

OCTOBER 17, 2017



SUMMARY OF DIABETES SUPPORT FORUM

SPOTTSWOOD AME ZION CHURCH: APRIL 28, 2017

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NORTH CENTRAL REGIONAL MENTAL HEALTH BOARD

SUMMARY OF DIABETES SUPPORT FORUM

EVENT OVERVIEW

On Friday April 28, 2017 – The State Innovation Model Consumer Advisory Board (SIM CAB), in partnership with the North Central Regional Mental Health Board (NCRMHB) and Spottswood AME Zion Church, organized a diabetes forum primarily reaching the African American community. The forum offered opportunities for participants to share their experiences with diabetes, to learn from each other, and to identify healthcare resources in the community. Dr. Mark Schaefer from the Program Management Office (PMO) and Cindy Kozak from the Department of Public Health attended and played an active role in sharing resources and helping people identify how to best address their concerns with diabetes. SIM CAB member Steve Karp shared his personal struggles with diabetes and led a lively discussion about people’s individual experiences with the chronic illness. The event occurred at Spottswood AME Zion Church in New Britain, CT.



The diabetes forum engaged about 35 participants. Many attendees were members of the Spottswood congregation, with some guests and faith leaders from other local churches. Members of the PMO staff and SIM CAB were also present to listen in to the conversations.



The event kicked off with registration and a full complimentary church dinner. The cook personally struggled with diabetes, so she made a hearty and nutritious meal to accommodate diabetic issues and to nourish participants. The Chair of Spottswood’s Health Ministry recorded notes on a large flipchart. Reverend Jackie King, the pastor of Spottswood, shared her personal experiences battling diabetes and encouraged members of her congregation to be frank and open about their struggles. People shared their struggles with cost management for diabetic medications and medical supplies. The discussions also addressed the role of health

insurance in helping people manage their chronic issues with diabetes, how to identify whether you are pre-diabetic, and local programs that helped address diabetes issues. The diabetes forum wrapped up with a short discussion about next steps and ideas to continue an ongoing support group within the church.

KEY FINDINGS:

- To be determined by SIM CAB members

1) INFLUENCE SYSTEMS CHANGE:

- Offer coordinated care

2) PROMOTE PROVIDER-CONSUMER PARTNERSHIPS:

- Offer more local/accessible specialists or health coaches
- Additional screenings – health fairs or mandatory screenings

3) ENGAGE AND EMPOWER CONSUMERS:

- Have more support groups
- Key messages to share with consumers:
 - People should feel that they have the right to certain expectations due to their monetary investment in healthcare coverage.
 - Address the intimidation that people may feel during a doctor’s office visit.
 - Bring a friend or advocate with them to an office visit

1. Do you have any Recommendations that Connect with the CAB Health Equity Priority? *Health equity involves the promotion of equal opportunities for all people to be healthy and to seek the highest level of health possible.*

- Health coaches would be helpful because people felt that more guidance was needed between the clinical encounter and being home and dealing with diabetes issues. Additional guidance is needed when people first find out about the diagnosis, and a health coach would help minimize expensive office visits and prevent people from facing diabetic crises.

EVENT DETAILS
WHAT WE LEARNED:

The group had a lively discussion of whether exercise and food maintenance helps address diabetes issues. Not everyone seemed to understand how to best take care of their health. People shared advice and encouraged each other to “eat regularly, to eat nutritious foods, and take care of your body.” One person recommended that to get the regular blood sugar test, to prick on the side of your finger – this will make it hurt less. Another person said everyone should go to Joslin Center for Diabetes – at the Hospital of Central Connecticut because they were helpful.

Many people agreed that it is one thing to *learn* what you need to do, but it’s another to *do* what you need to do. Everyone said they needed support, like the church, to follow through. Other people talked about lack of motivation to address their issues because “you can get used to the feeling of being diabetic.” One man shared a story about how he was diabetic and didn’t know it. He only discovered this when he got a test for another health issue

The group discussed costs of diabetes. Many people spent \$400-\$900 per month, even with health insurance. Three people out of the 35 participants shared they actively struggle with costs every month. To help address costs, one person worked with their doctor, then called CVS directly. This person had to proactively ask

questions to get the answers and figure out how to lower their costs. Another person had a specialist who wanted the patient to get a certain med, and the patient advocated for CVS to communicate with this patient's insurance company and look at the formulary to lower costs. The patient had to talk to CVS for 90 minutes to get them to help. A third person had to go back to specialist and work with her to figure out how to decrease medical costs. People felt that the primary care office should help navigate costs.

If the medication is not on the insurance formulary, then the patient has to pay the complete cost of that medication. Meds and supplies are expensive, but Medicare and company-sponsored health insurance help defray costs. When buying meds on a low budget, people considered trade-offs: food, rent, etc. Some drugs can be offered low cost or at no cost, through certain programs like tax write-offs. There are many new meds – a nurse at the event said you must be an advocate for yourself. “You must take meds as directed and know their side effects!”

The group also talked about how the Black culture affects their ability to address diabetes. Black people call diabetes “sugar” – many admitted there's a lot of ignorance about this topic in the Black community. However, since Obama helped with better healthcare, the Black community is trying to educate each other about how to address healthcare concerns.

To keep from feeling overwhelmed, people agreed that you need to learn to be in control of yourself and your body's needs. You also need to learn how to advocate for yourself.

In terms of what would be helpful, a nutritionist keeps one woman on track. The woman noted that when the nutritionist gives her compliments about being tall and thin or having good metabolism, this actually demotivates her, so nutritionists should stick to talking about how eating well will help with overall health. Another woman shared that her nutritionist is like a health coach – and that it would be nice to be able to check with them regularly. Health coaches can offer a lot of touches to the medical system between doctor's visits.

Tricks to staying healthy included having community support and access to healthcare screenings and treatment. People agreed that a mandatory screening or health fairs with free screenings were helpful to identifying pre-diabetes and diabetes. Pastor King learned she was pre-diabetic at a health fair screening. One person had a difficult time with getting diabetes care due to lack of a primary care doctor. It took 6 months to get her bloodwork done, since the availability of doctors is low.

People wanted to know about diabetes symptoms. Cindy Kozak, the Department of Public Health expert shared that these included fatigue, thirst, urination, wounds that won't heal, losing eyesight, and yeast infections. She said “you get used to feeling crappy, so many people don't feel anything!”

If people got to design a healthcare system, they wanted healthcare resources in their home area. In New Britain, there needs to be more local services and specialists. Specialists existed only in Hartford and Glastonbury only. Moreover, people wanted equal insurance for everyone. The Affordable Care Act is one step in the right direction, but there needs to be better health insurance. Finally, more support groups would help people with diabetes. One person recommended Weight Watchers as a support group since it doesn't cost anything if you reach your goal weight. Another person talked about a pre-diabetes program at Hartford YMCA, which is free and open to the public.

The group also discussed what caregivers need. Caregivers need someone to support them. Caregivers also need respite care for their loved ones, but there is a long waitlist for respite. Caregivers also need a check-off list to get more details about how to help their loved ones.

Participants shared tips to meet with doctors. They think it's best to get the first or last appointment of the day. Another tip was to bring in another person in with the doctor's visit; this offers a second set of eyes and ears. Asking doctors what is a good or a bad number for sugar count is important to people. Finally, people said you should always advocate. People are generally afraid to ask doctors questions. One person said we should write down questions before meeting the doctor, and ask to talk to the manager if people have trouble with customer services for their healthcare insurance. He asserted that we pay for health insurance, and we need to advocate for our needs. This participant shared a story about how he made sure the health insurance for his daughter's cancer paid for medical costs. To do this, he called them, figured out who to write a letter to, wrote the letter, and got a positive response because he advocated.

In terms of technology to help with diabetes care, everyone at the event uses a smartphone, but few use them for healthcare. However, half of the discussion group goes on the portal to see health records.

Among the recommendations that came out were to have more support groups, coordinated care, seeing more specialist, and additional screenings. Event organizer Steve Karp said the original vision was to have just a conversation, but Cindy Kozak of the Department of Public Health (DPH) was there to answer some questions during the forum. Ms. Kozak also provided a helpful ten-minute presentation at the end of the forum on DPH's services and how people can obtain assistance. Thanks to this presentation, participants walked away with more knowledge about diabetes. Having a professional as an informational resource during the event added dramatically to the success of what was originally envisioned.

CHALLENGES ABOUT HEALTHCARE:

These forums provide an opportunity to hear consumers' direct input and provide a voice to empower the consumer. Several people at the event talked about the cost barrier and how to address it with support and fostering communication between doctors, health insurance, and pharmacists.

None of the forum participants had a health coach, which may be helpful to people with diabetes. Two people had a nutritionist that functioned as a health coach by helping with the management of diet and exercise. However, health coaches would be helpful because people felt that more guidance was needed between the clinical encounter and being home and dealing with diabetes issues. Additional guidance is needed when people first find out about the diagnosis, and a health coach would help minimize expensive office visits and prevent people from facing diabetic crises. Additionally, perhaps increasing the role of the nutritionist is important in thinking about person centered care. Nutritionists and physicians were the only service providers mentioned at the forum.

SIM CAB FEEDBACK:

- To be determined by SIM CAB members

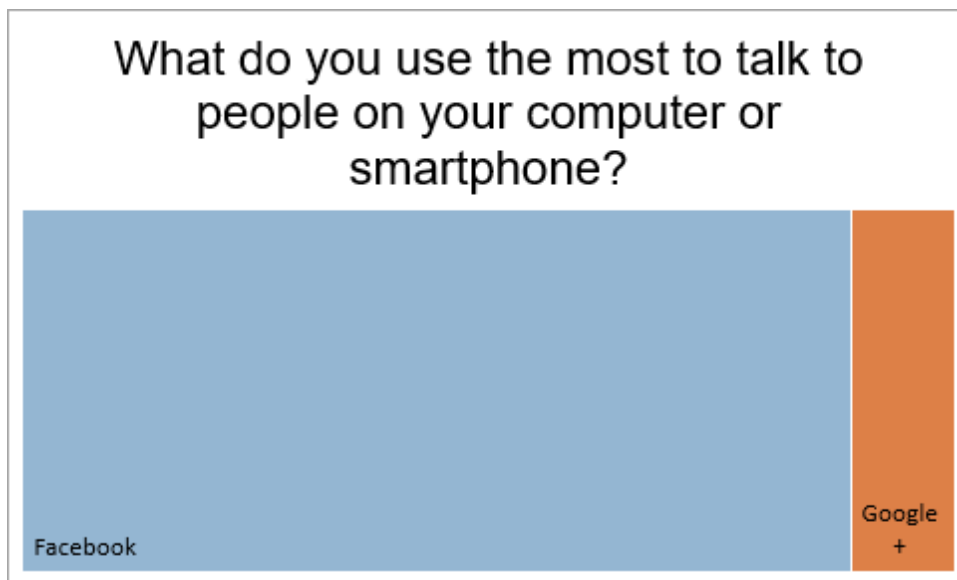
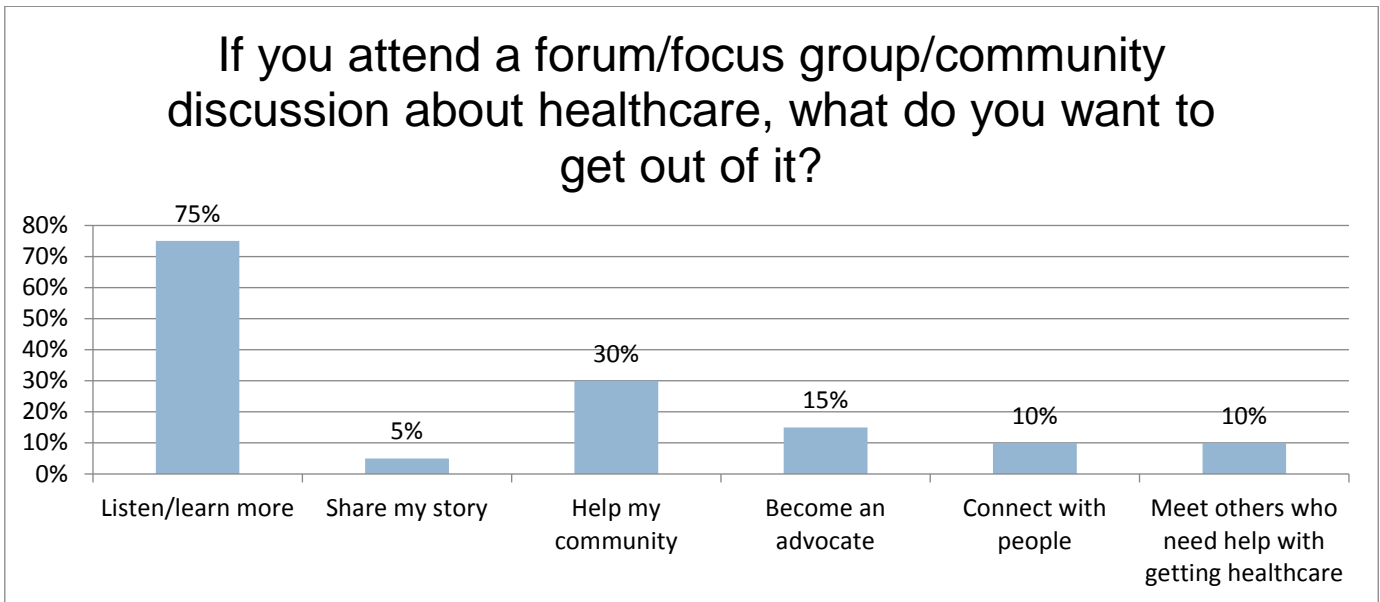
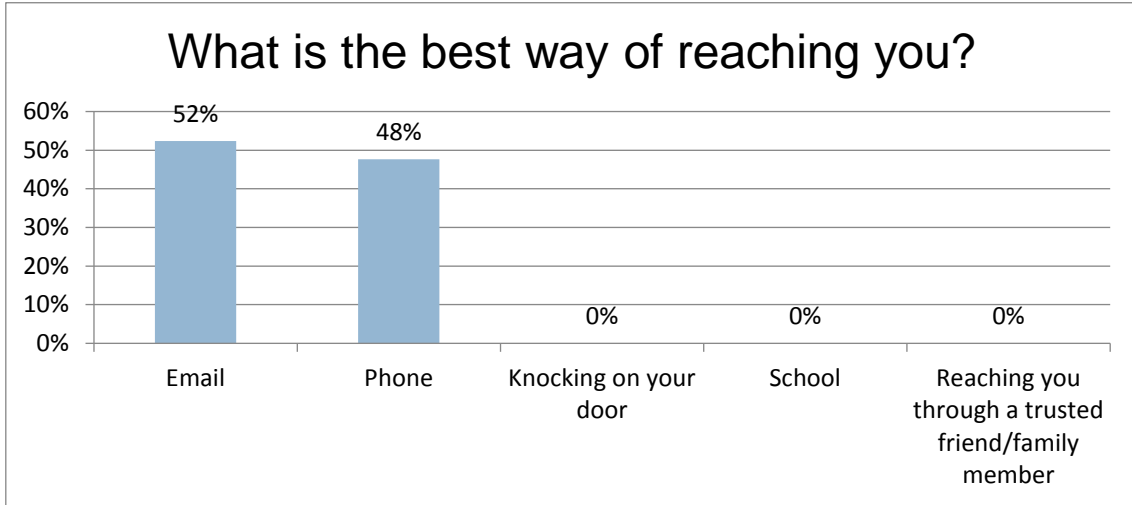
RECOMMENDATIONS:

- To be determined by SIM CAB members

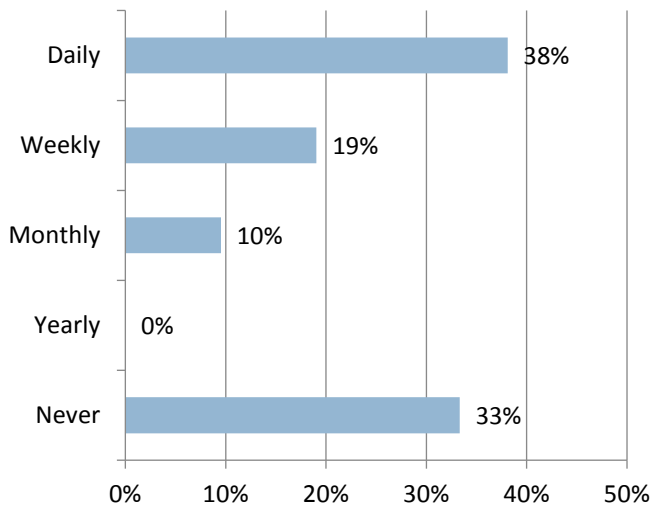
Discussions about self-advocacy led to one participant sharing a few recommendations. One recommendation was that people should feel that they have the right to certain expectations due to their

monetary investment in healthcare coverage. Another recommendation addressed the intimidation that people may feel during a doctor's office visit. The final recommendation was for a patient to bring a friend or advocate with them to an office visit, to serve as an extra set of eyes and ears.

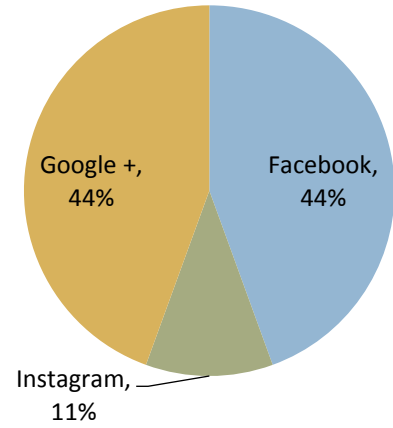
PRE SURVEY FEEDBACK



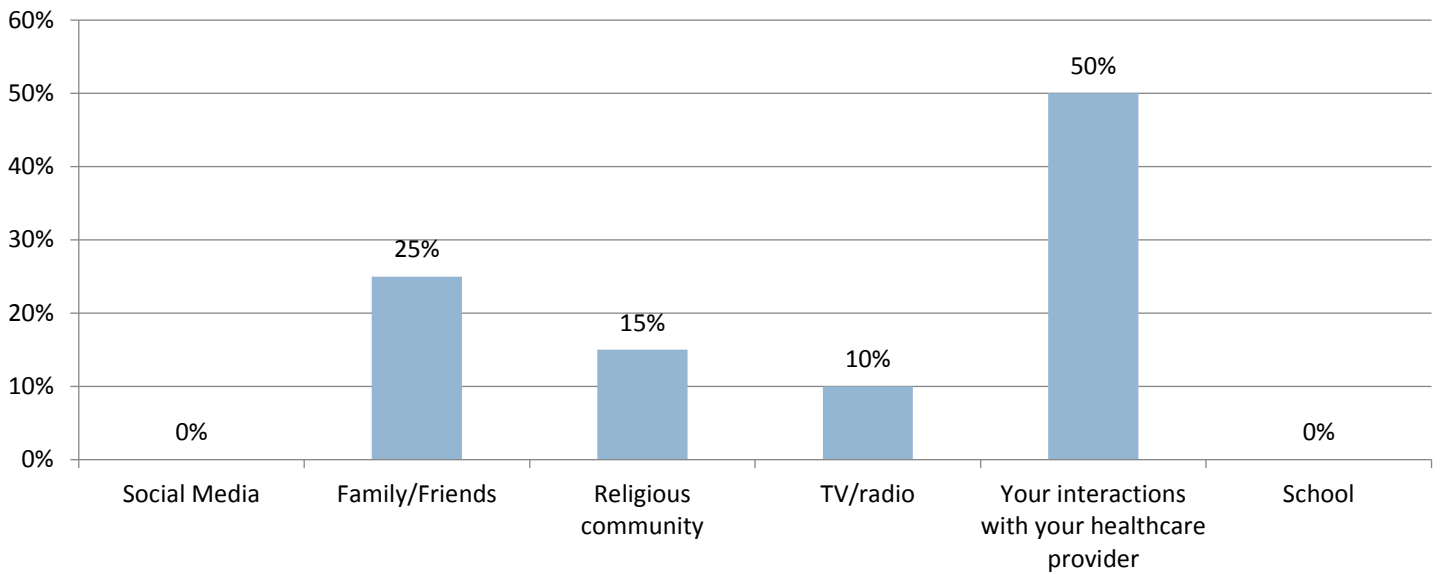
How often do you use social media?



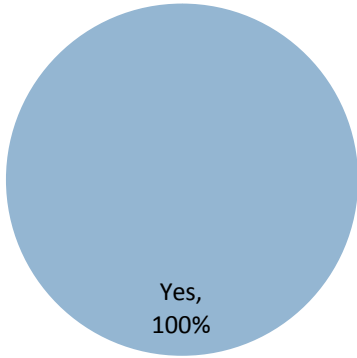
What would you most likely use to learn about or talk about healthcare?



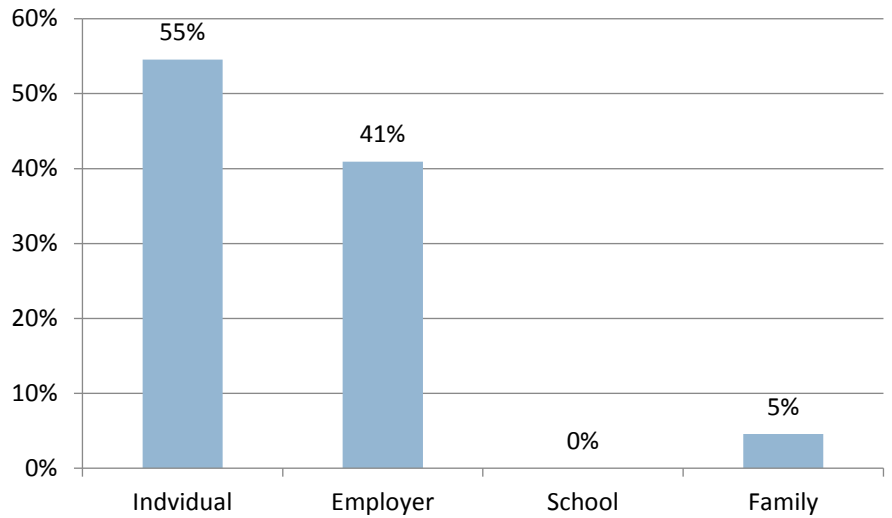
What affects your understanding of healthcare most?



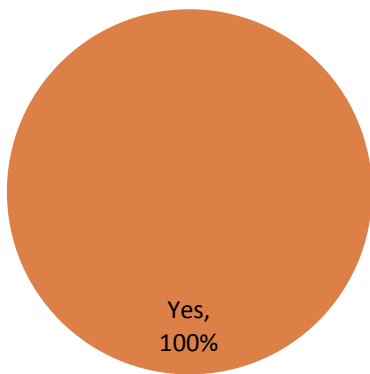
Do you currently have health insurance?



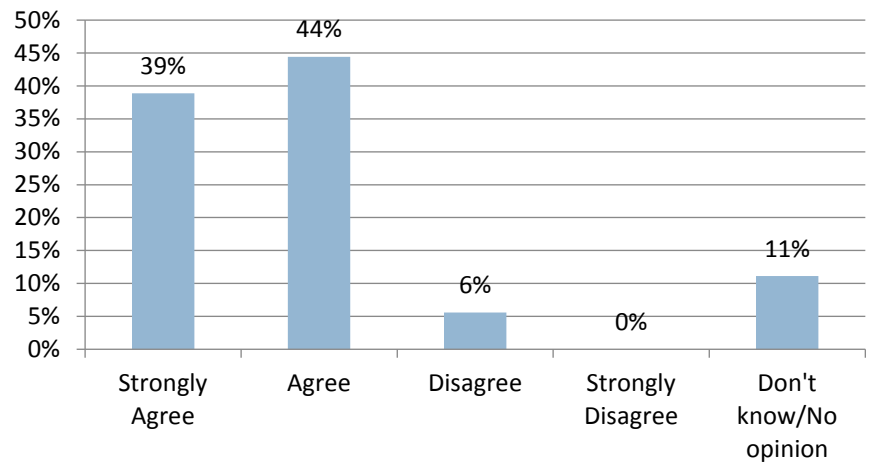
If yes, what type of insurance do you have?

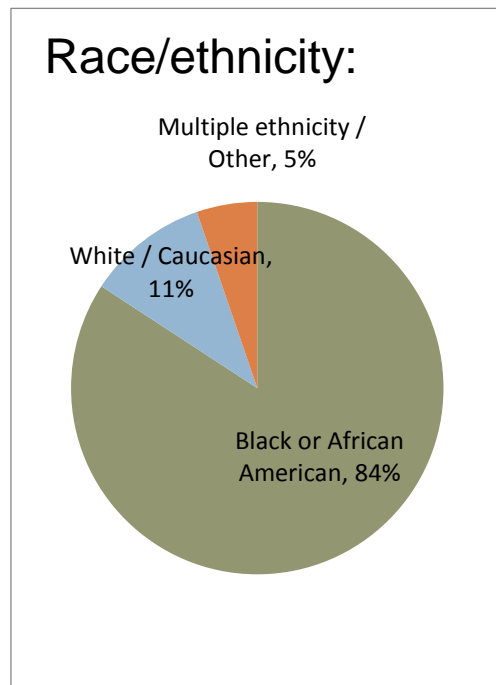
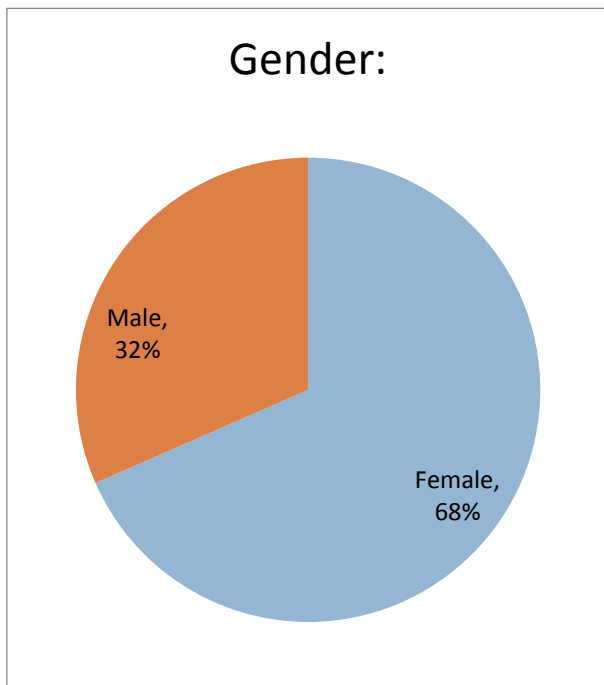
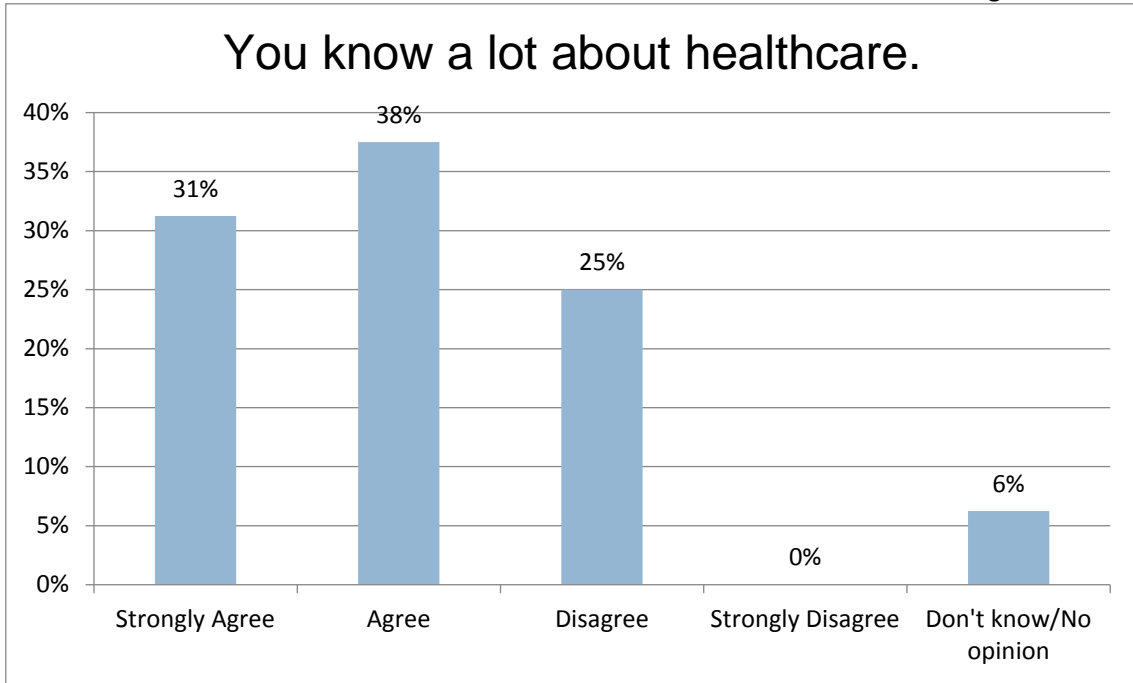


Do you have a primary care provider?

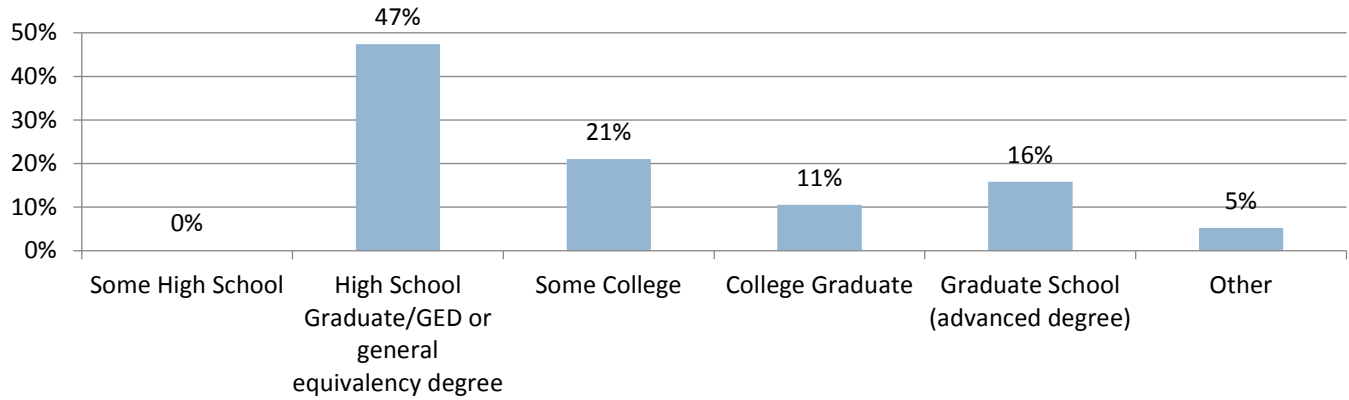


You feel that your doctor understands you and where you are coming from.

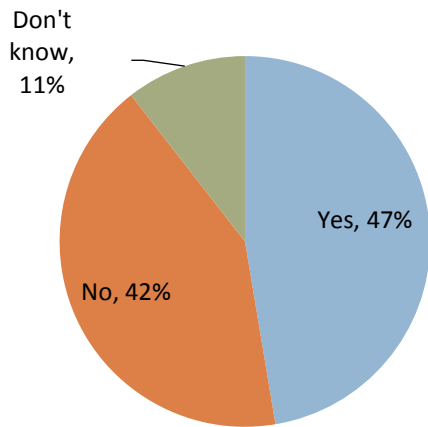




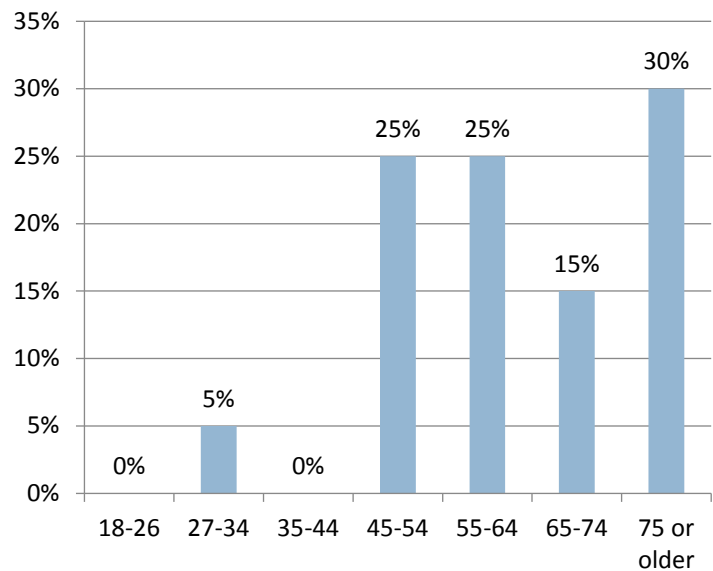
Which of the following best describes your level of education?



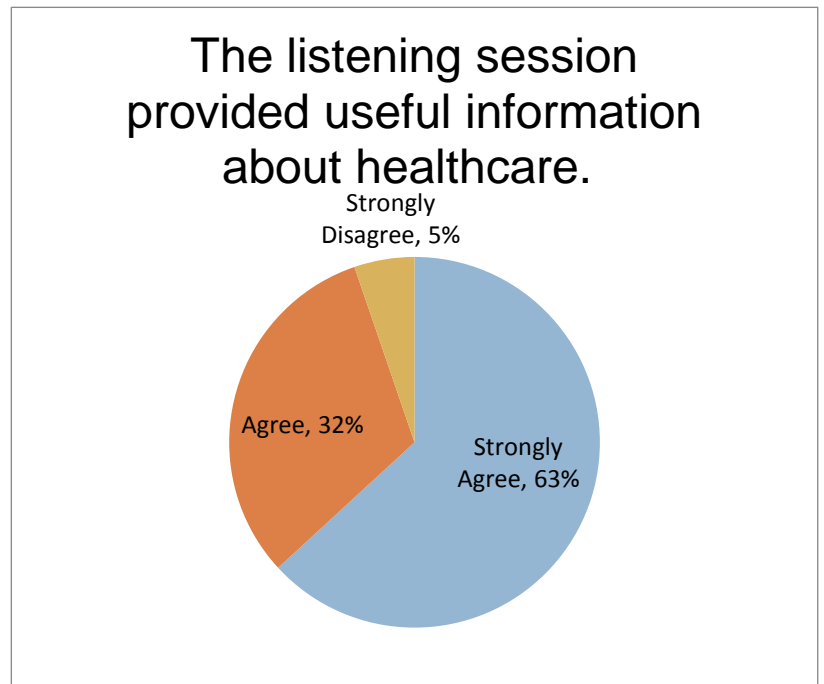
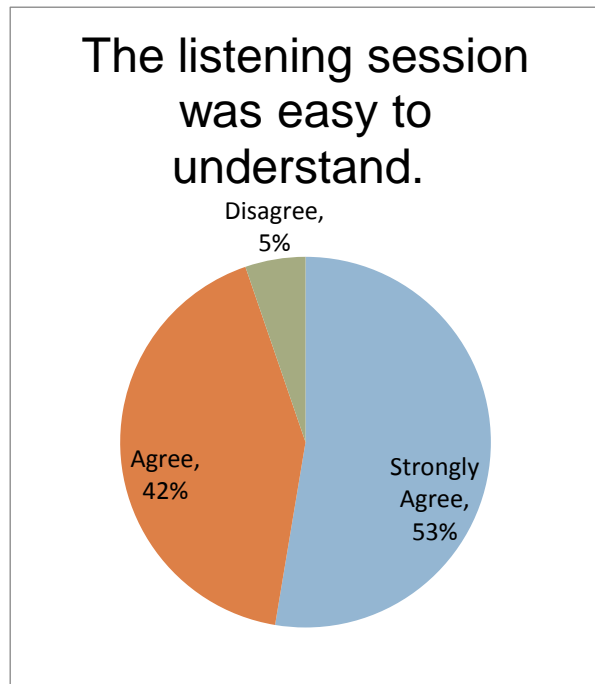
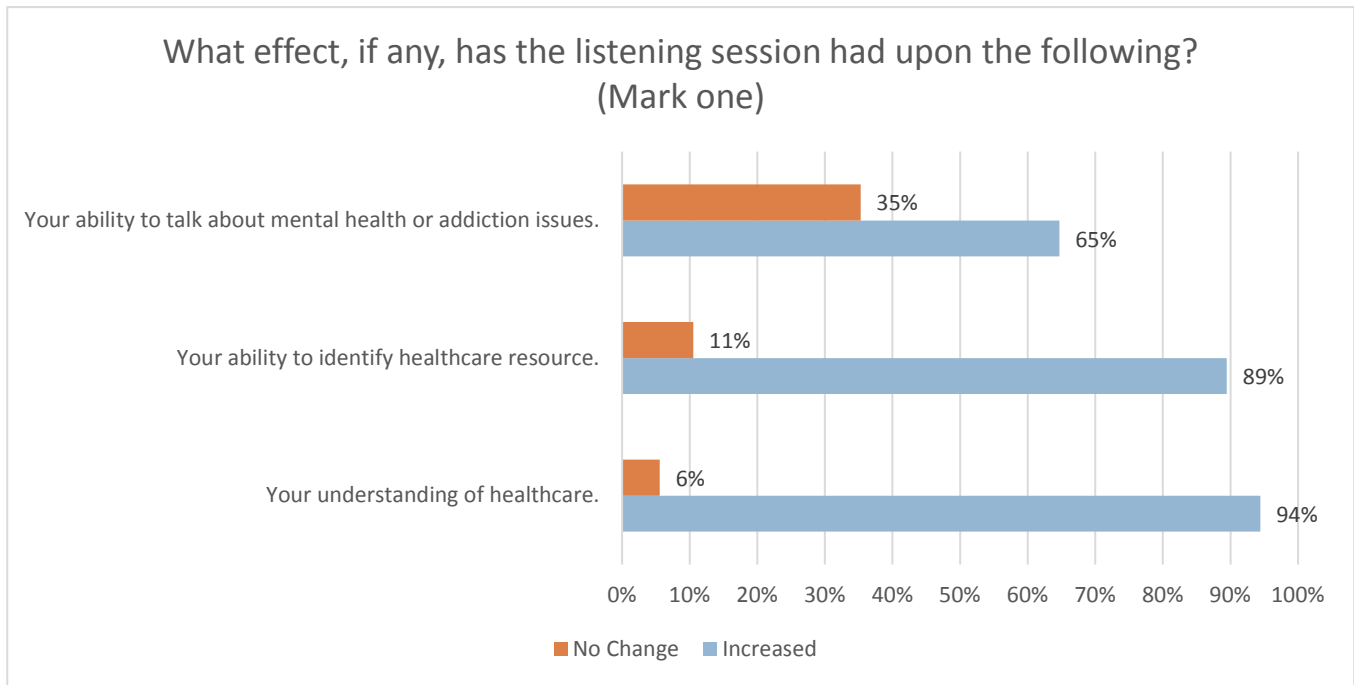
Do you think your religion affects how you view healthcare?



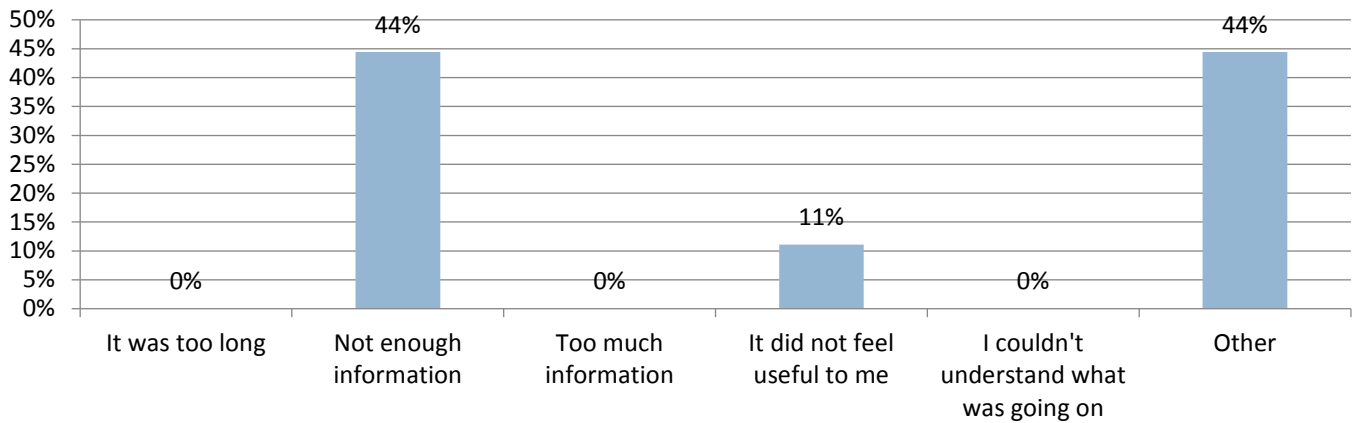
What is your age



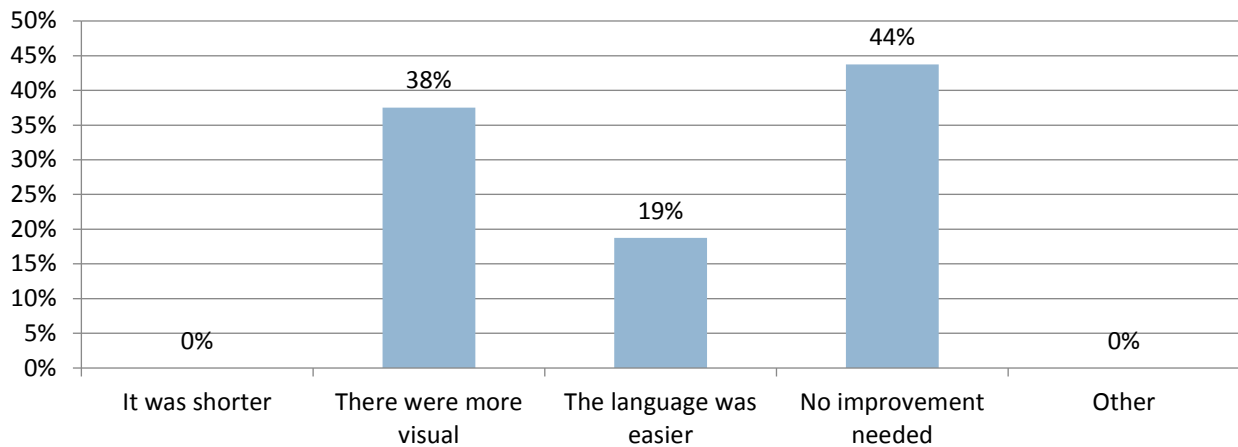
POST SURVEY FEEDBACK



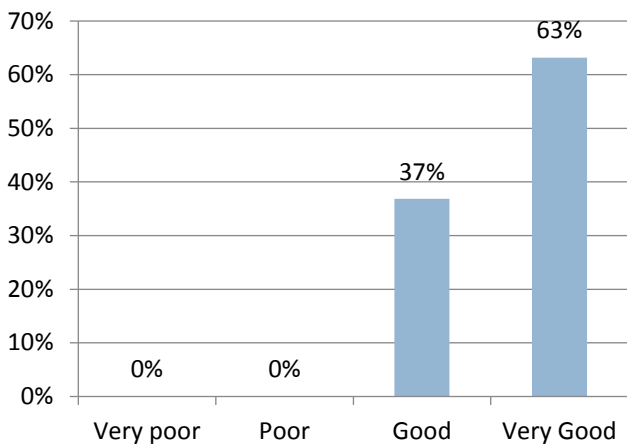
Describe what you liked least about the listening session?



The listening session could be improved if...



Overall, I would rate the listening session as...



Describe what you liked most about the listening session? (Mark all that apply)

