



connecticut state
innovation model

CT SIM CAB DIABETES LISTENING SESSION REPORT

SPOTTSWOOD AME ZION CHURCH, NEW BRITAIN: APRIL 28, 2017

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NORTH CENTRAL REGIONAL MENTAL HEALTH BOARD
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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.

OVERALL RECOMMENDATIONS:

1) INFLUENCE SYSTEMS CHANGE:

- Offer coordinated care
- “See more specialists and a broader range of health professionals, like a complementary and alternative medical intervention (CAM), or non-conventional interventions – like a health coach.”

2) PROMOTE PROVIDER-CONSUMER PARTNERSHIPS:

- Offer more local/accessible specialists or health coaches
- Additional screenings at health fairs or mandatory screenings at primary care physicians’ annual visits
 - Ensure medical examinations include retina, feet and other diabetic complications; make sure patients know their A1C number

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

Recommendations that Connect with the CAB Health Equity Priority:

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 finger-pricking on the side of the finger when doing the regular blood sugar test, indicating 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. Medications and supplies are expensive, but Medicare and company-sponsored health insurance help defray costs. When buying medications on a low budget, people considered trade-offs: food, rent, etc. Some drugs can be offered at low cost or no cost. Certain tax write-offs can help; for example, if you spend more than 7% of your income on healthcare costs and you itemize your taxes, then you can write off the rest of those costs when filing taxes. You have to balance costs of existing medications and learn about new medications. When it comes to medications, 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, one woman shared that a nutritionist keeps her 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.

At this point, since none of the participants brought up this topic yet, Dr. Mark Schaefer asked if anyone used health coaches, which are a type of Community Health Workers that help people navigate the healthcare system and manage chronic illness issues. In response, a woman shared that her nutritionist is like a health coach – and that it would be nice to be able to check with them regularly. Dr. Schaefer affirmed that health coaches can offer a lot of touches to the medical system between doctor's visits. Health coaches are not licensed; they are trained community members with experience in the healthcare system who can help other community members with healthcare issues. Registered dietitians can be health coaches, but most of the time, health coaches are effective because it is a peer-to-peer model.

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.

However, it is important to note that the American Diabetes Association does not do screenings because they can offer false results. There are two different tests to screen people for diabetes. The blood glucose test requires you to fast beforehand or you can get a false positive. The A1C test is more accurate but requires looking at your blood glucose over a 3-month span. Given the limitations of these tests, we should investigate whether there is a better way to figure out whether someone is pre-diabetic or diabetic on-site. The bigger

concern is if we screen people and refer them to primary care – there are not enough doctors. This issue is worth further investigation to address.

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, visiting the specialist more, and additional screenings. However, specialists may not be needed if primary care doctors have that knowledge about diabetes. Maybe the problem is there are not enough primary care doctors who have knowledge about diabetes. For example, a general internist may have better knowledge about diabetes than family physicians.

In reflecting on the event, the organizer Steve Karp said the original vision was to have a simple conversation among people with diabetes, but it was helpful to have Cindy Kozak of the Department of Public Health (DPH) present to answer some questions. Ms. Kozak also provided an informative 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 or a Community Health Worker, which may be helpful to people with diabetes. Two people had nutritionists that functioned as health coaches 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. Nutritionists and physicians were the only service providers mentioned at the forum. Perhaps increasing the role of the nutritionist is important in thinking about person-centered care. However, licensed healthcare providers are more costly and less accessible than health coaches.

SIM CAB FEEDBACK:

Diabetes is a topic that has come up over and over throughout our listening sessions. This healthcare issue is especially pertinent to many African American communities. We need to continue to work on addressing diabetes in healthcare reform efforts.

FUTURE CONSIDERATIONS:

INFLUENCE SYSTEMS CHANGE:

- As we are changing payment delivery, we should incentivize physicians to locate their practices in high areas of need to reduce barriers to diabetes care.
 - What are the recruitment strategies for specialists in the New Britain area?
 - What are the available options for people to advocate for themselves?
 - How are we ensuring that there are enough specialists in the areas that need them?
- How do we look at transportation barriers and how they can access healthcare?
 - Hartford Hospital centralizes services – which forces people to transport themselves.
 - How does this impact outcomes for people?
- Have community health workers better integrated into care.
 - When you have diabetes, you get 12 sessions of diabetes care under Medicaid with a registered dietician. This includes medical nutrition therapy. Even though those people are not CHWs, the model of holistic care approach is already there – there's a physician who refers you to a dietician, and a health coach, and you get an annual checkup. Make sure CHWs are integrated.

PROMOTE PROVIDER-CONSUMER PARTNERSHIPS:

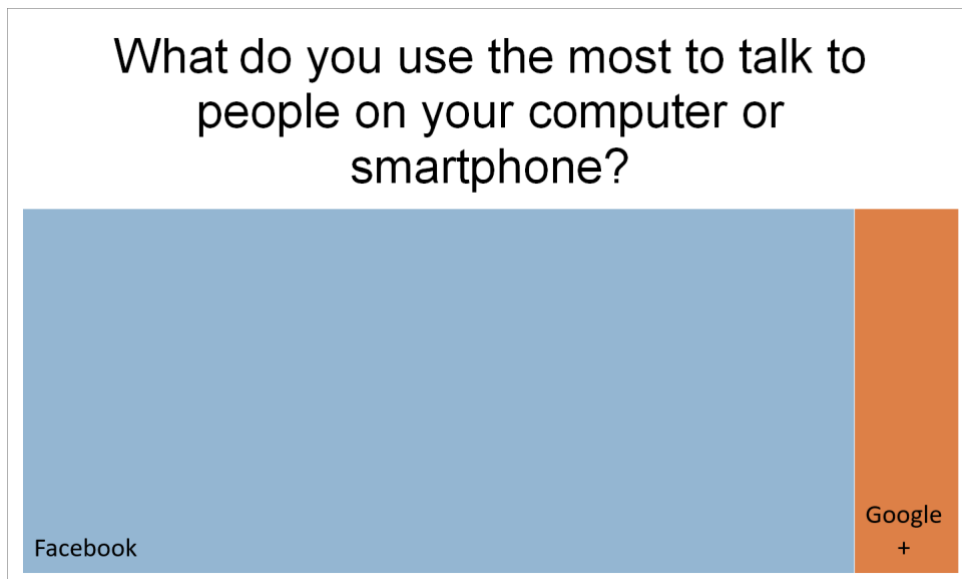
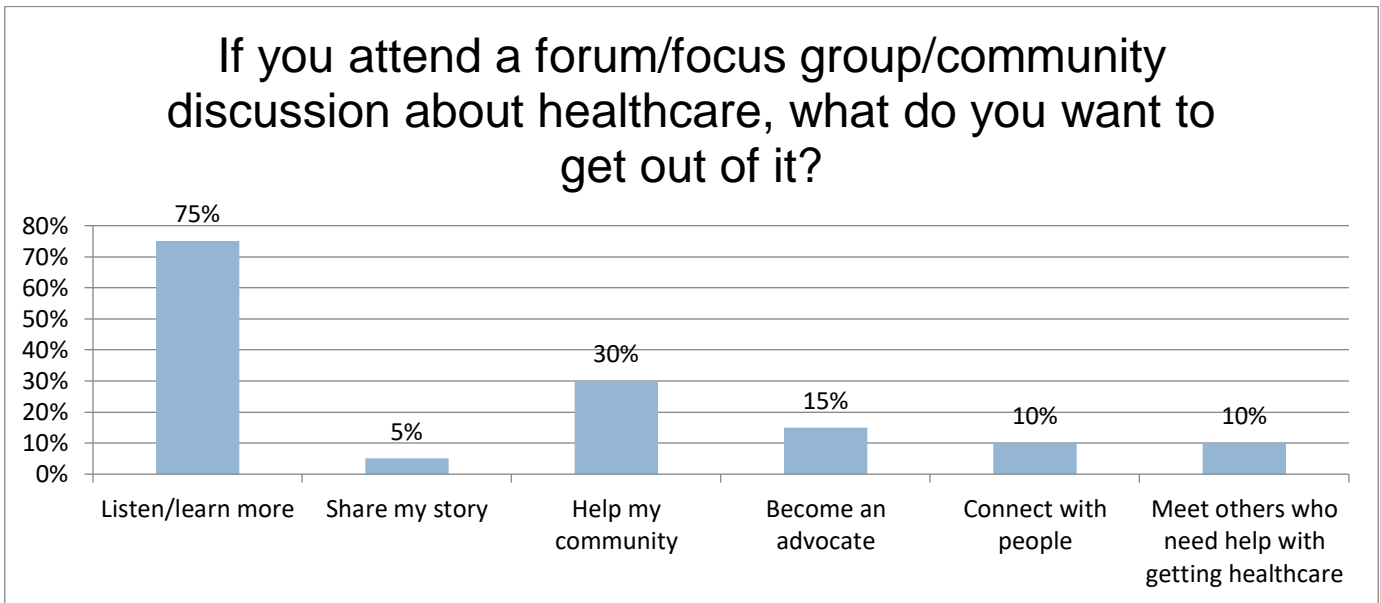
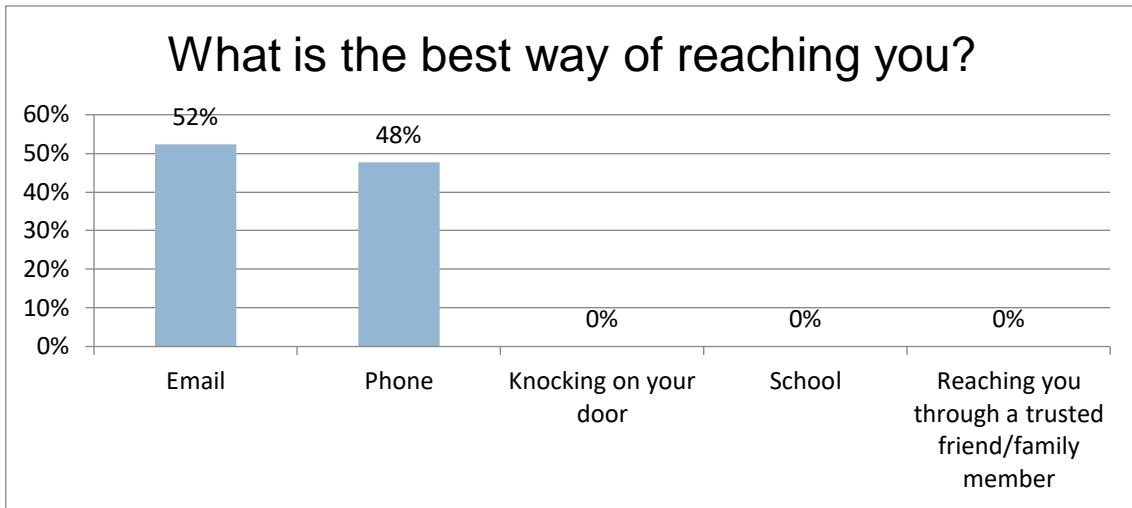
- Promote Choosing Wisely for patients and doctors to have better interactions.
- Ask the doctor to slow down in explaining difficult concepts. Repeat what the doctor said to clarify your own understanding and to help remember their recommendations. See if you can recite the doctor's recommendations to a relative.
- Encourage doctors and consumers to recognize and address their implicit biases, so they can better work together for better health. Ask doctors to complete CEU programs that address implicit biases and cultural competency.

ENGAGE AND EMPOWER CONSUMERS:

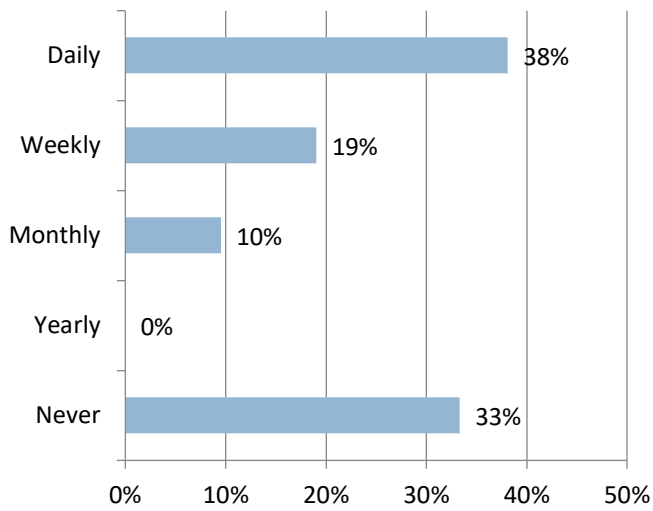
- Make sure consumers know Choosing Wisely questions.
 - Remind people they have the right to certain expectations of the healthcare system due to their monetary investment in their health insurance.

- Address the intimidation people may feel during a doctor's visit.
- Educate yourself continually about diabetes care.
- Seek out and engage health coaches or Community Health Workers to help you manage your diabetes.
 - Check with your insurer to see whether health coaches are available and covered.
 - Bring a health coach, friend, or family member to a doctor's visit, to serve as an extra set of eyes and ears.

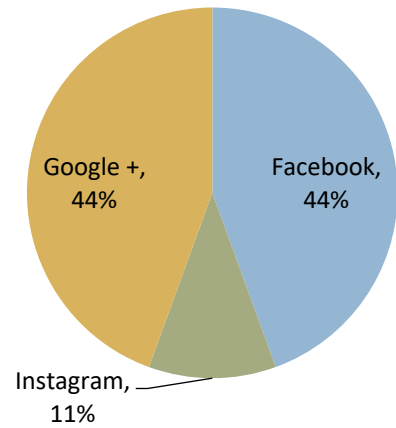
PRE-SURVEY FEEDBACK



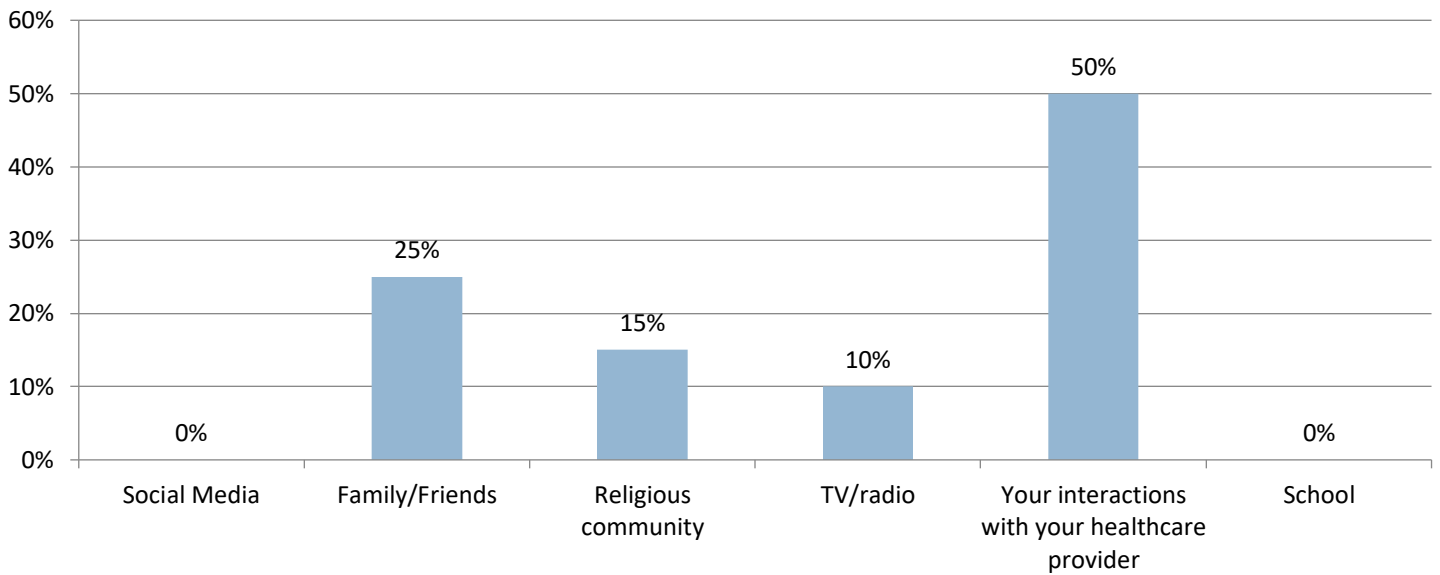
How often do you use social media?



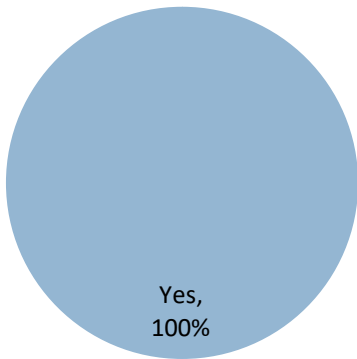
What would you most likely use to learn about or talk about healthcare?



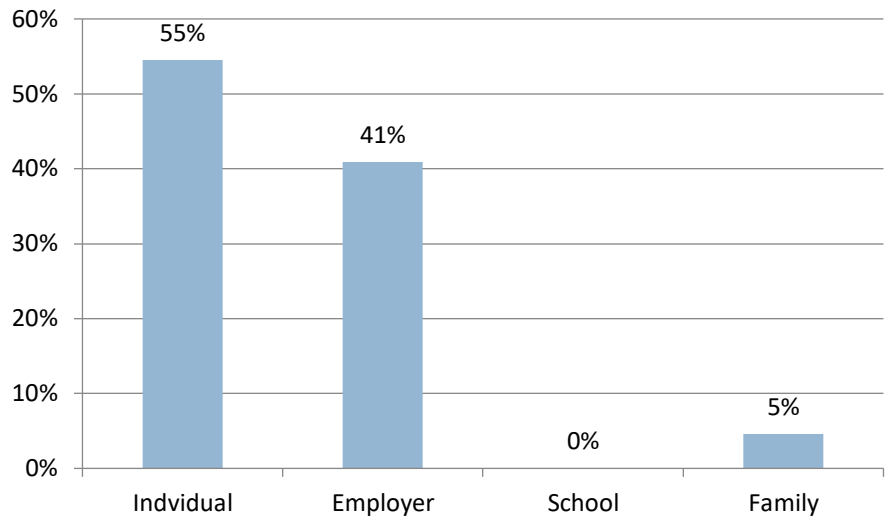
What affects your understanding of healthcare most?



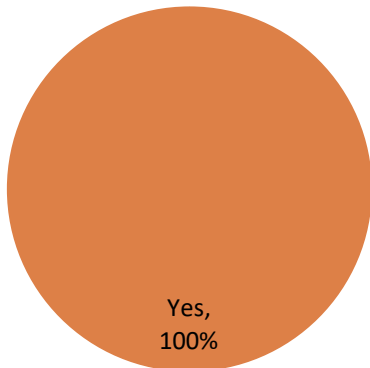
Do you currently have health insurance?



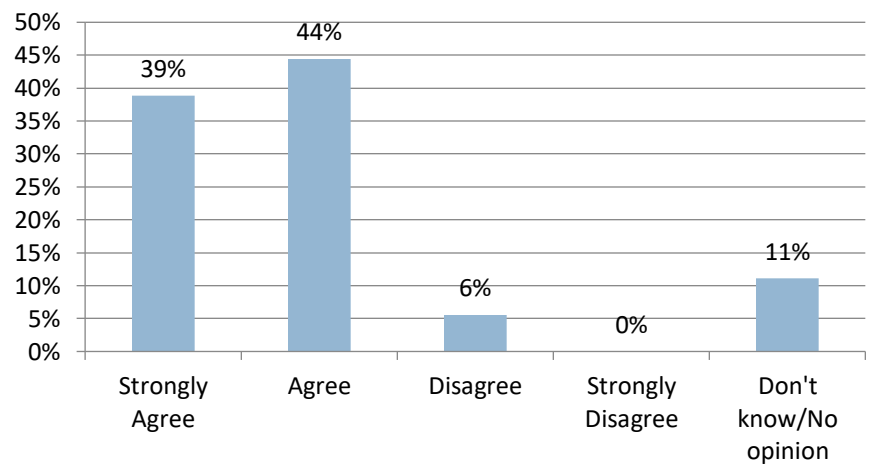
If yes, what type of insurance do you have?



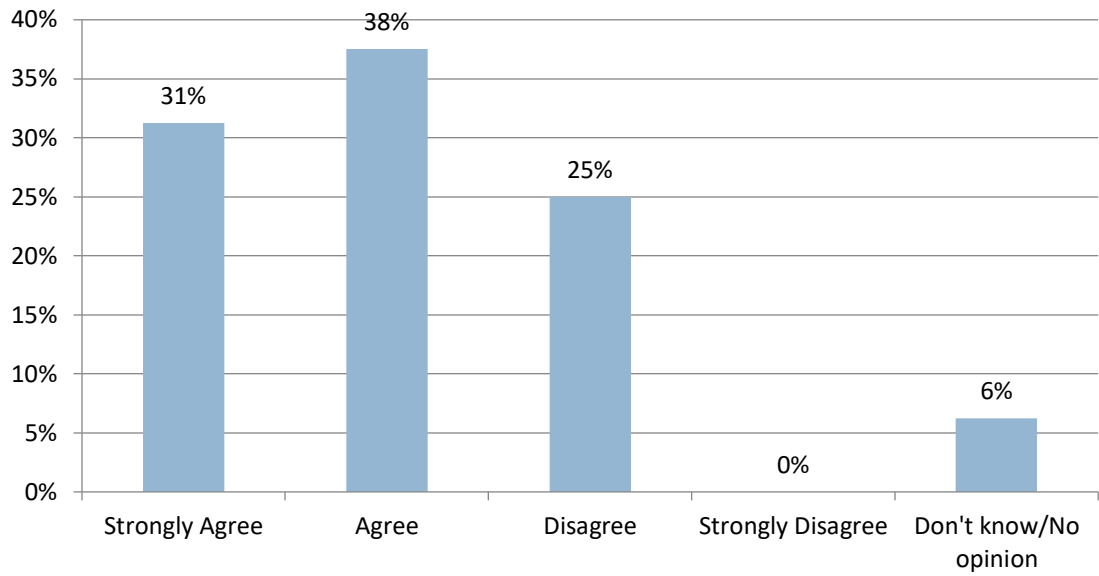
Do you have a primary care provider?



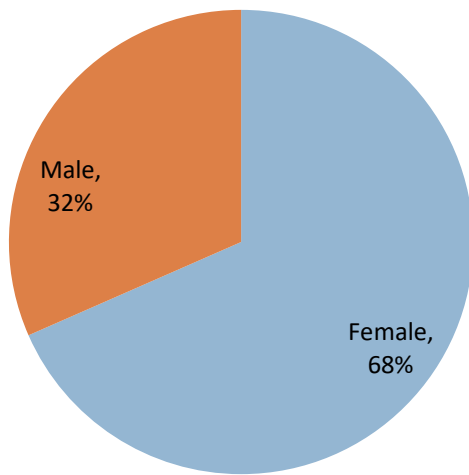
You feel that your doctor understands you and where you are coming from.



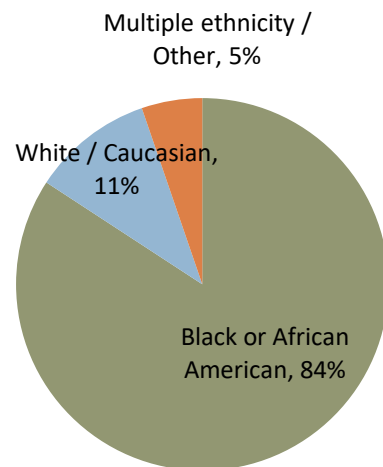
You know a lot about healthcare.



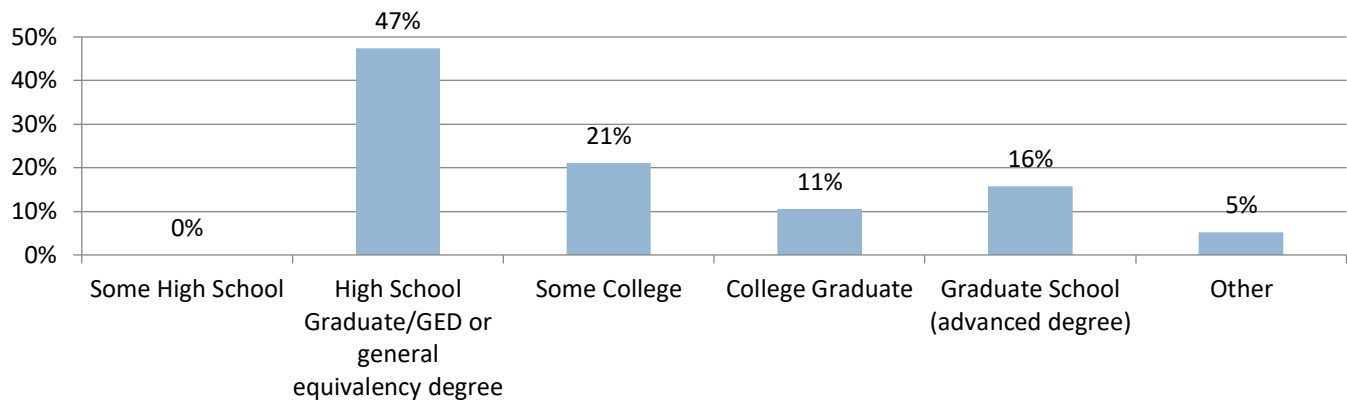
Gender:



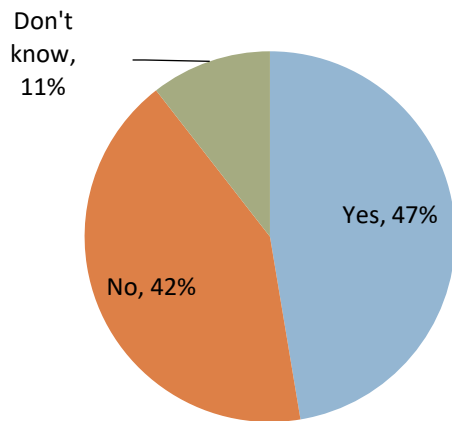
Race/ethnicity:



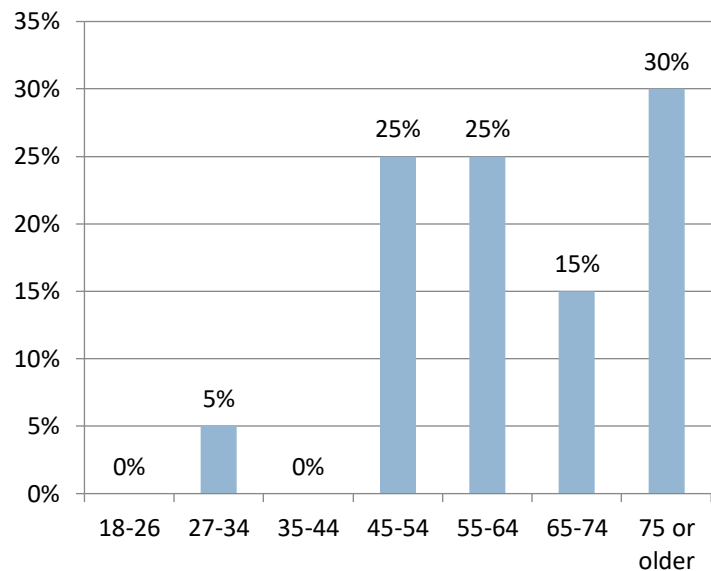
Which of the following best describes your level of education?



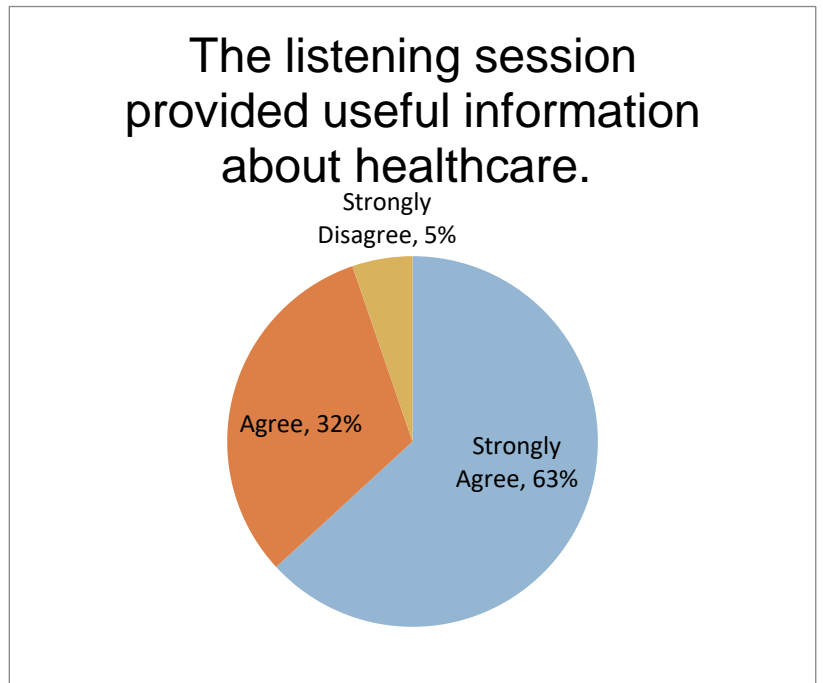
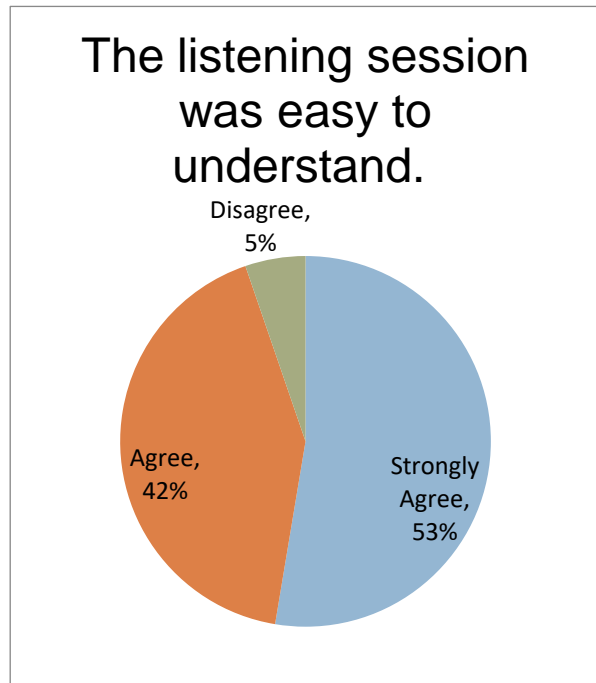
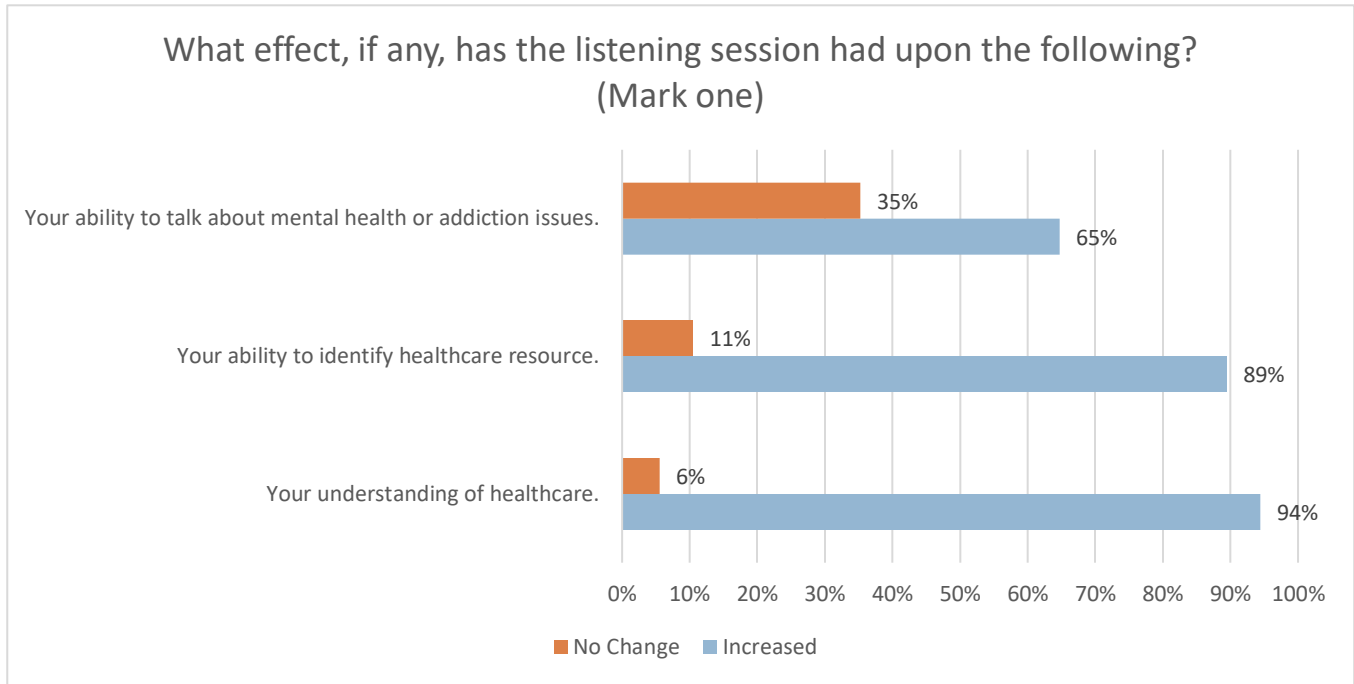
Do you think your religion affects how you view healthcare?



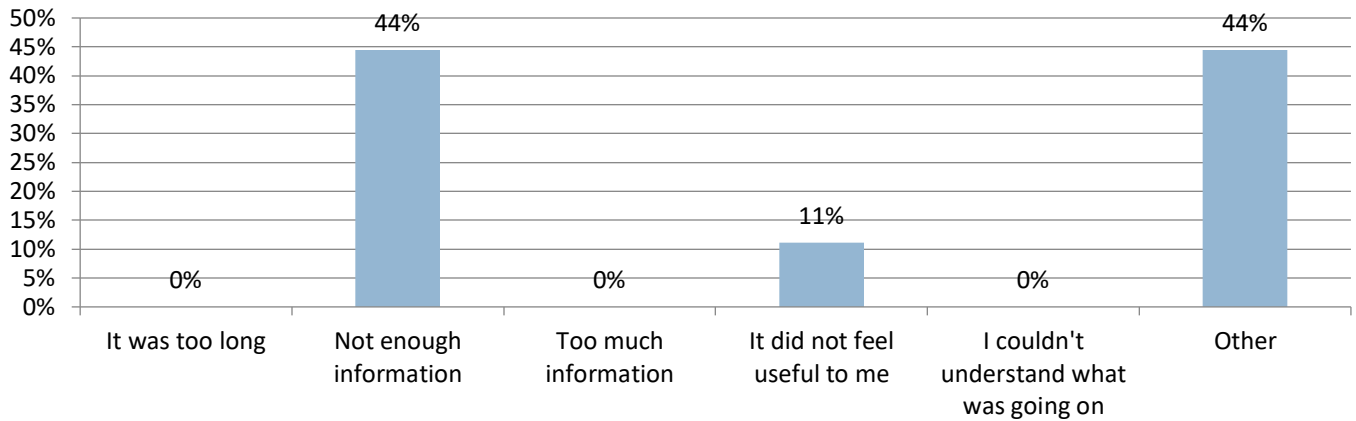
What is your age



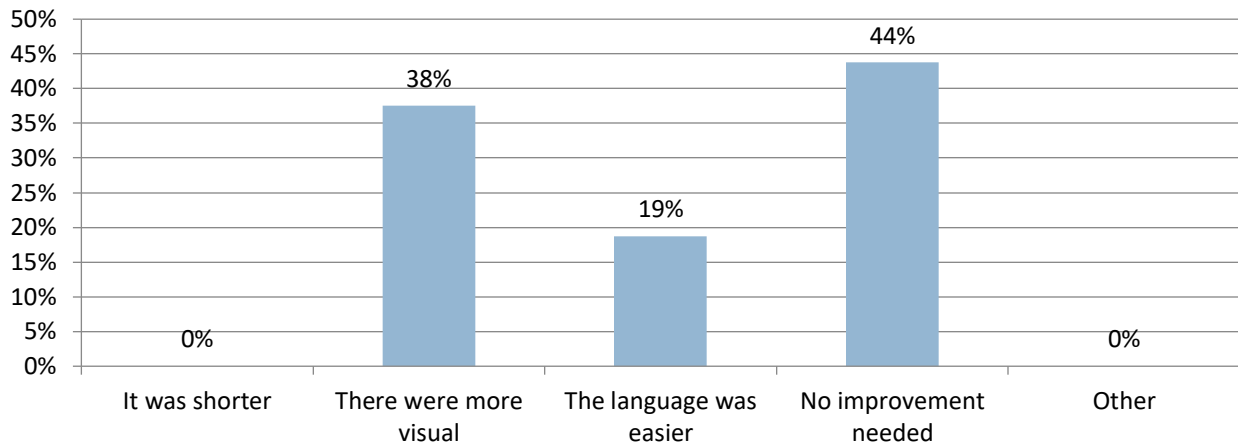
POST SURVEY FEEDBACK



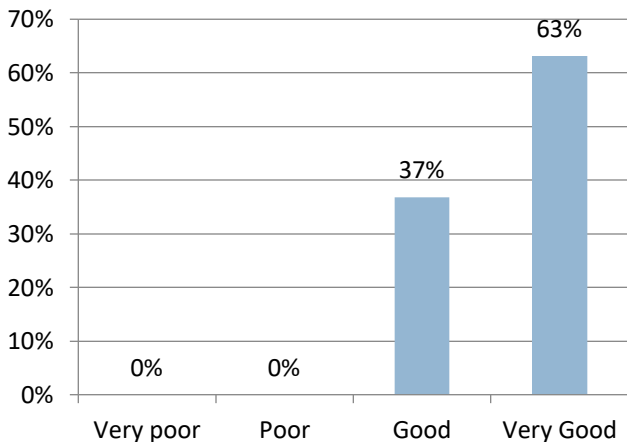
Describe what you liked least about the listening session?



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)

