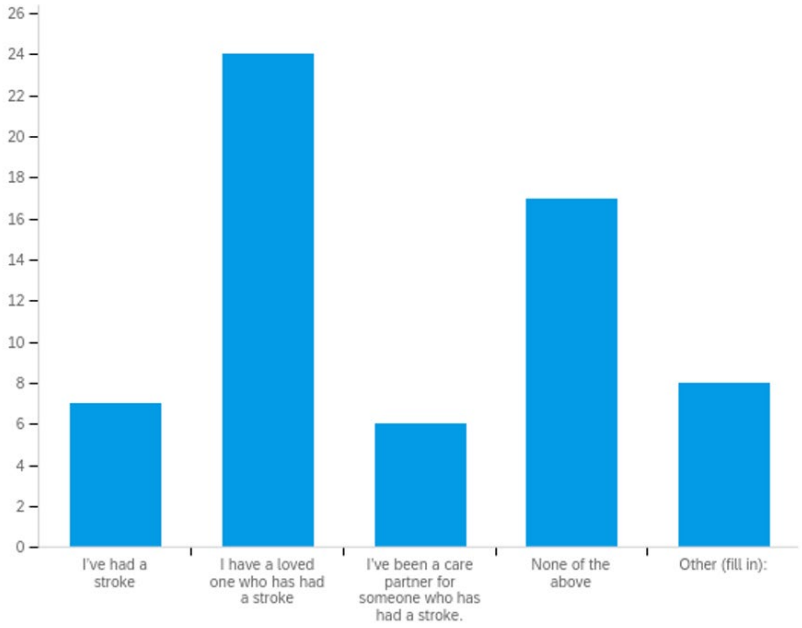
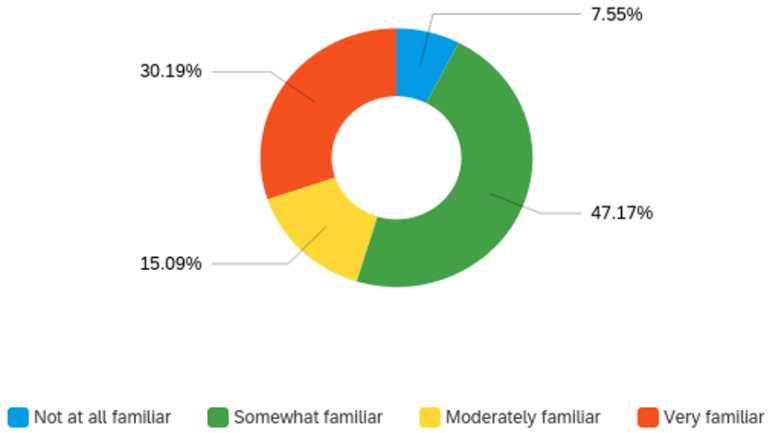
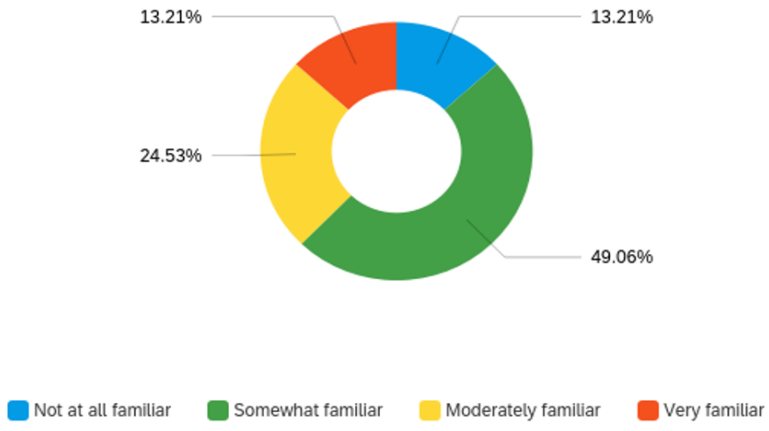
Race/Ethnicity

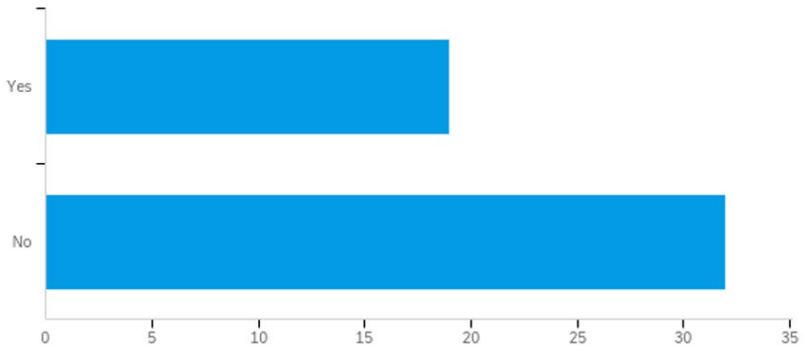
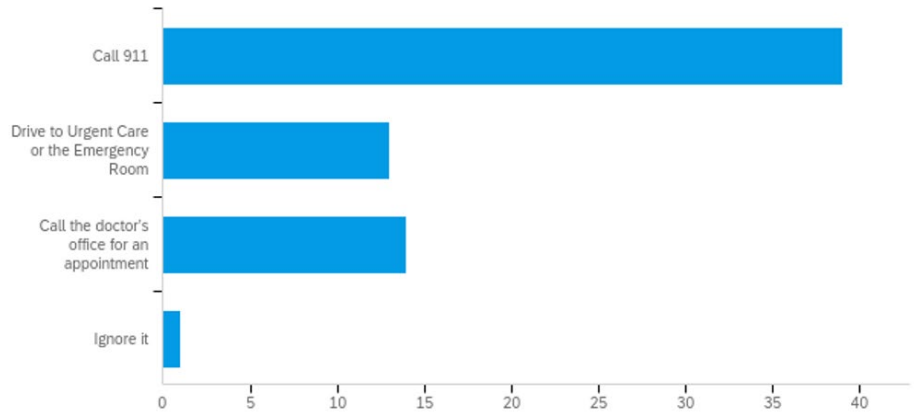
White or Caucasian	18
Other race not listed (please specify)	1
Hispanic or Latino	0
Black or African American	34
Asian	0
American Indian or Native American	0

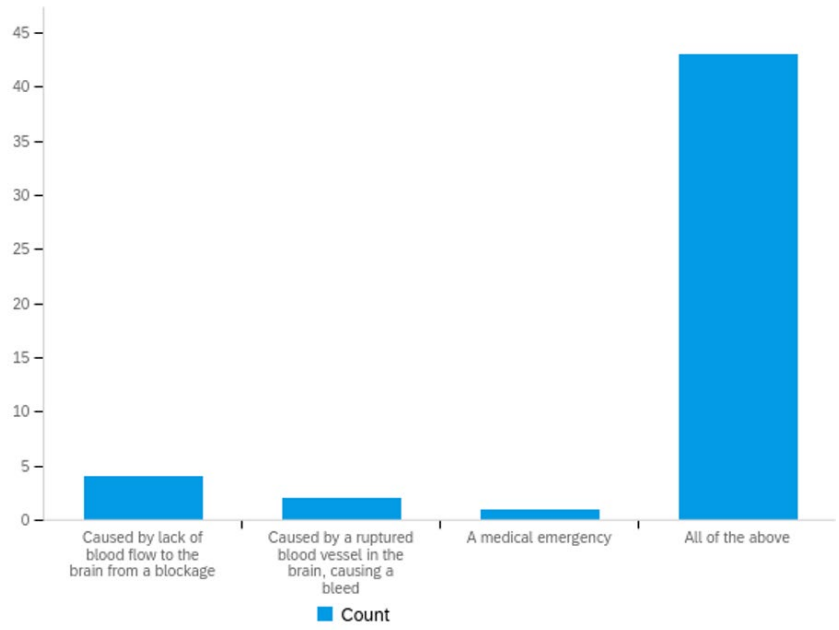
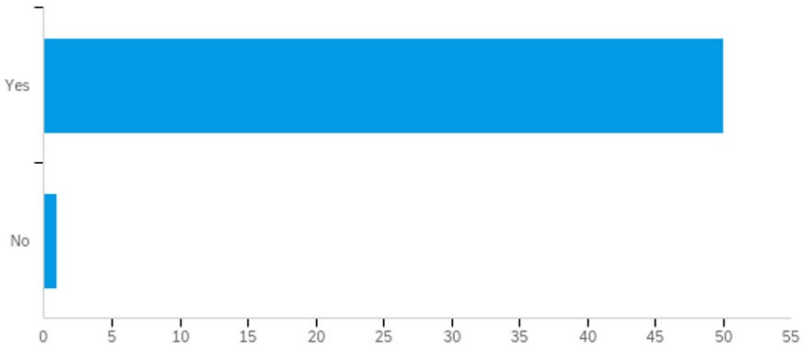
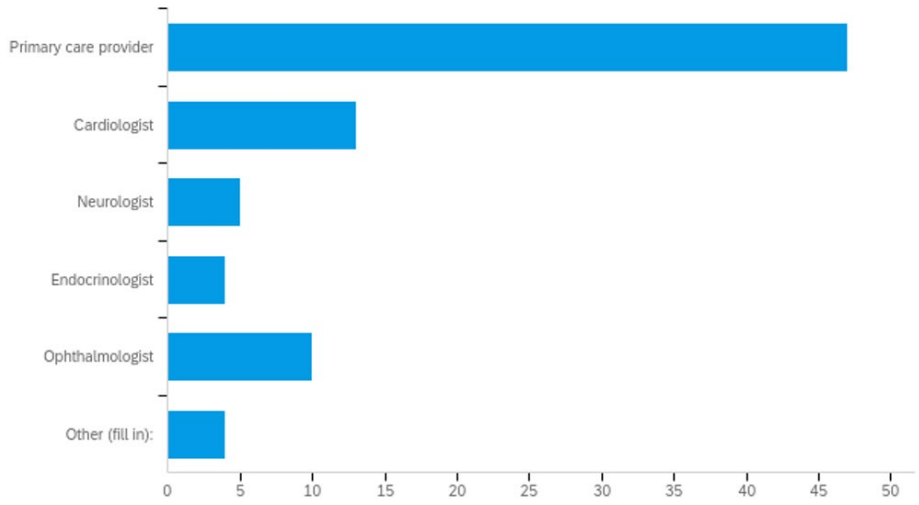
Highest Level of Education	
Employment Status	

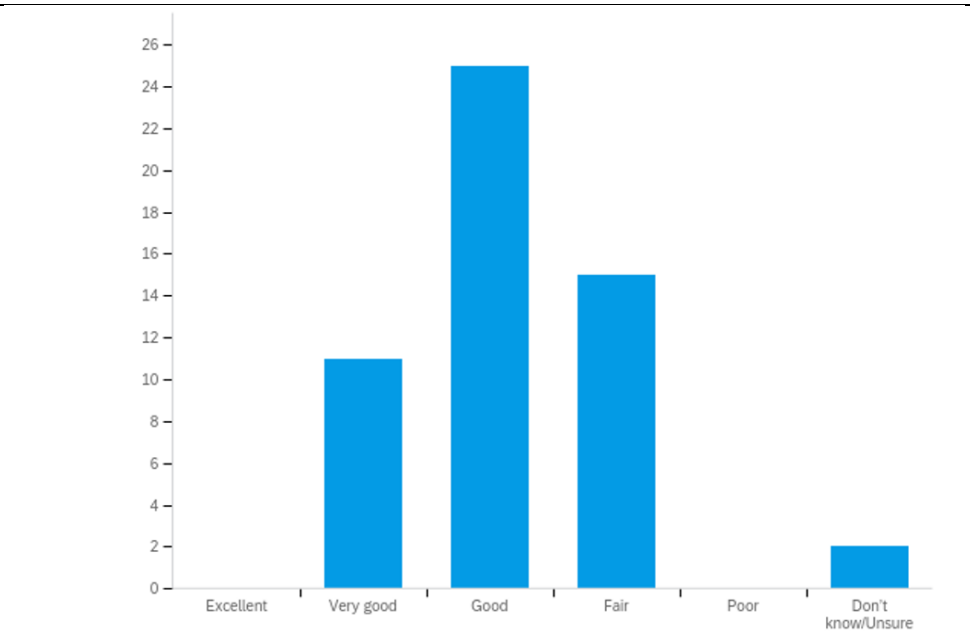
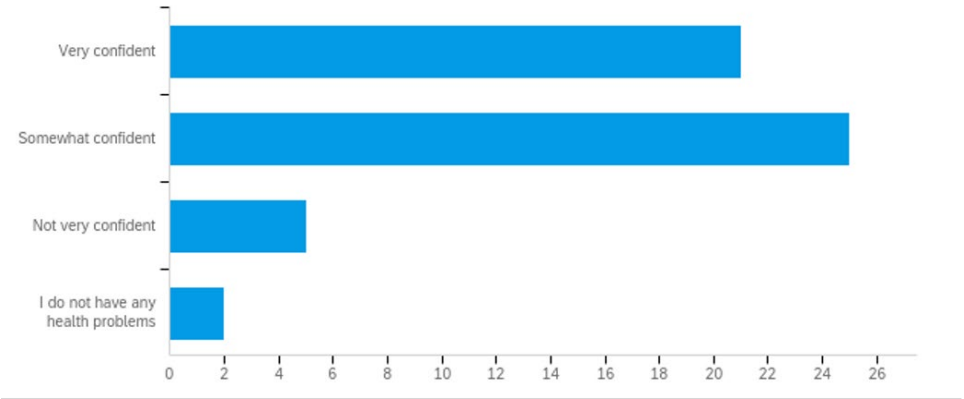
Yearly Household Income	
Marital Status	Never married/single: 5 Married: 26 Unmarried partner: 0 Divorced: 5 Widowed: 9 Separated: 0 Other (please specify): 0

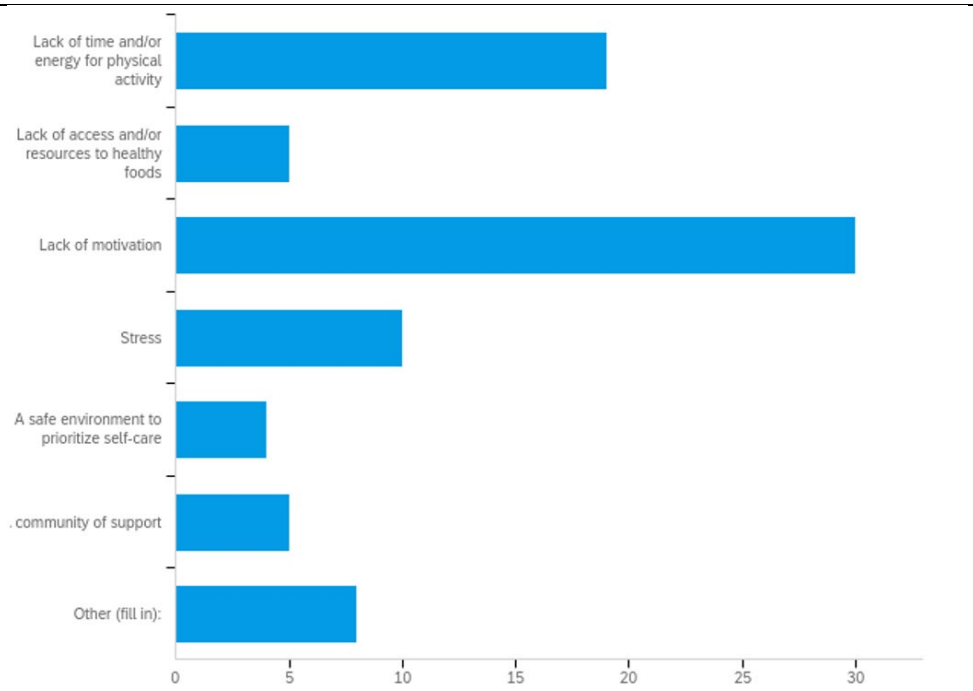
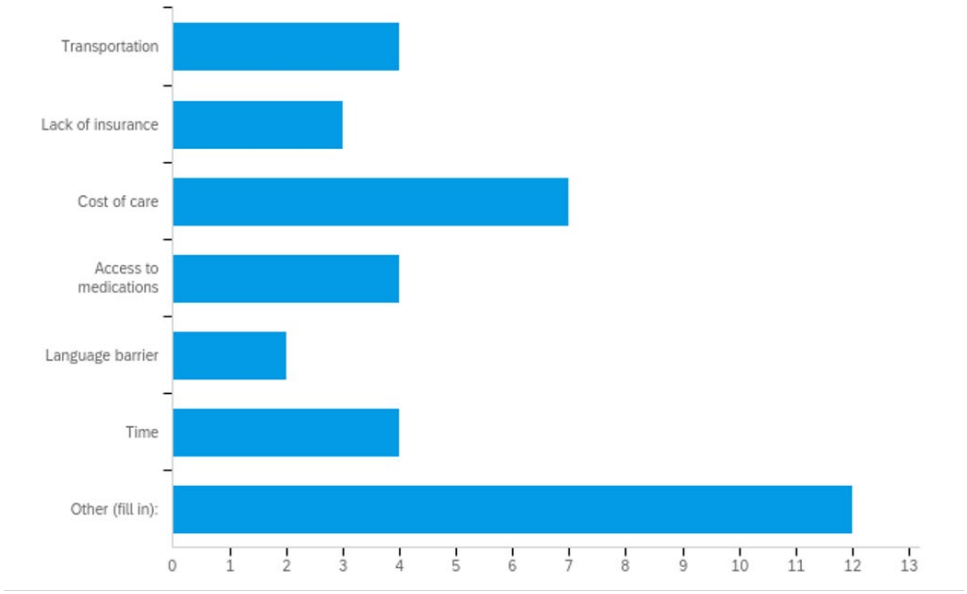
***Note**: Not all survey participants responded to all demographic questions, nor did they specify other where listed.

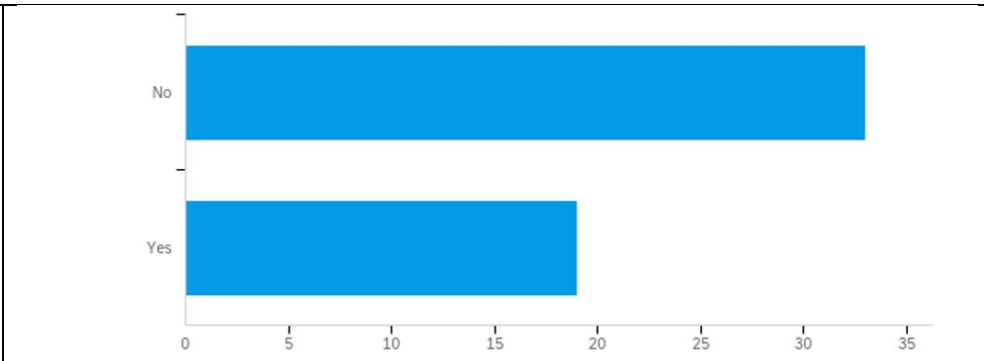
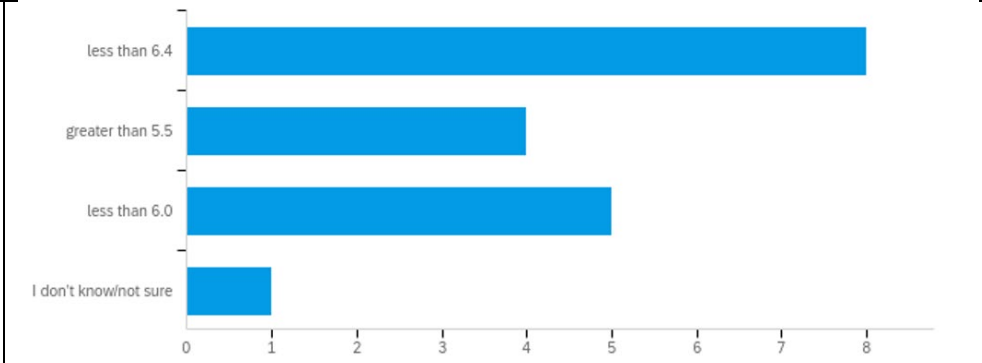
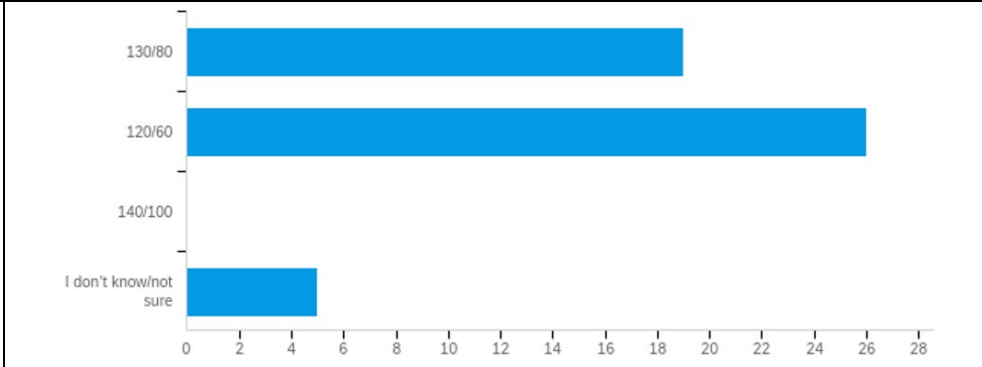
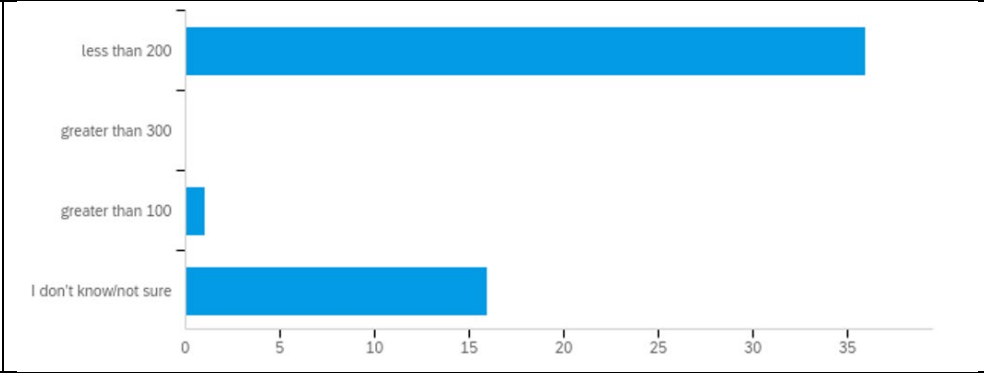
Experience with stroke	
Familiarity with the term "stroke"	
Familiarity with stroke risk factors	

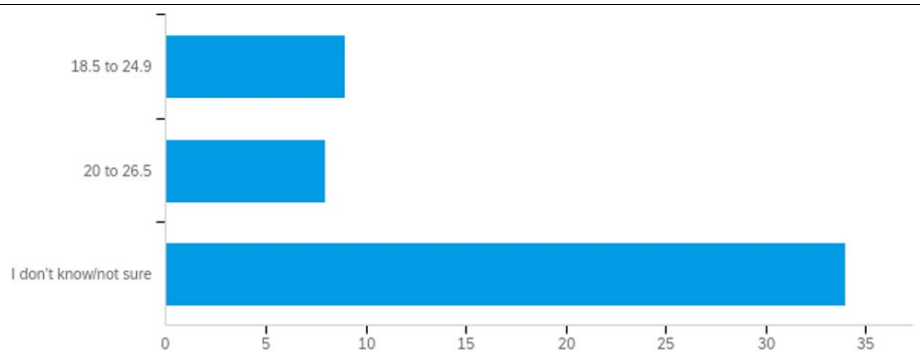
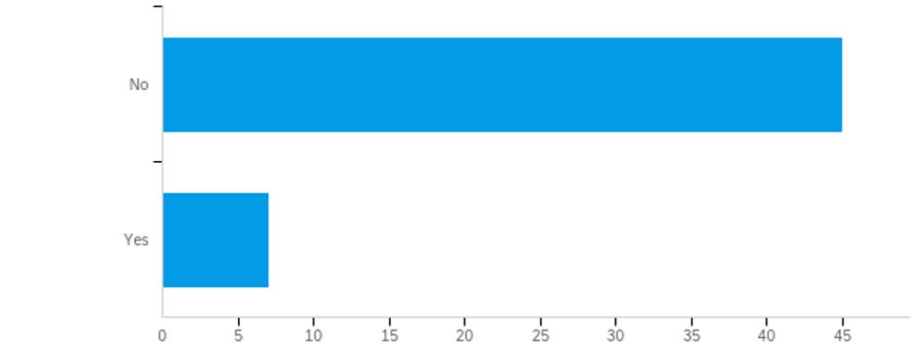
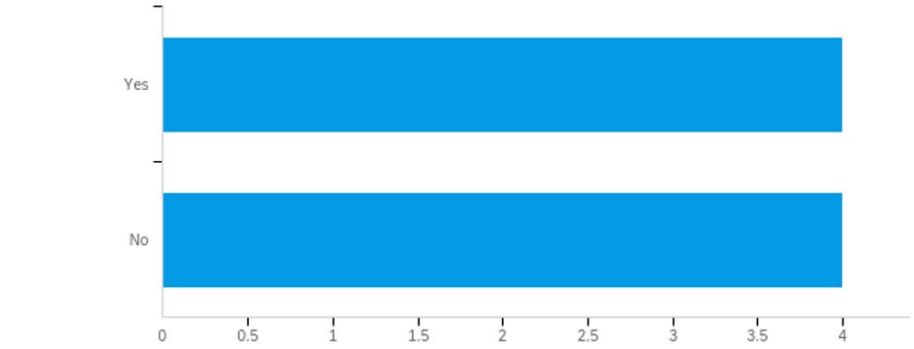
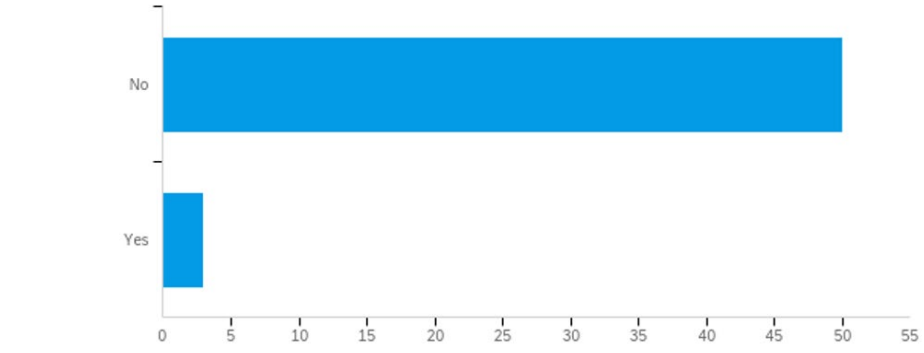
If known, list stroke risk factors:	 *This word cloud was created using the risk factors listed in participant responses, where the most repeated risk factors are bigger and bolder, and the less repeated risk factors are smaller and lighter.
Have you heard of the term BE FAST to spot a stroke?	
If you experience mild stroke symptoms or symptoms that go away, which of the following would you do? (Select all that apply)	

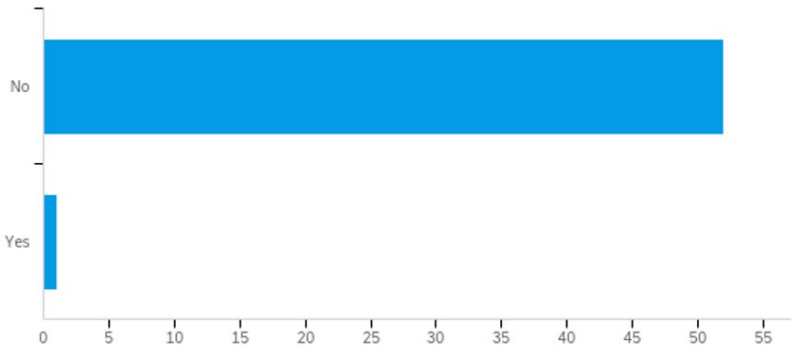
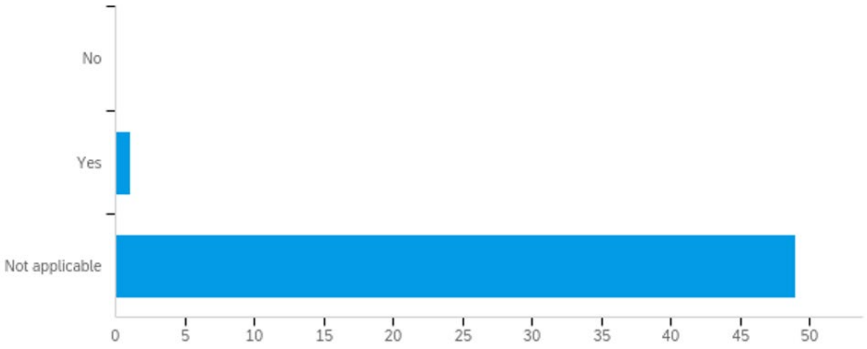
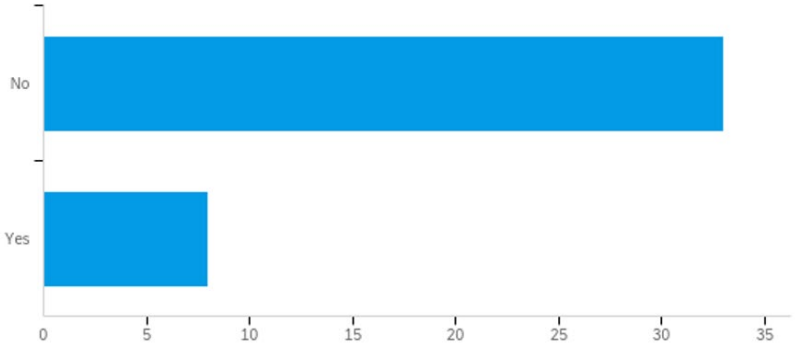
A stroke is:	
Do you have a healthcare provider that you visit at least once a year?	
If yes, what kind of provider? (Select all that apply)	 **Other:** Stroke specialist, Rheumatologist, Oncologist, Dermatologist

How would you rate your health?	
How confident are you that you can manage most of your current health problems?	

What are your barriers to living a healthy lifestyle (healthy diet, exercise, mental health)? (Select all that apply)	 **Other:** self-motivation, safe place to walk, no barriers, no barriers, none, medical issues, self-control
What are your barriers to accessing medical care? (Select all that apply)	 **Other:** no barriers, no barriers, n/a, n/a, none, n/a, none, none of the above, no barriers

Are you diabetic?	
If yes, what is your recommended A1C value?	
What is the recommended value for healthy blood pressure?	
What is the recommended value for cholesterol?	

What is the recommended value for Body Mass Index (BMI) for an adult?	
Do you have sleep apnea?	
If yes, do you use a CPAP?	
Do you currently use traditional tobacco products such as cigarettes, cigars, chewing tobacco, etc.?	

Do you currently use smokeless tobacco products such as e-cigarettes, vape pens, or juuls?	
Are you ready to quit using tobacco products?	
Are you aware of smoking cessation resources in your area?	

***Note:** Not all participants responded to all survey questions.

Survey Analysis

Most people that participated in the survey had some experience with stroke, whether they had a stroke, had a loved one that had a stroke, or were a care partner for someone that had a stroke. Seventeen people reported no experience and 8 reported “other” but did not fill in an associated response. Thirty-four of the participants were Black or African American, 18 were White or Caucasian, and one person reported “other” but did not specify. The survey results showed that the majority are familiar with the term stroke and are familiar with stroke risk factors; only 7.55% were not at all familiar with stroke and 13.21% were not at all familiar with stroke risk factors. 30.19% were very familiar with the term stroke, 15.09% were moderately familiar, and 47.17% were somewhat familiar. Only 13.21% were very familiar with stroke risk factors, 24.53% were moderately familiar, and 49.06% were somewhat familiar. Some of the

risk factors that participants listed were high blood pressure, diet, smoking, diabetes, cholesterol, obesity, family history, substance abuse, lack of exercise, overweight, heart condition, age, lifestyle, genetics, and medications. Nineteen people had heard of the term BE FAST to spot a stroke, but no one could list what the acronym stands for. Fifty people have a healthcare provider that they visit at least once a year: 47 have a primary care provider, 13 have a cardiologist, five have a neurologist, four have an endocrinologist, 10 have an ophthalmologist, one has a stroke specialist, one has a rheumatologist, one has an oncologist, and one has a dermatologist. No one rated their health as excellent, 11 rated their health very good, 25 rated good, 15 rated fair, and two rated don't know/unsure. Twenty-one people are confident that they can manage most of their current health problems, 25 are somewhat confident, five are not very confident, and two said they don't have any health problems. When asked about barriers to living a healthy lifestyle, 19 said lack of time and/or energy for physical activity is a barrier, five said lack of access and/or resources to healthy foods, 30 said lack of motivation, 10 said stress, four said a safe environment to prioritize self-care, five said community support, and six said other reasons including no barriers, self-motivation, a safe place to walk, medical issues, and self-control. When asked about barriers to accessing medical care, four said transportation is a barrier, three said lack of insurance, seven said cost of care, four said access to medications, two said language barriers, four said time, and 12 said other, listing no barriers or not applicable. Of the 19 people that are diabetic, only eight knew the recommended A1C value. Nineteen people knew the recommended value for healthy blood pressure. Thirty-six people knew the recommended value for cholesterol. Only nine people knew the recommended value for Body Mass Index (BMI) for an adult. Of the seven people that have sleep apnea, four use a CPAP machine. Fifty people said they do not use traditional tobacco products or smokeless tobacco products; three people use traditional tobacco products, and one uses smokeless tobacco products. One participant said they are ready to quit using tobacco products and 49 reported not applicable. Eight respondents are aware of smoking cessation resources in the area and 33 are not aware.

Focus Group Results

Focus Group Demographics

Faith Community	***A.x church***	***B.x church***	***C.x church***
Number of Participants	15	13	12
Race	15 African American	13 African American	12 White or Caucasian
Gender	• 3 Male • 12 Female	• 3 Male • 10 Female	• 3 Male • 9 Female

Faith Community	*A.x church*	*B.x church*	*C.x church*
Age	35 to 44 years 1 55 to 59 years 2 60 to 64 years 1 65 to 74 years 6 75 to 84 years 3 85 years and over 1	35 to 44 years 2 45 to 54 years 2 55 to 59 years 1 60 to 64 years 3 65 to 74 years 2 75 to 84 years 1	65 to 74 years 3 75 to 84 years 5 85 years and over 2
Highest Level of Education	• 2 High school • 4 Some college • 3 Associate degree or vocational training • 3 Bachelor's degree • 2 Graduate or professional degree	• 1 High school • 3 Some college • 3 Associate degree or vocational training • 4 Bachelor's degree	• 3 High school • 2 Some college • 1 Associate degree or vocational training • 4 Bachelor's degree • 1 Graduate or professional degree
Employment Status	• 1 Employed full-time • 11 Retired • 1 Self-employed • 1 Unemployed due to disability	• 5 Employed full-time • 2 Employed part-time • 5 Retired • 1 Self-employed	• 10 Retired • 1 Self-employed
Yearly Household Income	$25,000 to $34,999 1 $35,000 to $49,999 1 $50,000 to $74,999 3 $75,000 to $99,999 2 $100,000 or more 2 Prefer not to answer 5	$15,000 to $24,999 1 $25,000 to $34,999 1 $35,000 to $49,999 5 $50,000 to $74,999 1 $75,000 to $99,999 1 $100,000 or more 1 Prefer not to answer 3	$10,000 to $14,999 1 $25,000 to $34,999 1 $35,000 to $49,999 2 $50,000 to $74,999 2 Prefer not to answer 3
Experience with Stroke	• 2 have had a stroke • 10 have a loved one that had a stroke • 4 have been a care partner for someone that had a stroke • 1 had no experience with stroke	• 3 have had a stroke • 9 have a loved one that had a stroke • 3 have been a care partner for someone that had a stroke • 1 had no experience with stroke	• 6 have had a stroke • 5 have a loved one that had a stroke • 2 have been a care partner for someone that had a stroke • 2 had no experience with stroke

***Note:** Not all participants responded to all of the demographic questions.

Section 1: Barriers

Faith Community	Themes and Sub-themes	Quotes
A.x church	**Lifestyle**	**Lifestyle**

Faith Community	Themes and Sub-themes	Quotes
	• Diet, culture, tradition, race • Medical issues and genetics • Lack of motivation to exercise **Access** • Limited access to healthcare • Transportation issues • Lack of insurance **Advocacy** • Lack of health education • Mistrust of medicine and doctors • Lack of representation of people of color	"We love soul food… and that's truly an issue and concern." "We live in a community that are really good cooks… and we celebrate a lot… we eat really good stuff, but it's fried." "Tradition is a barrier, trying to control what we eat." "We seem to have a lot more obesity issues and just overall genetics." "It's a cultural, racial concern." **Access** "You need transportation and a place to stay… so folk turn it [care] down because it's not in the neighborhood and you have to drive back and forth." "So [access to] care in this area has been a real problem." "That's gonna deter somebody if they don't have the right insurance from going to the doctor until it's really bad." **Advocacy** "So often we are not educated about some of this information." "There's a mistrust [related to doctors]." "We have to really learn to monitor ourselves… we are our own advocates." "Not enough people of color in research trials."
B.x church	**Lifestyle** • Lack of motivation and time • Diet and lack of access to healthy foods • Income • Medical issues, genetics, and impacts of COVID-19 **Access** • Access to and understanding of technology • Limited access to healthcare • Transportation issues • Lack of access to facilities	**Lifestyle** "Of course, your income, financial strains are a huge barrier… and is a stressor." "We have to watch what we eat, especially all the greasy food and a lot of fried food." "A lot of low-income barriers in this area that prevents people to be able to buy the healthy foods and stuff that they need to provide themselves with a better diet." **Access** "There's nothing local [facilities]… you have to travel."

Faith Community	Themes and Sub-themes	Quotes
	• Lack of resources and technology in rural hospitals • Lack of insurance **Advocacy** • Lack of knowledge and resources • Lack of support, especially for caregivers • Feelings of not being heard • Medical mistrust related to race and doctors	"The transportation is an issue… a lot of the elderly rely on the younger crowd and the younger crowd has to work… another barrier is time constraints." "Even if they have Medicaid transportation… that's a struggle with the communication." "A lot of people have forgotten that not everyone is computer savvy or even has a high-tech phone or WiFi accessibility cause we're in a rural area." "Transportation, communication, and the ability to have WiFi in all areas to access those." "There's a database that they communicate and pull up charts from different areas and sometimes in the rural areas they don't have access to that technology." **Advocacy** "The lack of resources, people to get there to do what you need to get done… that support system is important."
C.x church	**Lifestyle** • Stress • Other medical issues **Access** • Limited access to healthcare • Distance to facilities • Quality of care	**Lifestyle** "I think stress is one [barrier]." "I think the greatest issue with me is my frustration and that aggravates the situation." "There are things that lead up to these major things... and maybe nothing can be done, but at least you know what is happening." **Access** "I would recommend if you think that you're having a stroke, go to Wilmington, do not go into Supply." "I had to drive him there and it took me probably 45 minutes."

Section 2: Impact

Faith Community	Themes and Sub-themes	Quotes
A.x church	**Mental Health** • Lack of support for caregivers • Feelings of being overwhelmed **Access** • Necessary care is too far away • People of color not receiving equal care **Advocacy** • Speak to multiple doctors in order to get the necessary help • Feelings of not being heard • Did not feel supported after leaving the hospital	**Mental Health** "Afterwards, it was the mental part." "Being a caregiver, it gets a little overwhelming at times." "If you don't have family to give you support, the caregiver finds themselves totally alone." "Struggle is not just about the person who has it [a stroke], it's about all the people… and that can mentally tear down a person." **Access** "Studies show that people of color have issues with getting equal care to other people." "We should get equal care." **Advocacy** "There's a trend that you have to see multiple people before you get an answer." "Somebody has to be the voice." "Shouldn't have to be that way to get the service you need." "Prior to having a stroke, they [doctors] could have done some things different but they just kind of overlooked it and said, 'well you'll be alright'." "It was kinda like you was on your own."
B.x church	**Mental Health** • Caregiver burnout • Feeling like a burden to caregivers **Access** • Being misdiagnosed • Waiting to seek care **Advocacy** • Feelings of not being heard • Medical mistrust related to race and doctors	**Mental Health** "You have caregiver burnout and sometimes the person that has experienced a stroke feels that tension or tries to do as much as they can to not be a burden on their caregiver." "We look at the patients but we don't take into consideration the person that is giving the care… there needs to be more out there for caregivers, more access and things shouldn't be so complicated." **Access**

Faith Community	Themes and Sub-themes	Quotes
		"Whether it's financial, no insurance, just don't like doctors- white syndrome- they wait until they are at death's door before they come in." "It is hard for African Americans to admit they need help… we've always been taught to dry it up and handle it… but mental health is real and it needs to be addressed." **Advocacy** "I had a stroke and the doctor told me it was heartburn and sent me home… had to go back when things weren't right." "Also, they don't feel the doctor hears them… they say 'oh it's in your head or whatever'." "They don't feel like they are being heard and at the same time they've given up their copay, money that could have been used for something else."
C.x church	**Access** • Misdiagnosis • Good experiences **Advocacy** • Impact of therapy	**Access** "Novant diagnosed me as being... dehydrated... and they sent me home. My husband took me the next morning to Wilmington... they did an MRI and I had a bleed in my right parietal lobe. I was definitely misdiagnosed." "I would never go to Novant Hospital... I went to New Hanover and got superb care." "They didn't even put down on my paperwork that I had a TIA." "I would say nothing but thumbs up... they were the greatest care." **Advocacy** "I would say to anyone therapy, therapy, therapy... I am an advocate for therapy."

Section 3: Solutions

Faith Community	Themes and Sub-themes	Quotes
A.x church	**Health Education**	**Health Education**

Faith Community	Themes and Sub-themes	Quotes
	• Technology education • Education about diet, health, and medicine **Lifestyle** • Lifestyle changes- education and exercise • Motivation **Advocacy** • Sensitivity training for doctors to ensure equal care • Knowledge and action • Sharing information **Access** • Rehab center • Walk-in clinic	"Programs to educate people, to let them know what signs and symptoms to look for." "We gotta get with technology because the doctors are moving to technology." "Not only educating about the risk factors but educating about the benefits of the resources afterwards." **Lifestyle** "We gotta do better." "You can set up some walking groups." "We need a key to motivate people to get involved." **Advocacy** "We need the knowledge so that you can become a strong advocate for yourself." "Sharing of information is so important… you learn so much from others." **Access** "I think there should be access to healthcare for all people where they are, regardless of insurance." "We need to continue to get more doctors in the area."
B.x church	**Health Education** • Diet and nutrition classes • Education about medications, insurance, and coverage **Lifestyle** • Cooking classes • Fitness classes • Motivation **Advocacy** • Knowledge to advocate for yourself • Social/support groups **Access** • Community/wellness center • Pharmacy programs • Food pantry	**Health Education** "Some people aren't taking the medicines right and then they go to the doctor and the doctors says they are non-compliant, but maybe it is financial, not understanding, can't read." "If we could get someone to educate on insurance, cause it is hard." "Know medical terms… put it in everyday terms so they can understand… you have to speak on their terms." **Lifestyle** "It has to be a holistic situation." **Advocacy** "People gotta learn to be an advocate for themselves." "Definitely have like social groups, anything that would help to talk about things and have access to those."

Faith Community	Themes and Sub-themes	Quotes
		Access "If you are going to offer classes or programs or groups, meet them where they are instead of having them try to get to where you are because you are more mobile than they are." "I think we need a wellness center that encapsulates everything from nutrition to medication… because there should be resources for the people here." "We need a wellness center… doctors can come and give exams… it has to be a holistic situation."
C.x church	**Health Education** • Signs and symptoms • Technology education **Lifestyle** • Diet and exercise • Holistic approach **Advocacy** • Support groups • Sharing knowledge/information **Access** • Better quality care	**Health Education** "Try to make people aware, so they know how to help a person... education about what to look for." "I think knowing the signs is so important." "That is one good thing about Novant, MyChart... they can pull it up and find out everything about you. But it can be confusing to use." **Lifestyle** "You just take care of yourself and do the best that you can by eating healthy and trying to exercise and do things to take good care of you." "I think with stress being a major contributor to stroke... some kind of holistic relaxation clinic that they could refer patients to... have an appointment and have relaxation therapy, that might help." **Advocacy** "I think having a support group helps." "You will learn more from listening to what people say and from talking to people like this." "I think having something in our community... just have meetings and invite people." **Access**

Faith Community	Themes and Sub-themes	Quotes
		"Better quality in Brunswick County." "Maybe something like they have in New Hanover, so these local people don't have to go to Wilmington, that's what we need." "The more local you can have it, where you have people that sort of know each other."

Focus Group Analysis

Almost everyone that participated in the focus groups had some experience with stroke, whether they had a stroke, had a loved one that had a stroke, or were a care partner for someone that had a stroke. Twenty-eight of the participants were Black or African American and 12 were White or Caucasian. There were quite a few common themes across all focus groups, including: lifestyle, access, advocacy, mental health, and health education.

Section 1: Barriers

Participants were asked about some barriers they face to living a healthy lifestyle and accessing health care, especially surrounding stroke care. The common themes discussed in the focus groups were lifestyle, access, and advocacy. The sub-themes that were discussed during the focus group at *A.x church* were diet, culture, tradition, race, medical issues, genetics, lack of motivation to exercise, limited access to healthcare, transportation issues, lack of insurance, lack of health education and mistrust of medicine and doctors. The sub-themes that were discussed during the focus group at *B.x church* were lack of motivation and time, diet and lack of access to healthy foods, income, medical issues, genetics, impacts of COVID-19, access to and understanding of technology, limited access to healthcare, transportation issues, lack of access to facilities, lack of resources and technology in rural hospitals, lack of insurance, lack of knowledge and resources, lack of support- especially for caregivers, feelings of not being heard, and medical mistrust related to race and doctors. The sub-themes that were discussed during the focus group at *C.x church* were stress, other medical issues, limited access to healthcare, distance to facilities, and quality of care.

Section 2: Impact

Participants were asked about the impact stroke had on their daily life and their experience with stroke care. The common themes discussed during the focus groups were mental health, access, and advocacy. The sub-themes that were discussed during the focus group at *A.x church* were lack of support for caregivers, feelings of being overwhelmed, necessary care is too far away, people of color not receiving equal care, the burden of having to speak to multiple doctors to get the necessary help, feelings of not being heard, and did not feel supported after

leaving the hospital. The sub-themes that were discussed during the focus group at *B.x church* were caregiver burnout, feeling like a burden to caregivers, being misdiagnosed, waiting to seek care, feelings of not being heard, and medical mistrust related to race and doctors. The sub-themes that were discussed during the focus group at *C.x church* were misdiagnoses, some good experiences, and the impact of therapy.

Section 3: Solutions

Participants were asked about solutions including programs or resources they would like to see related to stroke care and healthcare. They were also asked if they had unlimited resources, what would they like to see implemented in their community to make a positive impact when thinking about healthcare and preventative services. The common themes discussed during the focus groups were health education, lifestyle, access, and advocacy. The sub-themes that were discussed during the focus group at *A.x church* were technology education; education about diet, health, and medicine; lifestyle changes- education and exercise; motivation; sensitivity training for doctors to ensure equal care; knowledge and action; sharing information; community rehab center; and community walk-in clinic. The sub-themes that were discussed during the focus group at *B.x church* were diet and nutrition classes; education about medications, insurance, and coverage; cooking classes; fitness classes; motivation; knowledge to advocate for yourself; social and support groups; community/wellness center; pharmacy programs; and a food pantry. The sub-themes that were discussed during the focus group at *C.x church* were health education related to knowing the signs and symptoms of stroke, technology education, diet and exercise, holistic approaches, support groups, sharing knowledge/information, and access to better quality care.

Conclusion

In conclusion, there are several similarities and common themes related to stroke and stroke care across Brunswick and Pender counties, including lifestyle, access, advocacy, mental health, and health education. Stroke rates remain high in these areas, while preventative services and access to care remain limited. Many people reported the struggle to live a healthy lifestyle due to barriers and health inequities related to living in a rural area and even more specifically related to being a minority living in a rural area. Health education and resources are limited in these areas and many people feel that they do not know how to advocate for themselves and their families. The people in these communities feel like they are struggling to get the healthcare they need, and this takes a toll on their overall health, including mental health. As a result of the years of abuse and mistrust, many people feel that they cannot trust doctors and end up suffering instead of getting the care that they require. Participants discussed feelings of not being listened to by doctors and unequal care for people of color as barriers, as well.

Education, education, education was discussed repeatedly as one solution to positively impact the community's health. Many people feel they lack the knowledge to advocate for themselves

and live healthy lifestyles. It was also noted the importance of health education being catered to their culture. For example, providing healthier substitutions for common foods. Additionally, limited access to care and transportation were listed as barriers, and the solutions discussed were local community and/or wellness centers within the community for programs, classes, and wellness visits so that people can get the care they need in a place that they can more easily access it. Even a regularly scheduled pop-up clinic in the parking lot was noted as a useful resource. One participant stated that if we want successful programs, we must meet the people where they are to ease the burden of transportation issues. Also, meeting people where they are can help to build trust among communities and the medical field. Support groups and accessible resources for care partners and patients were also discussed as impactful solutions. Based on the feedback from the communities, health education will be incredibly impactful in these areas.

Limitations

One limitation is that the research was only conducted in faith communities in Brunswick and Pender counties, which may not be the most accurate representation of the entire population in the county. This is only a subset of the population. Also, people that attend these faith congregations may not live in the same area as the church. Often, people drive in to attend church. In this project, research was conducted based on the zip code of the church versus the zip code of the participants, thus some participants may not be representative of the data collection locations. Another limitation is the lag time of secondary data. At the time this report was created, the most recent Community Health Assessment for Brunswick County was published in 2019 and the Community Health Assessment for Pender County was published in 2018. Because of the time it takes to collect and publish research, this data may not be the most accurate at the time of the survey distribution and focus groups in the Fall of 2022 and Spring of 2023.

Another limitation, or more so barrier, was working in communities in which the data collectors did not have existing relationships or live in those areas. Thus, communication was challenging at times and not all faith community representatives replied in a timely manner. However, many of the church representatives had other personal and professional responsibilities in addition to their role in the faith community. Managing multiple schedules was also a challenge; however, we were able to work with the representatives to best meet their needs. The surveys were not as well received as we initially thought and thus, we did not receive as many responses as we hoped. One faith community reported the cleaning staff accidentally threw away the stack of completed surveys. Despite the limited response rate of the survey, the initial focus of the project was to conduct focus groups and the ones conducted were well attended and participants actively participated. A recommendation for the future may be to work more closely with the church representatives, training them to distribute the surveys, conduct the focus groups, and provide incentives for their time. Identifying existing community events to distribute the survey could also enhance response rates.

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Appendices

Appendix 1: Survey Flyer

CONTACT FOR MORE INFORMATION:

insert church contact
Leah Mayo, mayom@uncw.edu

Appendix 2: Focus Group Flyer

ROUNDTABLE DISCUSSION

We want to hear from you!

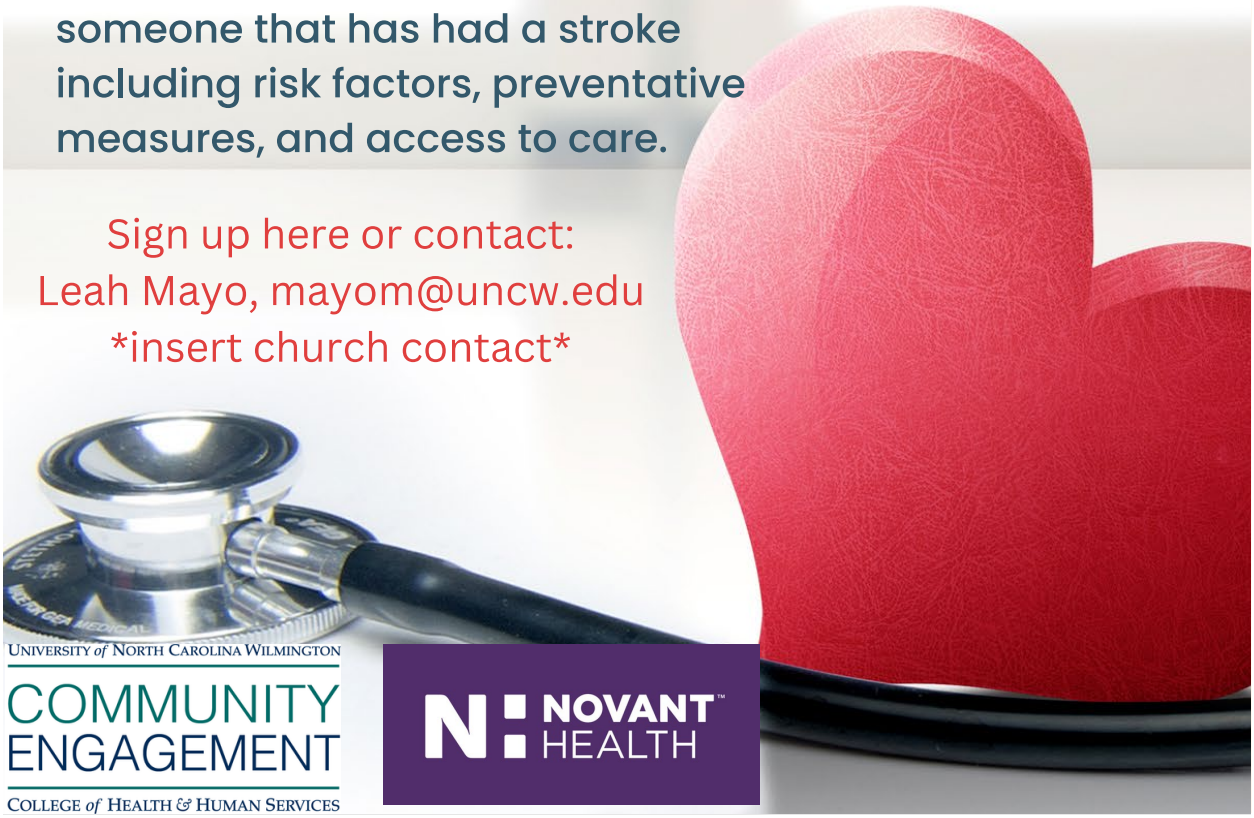
Join UNCW representatives for a 1 hour discussion about your stroke experience.

INSERT DATE

Insert Location

A discussion about your experience with stroke or as care partner to someone that has had a stroke including risk factors, preventative measures, and access to care.

Sign up here or contact:
Leah Mayo, mayom@uncw.edu
insert church contact



University of North Carolina Wilmington
COMMUNITY ENGAGEMENT
College of Health & Human Services

NOVANT HEALTH

Appendix 3: Survey

Novant Health Coverdell Stroke Program Survey

Supported by Novant Health & Facilitated by UNCW College of Health and Human Services

The purpose of this survey is to gain an understanding of the community's knowledge of stroke risk factors, stroke signs and symptoms, and stroke prevention measures, learn about community members' experiences with stroke and feelings towards stroke care, and identify disparities in access to care for populations at highest risk for stroke events. This is not meant to be a test, but used to gather information. The survey should take approximately 5-10 minutes and is anonymous, so the results will not be linked back to you. Participation is voluntary and you can stop participating at any time.

Section 1: General Stroke Awareness

1. How familiar are you with the term "stroke"?

- ☐ Not at all familiar
- ☐ Somewhat familiar
- ☐ Moderately familiar
- ☐ Very familiar

2. How familiar are you with stroke risk factors (conditions that put one at higher risk for stroke)?

- ☐ Not at all familiar
- ☐ Somewhat familiar
- ☐ Moderately familiar
- ☐ Very familiar

3. If known, list stroke risk factors:

_____

4. Have you heard the term BE FAST to spot a stroke?

- ☐ Yes
- ☐ No

If your answer is no, skip to question 6.

5. If yes to question 4, to the extent possible, complete the acronym BE FAST:

B _____

E _____

F _____

A _____

S _____

T _____

6. If you experience mild stroke symptoms or symptoms that go away, which of the following would you do? (Select all that apply)

- ☐ Call 911
- ☐ Drive to Urgent Care or the Emergency Room
- ☐ Call the doctor's office for an appointment
- ☐ Ignore it

7. A stroke is:

- ☐ Caused by lack of blood flow to the brain from a blockage
- ☐ Caused by a ruptured blood vessel in the brain, causing a bleed
- ☐ A medical emergency
- ☐ All of the above

Section 2. General Health & Wellness

8. Do you have a healthcare provider that you visit at least once a year?

- ☐ Yes
- ☐ No

If your answer is no, skip to question 10.

9. If yes, what kind of provider? (Select all that apply)

- ☐ Primary care provider
- ☐ Cardiologist
- ☐ Neurologist
- ☐ Endocrinologist
- ☐ Ophthalmologist
- ☐ Other (fill in): _____

10. How would you rate your health?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know/Unsure

11. How confident are you that you can manage most of your current health problems?

- ☐ Very confident
- ☐ Somewhat confident
- ☐ Not very confident
- ☐ I do not have any health problems

12. What are your barriers to living a healthy lifestyle (healthy diet, exercise, mental health)? (Select all that apply)

- ☐ Lack of time and/or energy for physical activity
- ☐ Lack of access and/or resources to healthy foods
- ☐ Lack of motivation
- ☐ Stress
- ☐ A safe environment to prioritize self-care
- ☐ A community of support
- ☐ Other (fill in): _____

13. What **are your barriers to accessing medical care? (Select all that apply)**

- ☐ Transportation
- ☐ Lack of insurance
- ☐ Cost of care
- ☐ Access to medications
- ☐ Language barrier

- ☐ Time
- ☐ Other (fill in): _____

14. Are you diabetic?

- ☐ No
- ☐ Yes

If your answer is no, skip to question 16.

15. If yes, what is your recommended A1C value?

- ☐ less than 6.4
- ☐ greater than 5.5
- ☐ less than 6.0
- ☐ I don't know/not sure

16. What is the recommended value for healthy blood pressure?

- ☐ 130/80
- ☐ 120/60
- ☐ 140/100
- ☐ I don't know/not sure

17. What is the recommended value for cholesterol?

- ☐ less than 200
- ☐ greater than 300
- ☐ greater than 100
- ☐ I don't know/not sure

18. What is the recommended value for Body Mass Index (BMI) for an adult?

- ☐ 18.5 to 24.9
- ☐ 20 to 26.5
- ☐ I don't know/not sure

19. Do you have sleep apnea?

- ☐ No
- ☐ Yes

If your answer is no, skip to question 21.

20. If yes, do you use a CPAP?

- ▢ Yes
- ▢ No

21. Do you currently use traditional tobacco products such as cigarettes, cigars, chewing tobacco, etc.?

- ▢ No
- ▢ Yes

22. Do you currently use smokeless tobacco products such as e-cigarettes, vape pens, or Juuls?

- ▢ No
- ▢ Yes

23. Are you ready to quit using tobacco products?

- ▢ No
- ▢ Yes
- ▢ Not applicable

24. Are you aware of smoking cessation resources in your area?

- ▢ No
- ▢ Yes

Section 3. Demographic Information

25. What is your experience with stroke? (Select all that apply)

- ☐ I've had a stroke
- ☐ I have a loved one who has had a stroke
- ☐ I've been a care partner for someone who has had a stroke.
- ☐ None of the above
- ☐ Other (fill in): _____

26. Which faith community are you a member of?

- ☐ Church
- ☐ Church
- ☐ church
- ☐ church
- ☐ None of these
- ☐ Other, please specify:_____

27. Enter your zip code: _____

28. What gender do you identify with?

- ☐ Male
- ☐ Female
- ☐ Non-binary
- ☐ Prefer not to say
- ☐ Other: (please enter) _____

29. What is your race/ethnicity?

- ☐ White or Caucasian
- ☐ Black or African American
- ☐ American Indian or Native American
- ☐ Hispanic or Latino
- ☐ Asian
- ☐ Other/race not listed (*please specify*)

  _____

30. What is your age?

- ☐ 18 to 24 years
- ☐ 25 to 34 years
- ☐ 35 to 44 years

- ▢ 45 to 54 years
- ▢ 55 to 59 years
- ▢ 60 to 64 years
- ▢ 65 to 74 years
- ▢ 75 to 84 years
- ▢ 85 years and over

31. What is your highest level of education?

- ▢ Less than 9th grade
- ▢ Some high school
- ▢ High school graduate
- ▢ Some college
- ▢ Associate's degree or vocational training
- ▢ Bachelor's degree
- ▢ Graduate or professional degree

32. What is your employment status?

- ▢ Employed full-time
- ▢ Employed part-time
- ▢ Retired
- ▢ Unemployed
- ▢ Unemployed due to disability
- ▢ Unemployed (homemaker, care partner)
- ▢ Self-employed

33. What is your yearly household income?

- ▢ Less than $10,000
- ▢ $10,000 to $14,999
- ▢ $15,000 to $24,999
- ▢ $25,000 to $34,999
- ▢ $35,000 to $49,999
- ▢ $50,000 to $74,999
- ▢ $75,000 to $99,999
- ▢ $100,000 or more
- ▢ Prefer not to answer

34. What is your marital status? (*select only one*)

- ☐ Never married/single
- ☐ Married
- ☐ Unmarried partner
- ☐ Divorced
- ☐ Widowed
- ☐ Separated
- ☐ Other (*please specify*) _____

Thank you for taking the time to complete our survey. When complete, please turn in to your church contact.

Appendix 4: Focus Group Protocol and Questions

Coverdell Stroke Roundtable Discussion Protocol

Consent & Participant Survey

Welcome people as they arrive and give them the consent form and pre-focus group survey to complete

- Participants must sign consent form prior to the start of the focus group.
- A short participant survey should be completed as participants arrive and while introducing the focus group.

Logistics

- Arrive at least 30 minutes early for set-up. Check with host to plan arrival time.
- Set-up chairs in a circle for participants and facilitators to sit within the circle.
- Check recorder to make sure it is charged.
- Place recorder in center of seating area and perform a test run.
    - Directions: https://helpguide.sony.net/icd/u56/v1/en2/index.html
- If available, set-up a table with food & incentive items (pass out incentives at end of discussion).
- Ground rules – verbally share and have posted on whiteboard or flip chart paper.
- Set up and use name tags or table tents.
- Decide who will be facilitator vs. recorder

Materials

What	Who
Consent Form (x12)	UNCW
Participant Survey (x12)	UNCW
Focus Groups Protocol (x2)	UNCW
Recorder Template (x2)	UNCW
Pens	UNCW
Recorder & Tablet	UNCW
Name tags & Table Tents/Markers	UNCW
Flip Chart & Markers	UNCW
If available, Refreshments	Novant
If available, Incentives	Novant
Laptop or clipboard/notepad with recorder sheet for notetaking	UNCW

Introduction

1. **Welcome**

   A. Introduction yourself and the recorder

   B. Ask someone to provide a prayer before we get into the purpose and questions.

   C. Explain the purpose and process. Allow participants to complete participant survey during introductions.

   Review the following:

   - Purpose:
     - Novant-NHRMC in partnership with UNCW is conducting focus groups within the communities of Brunswick and Pender counties as part of the Coverdell Stroke Grant. We want to learn from you, Brunswick and Pender County Residents, to gain an understanding of community knowledge of stroke risk factors, stroke signs and symptoms, and stroke prevention measures. We want to learn about your experiences with stroke and feelings towards stroke care and any disparities in access to care.
     - We will use this information to identify and address disparities in access to and quality of care for populations at highest risk for stroke events and develop plans to address these concerns. Your input is essential in developing strategies identified by community members.
     - The session will be recorded and {insert name} will be taking some notes, but all responses are confidential and anonymous, thus they will not be linked back to you or your name.
   - Process:
     - Last about an hour
     - Series of questions
     - Open dialogue -> this leads into ground rules
2. **Ground Rules:**

Review verbally and/or posted ground rules and ask participants if they have any rules to add. *Facilitators may add more to the list below as they see fit.*

a. Information provided is confidential and anonymous
b. No right or wrong responses – we just want to know what you think
c. Respect
    i. No interrupting or side conversations
    ii. Only one person to speak at a time
    iii. Respect opinions of others. Everyone's opinions are valid although you may have a different opinion
d. Everyone should participant
e. Silence cell phones
f. This session will be recorded but for internal use only. Nothing you say will be linked back to you in anyway.

3. **Turn on recorder**
4. **Ask if any questions before getting started**

Questions

Round robin:

1. Introduce yourself and share your relationship to stroke – for example, have you experienced a stroke, served as care partner for a loved one who had a stroke, or been told you are at risk of a stroke.

Section I: Barriers

2. There are many risk factors for stroke that overlap with other preventable conditions. What barriers or obstacles, if any, do you experience to living a healthy lifestyle (and in turn help prevent strokes)?
3. Based on your experiences of having a stroke or of a loved one having a stroke, what barriers or challenges did you face, if any, to receive care after the stroke?

Section II: Impact

4. How would you describe your stroke care experience? Let's break it down by timing, starting with....
    a. Before Stroke:
    b. During Stroke/Hospitalization:
    c. Once home:
5. Again, after experiencing a stroke, what impact did the stroke have on your daily life?
    a. Think physically, mentally, or socially

Section III: Solutions

6. What resources, program or education do you think would benefit people during stroke care?
    a. What else do you think could be helpful to aid in recovery?
7. What resources or programs do you think could benefit those at risk of having a stroke?
8. When thinking about healthcare and preventive services, if you had unlimited resources, what would you implement to make a positive impact on your community?

Thank you and Close

- Time and input are valued.
- Make a note that the final report will be provided to the church when completed.
- Ensure everyone has completed the consent form and participant survey.
- If provided by Novant, give incentives to participants
- Answer any lingering questions participants may have.
- Thank everyone for their time and input
- Stop recording

Clean Up

- Collect & organize all materials.
- Make sure recorder is turned off and session was recorded.
- Recorder to clean-up and type notes and send to UNCW.
- Return room to the original set-up.
- Thank host.