



# Civil Justice in Healthcare: the Affordable Care Act and the Black Community in CT

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# Executive Summary

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Over the summer of 2015, the North Central Regional Mental Health Board (NCRMHB) organized a series of 15 Community Conversations about the Affordable Care Act (ACA) in Black communities all over the state of Connecticut (CT). These communities included many congregations in New Britain, Hartford, Bloomfield, and Middletown, as well as peer-led recovery organizations from Bridgeport to East Hartford. Over 150 people who had lived experience with mental health or addiction issues, or who identified as Black or African American participated in the dialogues. The Community Conversations consisted of small group dialogues, involving 7-10 people, two trained Black facilitators, and a Peer Health Navigator who identified as someone with lived experience in mental health or addiction. The Conversations lasted about 3-4 hours each and had an arc that allowed people to talk about health care, health coverage, and issues of mental health and addiction. At the end of each Community Conversation, participants developed action steps to create change for themselves and for their communities.

## **Issues of reaching the Black community and the importance of Peer Health Navigators:**

The NCRMHB embarked upon this project because research indicates that African Americans who are vulnerable to mental health issues have the tendency to underutilize mental health services. Researchers Cornelius and Hoberman noted that factors such as access to insurance coverage, affordable services, perceptions of discrimination, and ethnicity of the service providers serve as barriers to service among African Americans (Cornelius, 2000; Hoberman, 1992). The NCRMHB wanted to better understand how the ACA affected African Americans' ability to access mental health and addiction services as well as healthcare. In our research, we found that African Americans are likely to use emergency services or seek treatment from a primary care physician rather than a mental health professional. "African Americans more often sought professional help for physical health problems rather than emotional adjustment problems, death of a loved one, interpersonal difficulties, or economic difficulties" (Stone and Conley, 2004).

Even if Black people do seek help for mental health services, many stop after the first session. According to Sue and Sue (2003), 50% of African American patients terminate after the first session, while only 30% of Caucasian patients terminate after the first session. In the same study, African Americans attended an average of 4.7 sessions, while Caucasians attended almost twice as many, an average of 8.7 sessions. Why is this phenomenon occurring? Perhaps cultural and linguistic barriers play a role. The relative paucity of Black mental health service providers may also have an impact. The 2001 Surgeon General's Report indicates that the

percentage of African American mental health service providers is proportionally small. African American mental health professionals are psychiatrists (2%), psychologists (2%), and social workers (4%). This means that mental health professionals must do a better job at being culturally and linguistically sensitive in order to facilitate better healthcare. This is why the NCRMHB cultivated a cohort of Peer Health Navigators. These are people in recovery who are trained to be culturally competent, who are willing to share their mental health and addiction experiences, and who can offer resources in order to help the Community Conversations feel safer to Black people living with mental health issues.

### **Themes:**

Throughout the Conversations, we heard many themes repeated about access to care as it relates to the ACA. In identifying issues with the ACA, people often confused Medicaid and the insurance from the healthcare exchange. For example, both negative and positive experiences having to do with Medicaid were often attributed to the ACA's healthcare exchange insurance. Many people who thought they had insurance under the ACA's healthcare exchange actually had Medicaid. The difference is Medicaid is a publicly funded state insurance and thus has different requirements for enrollment and offers different benefits than the ACA's private, federally subsidized insurance. While some people said the ACA was not affordable, citing high premiums or deductibles, many people felt it saved them money. One person said, "I didn't think [health insurance] was that important, then I woke up from a coma having received probably over \$100,000 worth of care!"

Some people had negative associations with the ACA and only enrolled to avoid penalties, but the overwhelming majority of participants had a positive association with the ACA. Many Black people associated the legislation with Obama, often calling it "Obamacare" because he was the Black President. However, many people expressed concern that "Obamacare" would disappear after Obama's term ended.

### **Common issues faced:**

Participants discussed the many reasons behind health disparities. One reason is that people cannot find healthy food in poor neighborhoods. Another is people are afraid of following doctors' advice due to cultural differences.

In regards to the ACA, people discussed how access to information has been difficult for the Black community. Access Health CT needed to address issues of trust for Black people because the ACA was new and people needed to learn to accept its reliability. However, there were many stories of Access Health CT losing paperwork. Access Health CT dropped many people

from their insurance due to documentation issues. Even if they did manage to secure health insurance their relief was temporary; the cycle of redetermination felt relentless. Every six months people had to resubmit paperwork. Once they got insurance people did not understand the ACA's insurance coverage. It was unclear which doctors accepted what insurance. People did not even know the Open Enrollment dates.

People talked about how it is easier to go to the DSS office than to Access Health CT for help with insurance. Many people talked about a need for Access Health CT offices in impoverished neighborhoods, like in the North End of Hartford. This office would also need a Spanish-speaking and culturally competent staff. People were curious about the communications gap between DSS and Access Health CT. Many people wondered why paperwork got lost between the two agencies and why they do not share information.

Some participants felt that Black families tried to fix problems alone. Many Black families struggled without community support. People also talked about grappling with stereotypes of mental illness. Professionals worried about disclosure and making the workplace uncomfortable by talking about their mental health or addiction issues. For these reasons, people felt that we needed to have more Community Conversations to learn about the ACA and share resources with peers in a safe setting.

The following churches participated in our Community Conversations:

- Bethesda Apostolic Church – New Britain
- Cross Street AME Zion Church – Middletown
- First Cathedral Church – Bloomfield
- Grace Church – New Britain (2 Conversations)
- Peace Missionary Baptist Church – New Britain
- Phillips Metropolitan Church – Hartford
- Saint James Baptist Church – New Britain (2 Conversations)
- Spottswood A.M.E Zion Church – New Britain (2 Conversations)
- Vision of Faith Ministry – New Britain

The following Peer-Run/Recovery Community Organizations (PRO/RCOs) participated:

- Connecticut Community for Addiction Recovery (CCAR) – Bridgeport
- InterCommunity (IC) – East Hartford
- Toivo – Hartford

### **Surveys:**

People also completed pre and post surveys to share their perspectives. These surveys covered a range of questions, covering everything from people's understanding of health insurance to

mental health. The survey included questions about people's experiences of the ACA. It asked questions about their knowledge of the ACA, why they think it is important, and how they think it could be improved. The survey also asked respondents to give an overall summary of their experience with the Community Conversations, as it related to their understanding of the ACA. A total of **144 responses** were received from over 150 surveys administered at the Community Conversations.

Items on the survey were worded as positive statements or direct questions, and included the following topics:

- Knowledge of the ACA
- How mental health and addiction services can be improved
- How to move forward with resolving issues with the ACA

Community partners, strategic planning committee members, and NCRMHB staff all took part in developing the survey forms. Staff first administered the completed surveys at the Facilitators' Training, and then subsequently in each Community Conversation. The complete survey questionnaire results are included later in this document for reference.

In pre-conversation surveys, many people (42%) did not know whether the ACA solved health problems. There was a wide variance regarding people's knowledge of the ACA. Although most people thought that health insurance was very important, 55% knew nothing about the Essential Health Benefits and 58% of participants did not know whether the ACA affected them. Most participants (63%) knew nothing about the Culturally and Linguistically Appropriate Services (CLAS) standards, but many people knew they could get a free language interpreter from health providers.

People's questions about the ACA:

- How to enroll
- How to get health care after enrollment
- How it changes my out-of-pocket costs
- How it changes my ability to see the doctor that I want

Issues with the ACA:

- Enrolling & staying enrolled
- Access to healthcare

In post-conversation surveys, 83% of participants felt they increased their knowledge of the ACA and health insurance. Most (78%) continued to think that health insurance was very important. The number of respondents who did not know whether ACA could help solve health

problems dropped from 42% to 12%, while those who felt the ACA can help solve health problems almost doubled, increasing from 47% to 81%. Numerous participants (55%) entered the conversations not knowing whether the ACA affects them, but by the time they left, less than 1% did not know how the ACA affects them. Many (42%) noted that the ACA “saves my family money.” Most participants (81%) agreed that the Community Conversations improved their ability to discuss mental health and addiction. By the end of the conversations, the percentage of people who thought that the ACA helped with mental health and addiction rose from 49% to 83%. The percentage of people who had no knowledge of CLAS standards reduced significantly, from 63% to 3%. People also increased their knowledge of Essential Health Benefits from 1% to 26% who knew a lot, and from 45% to 98% who knew at least a little.

The majority of participants (93%) agreed that the discussion guide was easy to understand and 90% thought it provided useful information about health coverage and enrollment. The guide purportedly helped people understand what to do with health insurance. There was a 63% “very good” rating on the discussion guide. One person stated they thought the guide was “very helpful” because it increased her “knowledge about ACA and dispelled myths.” Another person said the guide “gave me great information to give to others.” Someone said the guide “breaks down information into understandable chunks.” People felt the guide also helped them “understand what I need to do about getting health care.” Many enjoyed learning the benefits of the ACA and some wanted to know more. Most people said the Myths & Facts Section was their favorite part to read and discuss. Some people especially enjoyed meeting with others who shared their experiences with health care and mental illness. Others wanted more examples and easier language in the guide, but 97% agreed the guide was good.

### **Conclusions about Community Conversations:**

The feedback about the Community Conversations was overwhelmingly positive, one person said, “This was outstanding!” Participants agreed that more Community Conversations would be helpful to people’s understanding of the ACA. Over 97% of participants who knew nothing about CLAS standards learned something new. Overall, people enjoyed the conversations because they liked learning about the ACA, sharing their voice, and meeting people.

Participants had many questions. One person wondered, “How many recently enrolled people have had physical and other diagnostic tests during their first year of coverage?” Another asked, “How can individuals have a database to address questions or a Q&A about the ACA?” People wanted to learn more about the different plans and costs, as well as enrollment details and upcoming enrollment dates.

Participants also had constructive criticism. Some people wanted shorter Community Conversations over the course of more sessions. However, when we conducted two shorter sessions per Conversation, we lost and gained new participants at each session. The discontinuity was disruptive. We decided to go back to one long Community Conversation for the duration of the project.

Pastors seemed to play an incredibly influential role in the lives of their congregation. However, many pastors did not feel comfortable talking about health insurance because they did not know enough about the new healthcare legislation. The Community Conversations allowed space for pastors to share their questions, to hear what people had to say, and to learn about the ACA as well as learn about mental health and addiction issues with their congregation in a safe setting. The Women's Ministry at St. James Baptist Church coined their Conversation session as "The Balm in Gilead: Jeremiah 8:22." They believed that "We as African American Christians are equipped to help each other to heal."

# Community Conversations: Churches

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## Bethesda Apostolic Church (NAACP)

The Bethesda Apostolic Church has a strong NAACP influence. At the beginning of this Community Conversation the pastor talked about the purpose of the church. The purpose is to incorporate the work of the NAACP and to aid the African American community. The church especially wants to address dementia and diabetes. Additionally, the church wanted to **help people navigate the welfare system**. The pastor asserted that this would become a movement within the church. He felt that when people are sick and do not know what to do, they are afraid and will need guidance most.

People agreed that it takes community teamwork to accomplish what is needed to be done. Hospitals are not healing; they are not doing their job. This is partly due to the economics of care. There is fear of the healthcare system in the Black community.

People talked about the “Black Lives Matter” movement. They discussed how Black men are targeted, and when Black men hurt, the whole family hurts. People also talked about **how unusual it is for the Black community to have medical insurance**. Hence, they want to learn more. The group also had a passion to help young girls and address women’s needs.

A doctor in the group said she had a difficult time convincing Black men to take medications for blood pressure, because impotence could be a symptom. This idea of manhood impeded some Black men from taking steps to become healthier. To complicate the issue, some physicians who might not be **culturally competent** assume that Blacks do not care about their own health, which might affect the way they offer care to Black people.

Moreover, people cannot find healthy food in poor neighborhoods. For example, whole wheat bread is a rare commodity in some neighborhoods. People noted that prices for food go up on welfare money receipt days of the 1<sup>st</sup> & 15<sup>th</sup>. Racism and discrimination have a huge impact on health as well.

Many people agreed that we need **more Community Conversations**. They also suggested inviting more people to these educational meetings. People talked about the need for additional information through cable TV, commercials, public service announcements, tax returns, parent notices (schools), and websites. Finally, people agreed that we need more services in different languages.

## Cross Street AME Zion Church

At this church, a woman talked about struggling to find help for her addiction. She felt that she kept going through a “revolving door” of services until she found help from the Reverend at the church and attended a Bible recovery class. People also stressed the importance of talking about mental health issues openly without stigma. The pastor spoke passionately about the **importance of building health ministries to break down silos between health services**. She said that many places do not know how to embrace people who are lost. She also asserted, “In church, we need to understand that everyone has a problem.” Moreover, she said that many services are unconnected, that “they exist in their own bubble.” Another pastor said he needed to help his people take care of the spiritual and the physical.

People’s views on insurance varied. One person said, “Insurance is for everybody!” Another person signed up for insurance on the Exchange and six months later was asked to fill out redetermination forms to keep her insurance. The **cycle of redetermination forms felt relentless** to people. One woman said every 60 days they are shut off from insurance and have to complete a new redetermination form to renew. Another woman struggled to renew when Access Health CT, the state’s healthcare Exchange, refused to accept her application without verbal verification from her 10-year old son. They demanded to talk to her child over the phone. This conversation left this woman feeling mistrusted and unsure about her enrollment status. People also talked about the Affordable Care Act not being affordable. In terms of enrolling, people did not know they could go online or call to get help. People said that **barriers included both transportation and lack of education**. They agreed that every church needed to talk about health.

In terms of people’s concerns about the ACA, people talked about the **overwhelming number of questions for re-certification**. People wondered why they needed to fill out the entire form again if they already filled out the form once. They said sharing their personal information repeatedly was difficult. Other people talked about how phone access to Access Health CT was problematic. When people called, they were offered an **automated voice service** and they had to make choices that sometimes led them back to the beginning. This was frustrating for people.

When we discussed mental health, people talked about a fear of being judged. They said **African Americans do not feel okay talking about being depressed**. There was a lack of trust – people were prideful. They talked about needing to trust God to get through this because everyone has struggled.

There was also talk of church gossip and how it needs to be more considerate and “Christ-like.” People agreed that folks “should talk, not gossip.” Years ago, Black people said they **did not talk**

**to therapists for fear that their community will gossip** about them or cast them aside.

However, Black people agreed they would talk in a safe church setting. People also said they need to be educated about available services. Everyone acknowledged the need to find recovery communities and to talk about the issues. There was a lot of stigma.

This group, like many others, emphasized the **need to have more Community Conversations**. Participants appreciated the opportunity to learn and share with peers in a safe setting.

### **First Cathedral Church**

Participants at First Cathedral Church were eager to dive into the conversations. From the beginning people shared deeply about themselves and their perspectives. People complained about missing paperwork, a flawed system, and changes in enrollment policies from year to year. People also discussed the language barriers in the application process. The group agreed it is important to meet the community where they are. Participants dreamed and talked about what it would take for free insurance for all. Our Peer Health Navigator commented that this was her favorite Conversation to be a part of simply because the community was so open and willing to tackle difficult issues together.

In regards to mental illness – people said anyone could suffer from these issues. Therefore, it is important to understand how to relate and support people. Patients should be treated as human beings. We need to eliminate stigma. Nonetheless, some people felt they were walking on eggshells with family members suffering from mental illness. Many felt uneducated as to how to assist people who were struggling. People with mental health issues felt stigmatized with family, peers and co-workers. They felt as though they put family members through stress because they struggled with their diagnosis. The feelings of denial came from the suspicion that providers diagnose immediately and are too quick to prescribe drugs. People felt they needed an advocate. One Ph.D. student articulated the importance of talking with a patient’s family to understand the patient completely in order to diagnose correctly. People also discussed the importance of family members to engage with people in recovery from mental health or addiction issues.

Many aspects of the ACA stood out to participants. One was the imperative to publicly justify rate hikes. People suggested that Medicaid and ACA insurance cards should look just like private insurance cards. People also felt unable to understand how to navigate the exchange’s website and complained about the long hold time with Access Health CT. Many were unable to find a policy where the premium was affordable. Some people would rather take the tax

penalty than pay a high monthly premium. Participants asserted, “Health insurance does not equal health care.” People also discussed language barriers.

Some people talked about how Black people “don’t claim that” – which is a denial about illness and an avoidance of seeking quality treatment due to pride. Medical jargon was difficult on many people, and the African American community does not trust the medical community. People also admitted that doctors are human. They said, “Be your own advocate.” The faith community can help people navigate the system. People asserted that each person has the power to hire or fire their doctor. They also encouraged people to do their due diligence and ask the doctor many questions.

The penalty fee for being uninsured did not seem fair to participants. People questioned Medicaid vs. Medicare. They wanted to know what happened with a family status change. The group discussed culturally and linguistically appropriate services (CLAS) and wondered, “How do we educate people about ACA to make an educated decision?” Everyone agreed that people have to be prepared. Insurance is supposed to protect us. People also asserted, “We don’t have to know everything; it’s okay to say, ‘I don’t know.’”

To talk about mental health, people felt they needed more opportunities to talk about their challenges. People wanted to humble themselves, to get family support, to remove the stigma, and to get more education. Some people talked about the need for more conversations and being around positive people. People felt that love for others helps, as does understanding behaviors. Meeting a person where they are and establishing trust are also positive. Negative feelings such as guilt, hurt, shame, anger, and embarrassment stopped people from talking about their mental health and addiction issues. Fear and not knowing what to say or lack of understanding also prevented people from talking. One woman said she just wanted to be viewed as normal.

In terms of Essential Health Benefits, people felt that emergency services were most important to them. One participant felt these services were important to be covered, “just in case we need it.” Other Essential Health Benefits worth noting include coverage of hospitalization, rehabilitation services and devices, prescription drugs, and preventive services. People also appreciated the fact that mental health was covered; one person was interested in learning more about eating disorders. Others wondered whether everyone with mental health issues was covered under the Essential Health Benefits.

People agreed that having a primary care physician (PCP) was important. They felt that PCPs knew their history, worked on preventative care, and helped them avoid the Emergency

Department. Additionally, people liked that PCPs knew them personally. People also wanted to talk about co-payments and acknowledged that supplemental income is not enough to pay medical bills.

To educate people so they better understand the ACA, people said hold more community forums. They also said, “Don’t assume! Ask.” Participants agreed that it was important to educate yourself first. Do not force it on anyone. To continue educating people, the group suggested having sessions like this. People also talked about referring others to an agent. Many people thought it was important to share personal experiences and invite others to a training about the ACA.

To do a better job of reaching people, the group said we needed to work with Access Health CT. Other organizations to involve are the welfare office, the Social Security Administration, and the Department of Mental Health and Addiction Services (DMHAS). Local mental health agencies to involve include Chrysalis Center, Connecticut Mental Health Association (CMHA), Community Health Association (CHA), the Urban League, the Veterans’ Administration, shelters, food banks, and the Central Access Network (CAN).

In terms of improvements, people felt that there should be education for service workers dealing with mental illness. People also wanted better emergency rooms to handle mental health cases, and better follow-up for medical staff. At First Cathedral, there was training from a doctoral student to help those with mental health issues. People talked about alternatives to calling police for mental health crises. Everyone agreed that healthcare needed to have more people of color working in the field. There should also be a spiritual doctor for people, as well as specialized case management. More people with mental illness working in the field might help too. People talked about recovery specialists and provision for sensitivity training. Educating church members was also important to people. Finally, people talked about early detection of mental health issues.

In terms of advocacy, people think that they have a voice at the state level. Voting is a way to petition.

To help others, people want to develop a relationship with someone who struggles with substance abuse or mental health, saying “each one teach one.” People believe that doctors need to get more involved in the treatment plan of the patient. The group advocated for speaking up against injustice against those suffering from mental health issues. People agreed it is important to call out disrespectful behavior immediately.

Folks also said we needed to educate children to be tolerant of others with mental illness or physical disabilities. There should be zero tolerance for bullying, and we should provide encouragement for positive, compassionate behavior. People said we ought to advocate for ourselves.

In terms of early detection, parents are the first to know something is wrong. They should go with their gut feeling and identify irregular behaviors from their children. They should ask for assistance and acknowledge there is an issue. Caregivers can also keep parents informed of changes in behavior or mood. Hence, training caregivers on changes in behavior is important. People said there should be collaborative assistance with physical and mental illness in the schools.

### Grace Church

People at Grace Church shared many stories about their experiences with healthcare. One woman was dismissed from the hospital, even though she was not well, when insurance ran out. Another person said treatment that people receive in mental health facilities is bad and wondered what can be done. The pastor of Grace Church recounted a story where in his work as a probation officer, one of his young clients kept being caught and going to jail. The child admitted he intentionally got in jail to have medical care.

People liked that under the ACA, **no one can be denied benefits even if they had pre-existing conditions**. While no one had signed up for the ACA, **people heard the ACA coverage was better than that of employers**.

People felt the biggest challenges had to do with lack of information. **Access to information is difficult and issues of trust had to be addressed**. Because the ACA was something new, people needed to trust its reliability. In terms of cultural background, **people felt being Black resulted in a communication issue with health providers**. People felt that doctors should explain more about the medical procedures.

The Essential Health Benefits that stuck out most to people were vision, dental and overall wellness benefits. They also liked pediatric care under age 19. Most people agreed that **having a primary care physician was positive and necessary**. One person did not have a problem using a walk-in clinic, but she said that is because she can self-advocate.

Participants thought that **churches were a positive place to advertise about the ACA**. People think that everyone needs to speak up to ensure that everyone can get health insurance. One

resource cited was 2-1-1. The group felt that the community needed more resources available 24/7. They also wanted more warm lines and respite beds for people.

To help others access better health care, people wanted to schedule more Community Conversations, and **create inserts for church programs to share**. On this insert, people suggested having information on enrollment, explanations of the ACA, the penalty costs, and myths and facts about the ACA.

### **Grace Church (Group II)**

In this conversation, people talked about how the **elderly are afraid of going to get information on coverage**. To reach the community, people suggested leveraging churches and engaging with advocates. People wondered, “How do we make the services available to everyone?” Others noted, “You cannot find a problem if you do not know you have it.” Self-awareness is a big part of seeking out help. To do this, people suggested doing door-to-door outreach, reaching people where they are, and addressing cultural competencies. People also wanted to make the Access Health phone number well known (it is 1-855-805-4325).

Once people get insurance, the recommendation is to make a list of things to talk to the doctor about before going.

There is a huge issue with health care for the homeless. They are not aware of available services. To address this issue, information should be stated clearly about available services. Doctors need to state clearly the situation their patient is facing.

In terms of addressing mental health, people think that churches should be available for people to talk about these issues. Pastors should encourage people to get help. There should be support groups and counseling available, and people should share these resources. We must make services available for someone who needs the services instantly.

People’s impressions of the Essential Health Benefits were overwhelmingly positive. People liked the **inclusion of dental and vision benefits, especially for children**. They also enjoyed the wellness benefits, preventive care, and coverage at parity for mental health and addiction, including rehabilitation and aftercare.

People seemed to **know why it is important to have a primary care physician**. They cited that they would receive better care, have someone who knows them, get comfortable with a

consistent person, build a relationship, avoid the Emergency Department or urgent care, have one place for medical history, and hopefully get better advice and quality care.

To educate people about the ACA, people think there should be a variety of techniques. Among them, people talked about engaging churches, posting positive ads on buses and shelters, using social media, offering referrals, word-of-mouth, teaching people about the penalties for not having insurance, door-to-door contact, posting in malls and schools, and starting a church ministry focused on health care.

In terms of what is being done well, people liked our ACA Community Conversations and the supporting materials. They also thought enrollment support within towns that were town-sponsored were great. Finally, people **liked help from the Access Health CT Navigators**.

For resources, people talked about the Access Health CT website. People also discussed calling 2-1-1, using Google to find out more information, and looking for support groups for specific illnesses. Other resources included the Department of Social Services, church members, and State Representatives and Senators.

People had a few ideas for mental health and addiction services. They wanted more resources available 24/7. They wanted **more “warm lines.”** The NCRMHB resource list was cited as useful. People also thought we could offer more support groups for mental health conditions. Finally, people wanted to **create respite locations rather than use in-patient hospital services**.

People felt that they could take a few actions to help others with accessing health care. Some folks talked about building a **buddy system to mentor others**. Others thought they could provide support as needed. People talked about advocating for more services with State Representatives. People also wanted to research funding opportunities and follow up on the Community Conversation. People wanted to commit to telling at least one person about the ACA.

When we discussed challenges, people talked about the **lack of information**. The access to information is poor. Therefore, signing up becomes a difficult process. People wondered whether there was a fee to sign up.

Many people learned for the first time that signing up was free, and that people’s income determines the cost of insurance via the ACA.

## Phillips Metropolitan Church

At Phillips Metropolitan Church, people talked about eligibility issues in terms of their experiences with the ACA. It was unclear what was required for eligibility. People wondered whether college students out-of-state qualified for Medicaid.

When people discussed mental health or addiction, they discussed what they knew about depression, anxiety, and bipolar issues. People discussed proper medications and dosages. They also talked about relationships with providers and the need for help to navigate through the system. People discussed their struggles to express their needs to providers. Folks agreed that young adults especially needed support.

People talked about the need to have an eligibility specialist in clinics to help people understand benefits. When more people have insurance, there is more access to health care, and people are able to use services. However, this also means increased wait times. People discussed the myth about whether there is a cap on the amount of patients with affordable care. Many folks were concerned about potential high deductibles. People also wondered how insurance companies were held accountable.

There was discussion about whether people can get cheaper rates with the ACA or Husky (Medicaid). People were concerned about an increased premium. They also worried about complications with asking for tax information for the ACA.

Many felt that the ACA had a difficult application process that was not user friendly. People said that customer service representatives were not consistent. Accessibility to enrollment was also inconsistent. People wondered, “Where are walk-in centers?” Communities need more conversations about the ACA. Community Conversations provide more exposure to the facts and information. Currently people felt that there is no trust with the medical community among African Americans. There are not that many medical professionals of color, which creates tension between patients of color.

Participants had many questions about health insurance. One question was, “When does someone qualify for Medicare?” Another was, “How do people pay for ACA penalties?” People also wondered whether the ACA included dental.

**In terms of mental health, people were concerned about stigma.** They felt that mental health stigma could affect their job. Many felt that their entire life was tagged with labels and pre-judgments. Most people chose not to disclose their mental health issue to someone unless they

were an advocate. Some people may have endured physical abuse for their mental health issues. People also talked about stereotypes. It is assumed you are “slow” or violent if you have a mental illness. Professionals worried about HR disclosure and making the workplace uncomfortable by talking about their condition.

People with addictions do not want to be labeled as having a mental illness. People also talked about how some folks with mental health struggles may self-medicate, which adds addiction to their struggles. People in recovery who take medication may have challenges with substance use. There was concern about overdose due to co-mingling medicine. Some folks admitted they go to Alcoholics Anonymous (AA) and do not disclose they are taking medication due to the stigma against mental illness.

In terms of Essential Health Benefits, people agreed that laboratory services were very important. People also appreciated referral lines. Folks call insurance companies that are “in network” by learning about them via word-of-mouth. People appreciated knowing their rights. They wondered about caps on what doctors are charging to save on health insurance costs.

For next steps, people believed deeply in churches getting involved. There should also be more Community Conversations. People said that information is best spread by talking at church or work, via word-of-mouth, using a grass-roots approach, and more one-one conversations. Some resources people mentioned include Access Health CT’s website, DSS, the doctor’s office, 2-1-1, and utilizing enrollment centers.

One of the top Action Plans was to reduce the stigma of mental health issues by having small community conversations. People also thought it would be important to increase the number of qualified providers who accept ACA and Husky (Medicaid) insurance.

People wanted to figure out how to offer “one stop shopping” for medications, treatment advocates, and primary care providers, as well as make “collaborative care” the norm not the exception. Another idea was to promote a support team for people with mental health issues.

One idea involved creating forums to identify disability issues at earlier stages, perhaps as early as high school, which could be tied to afterschool programs. People thought it would be a good idea to have halfway homes for young people with mental health issues to get back on their feet. People also wanted more “halfway houses” or re-entry programs for people who are released from mental facilities.

People agreed there needs to be early detection for better treatment and to better educate teachers about mental health and addiction issues. A last Action Plan was to have more people working in the field who have had a mental illness.

### Spottswood

Many challenges with the ACA surfaced in this Community Conversation. One person shared that people with Medicare have 20% out-of-pocket expenses. Another person said he was unable to seek help, not motivated to look, and overwhelmed. People felt that they did not know their rights. One person shared a story about how in the Marketplace, Navigators told people over 65 that they cannot get help. This is a concern because many people over 65 are on a fixed budget, and they cannot afford insurance or are dropped from coverage. One 70-year old woman was told, “You do not qualify for coverage.”

People talked about the gap in knowledge regarding insurance coverage. Some folks said they may be educated but they still do not understand what the ACA offers. For this reason, people wanted to simplify the language of the ACA to get an explanation of what the policy means. People felt they **needed to be assertive in getting an understanding of the ACA**. Via the Conversations, people learned for the first time that those who are on Medicaid or Title 19 (making \$16,000 or less) could not get on Obamacare. People wanted to know if the ACA offered dental and eye care. Many wondered about the age limit to enroll for the ACA.

Another frustration stemmed from the fact that people had to submit documentation and were often rejected due to mistakes in filling out forms or missing paperwork. Everyone agreed that documentation was difficult. People who were educated struggled with documentation and people who lacked literacy fared even worse. Paperwork was difficult to fill out and mail back. Many suspected that Access Health CT lost their forms. People were regularly dropped from their insurance plans due to “lack of documentation.” One woman’s mom was **dropped from her prescription insurance do to “lack of documentation” despite submitting everything on time, and she had to wait months to re-enroll.**

In terms of what prevented people from talking about mental health and addiction, people cited a variety of factors. These include shame and stigma, the label of having a mental illness, lack of knowledge, and lack of family support. People may also be in denial, not recognizing mental illness, or against taking medication. Some people feel that others may blame them for suffering with mental illness, that something they are doing is causing the problem. They may

fear isolation, so they do not talk about mental health struggles. People think most folks would avoid a person with mental health issues.

To get the word out about the ACA, people had a myriad of ideas. They included announcement on websites, flat screens, newspapers, churches, shelters, newsletters, Sunday bulletins, and emails. Many also thought it would be a good idea to have more Community Conversations. People also thought CPTV public information television could help spread the word. Civic organizations, the NAACP, and Social Service Agencies were also cited as useful organizations to spread the word.

Participants from this congregation thought that each church should have a representative to talk to the insurance commissioner. This way they can contest rate hikes and have a health advocate on a congregation level. People also discussed the need to collaborate and not be doing the same work separately in silos.

Three pastors participated in this conversation, which helped enrich it with a breadth of perspective. One pastor helped people sign up for the ACA but had **no idea that the ACA helped with mental health and addiction issues**. Another pastor started a group called Community Partners in Action (CPA) that helped people with health care access. He talked about how great it was that a Black president made widespread insurance accessible, but now people claim it does not work. He sees it as the work of the church to address this issue.

In the past, people were turned down from insurance due to pre-existing conditions. They need to be told they can get insurance now. People felt they needed an outreach program to tell people about benefits and that they could do it as a church. People also talked about how health insurance does not pay for everything and how people need to be aware of copays and deductibles. Some people were surprised that if you have Medicare you are no longer eligible for the ACA. People interpreted this as an age limit to enroll in the ACA.

Many participants feel that Black families try to fix situations by themselves. Not everyone has an advocate in the family. Therefore, many families struggle alone with mental health or addiction issues.

A social worker was also a church member and offered help with follow-up. People also discussed developing a Health Literacy training, which would be 5-6 hours over the course of one day. Spottswood would be able to help others via the train-the-trainer concept. The purpose of the training is to help others walk through insurance plans and maximize primary care visits. The church also wanted to have a person knowledgeable about the role of the Insurance Commissioner.

Some Action Ideas included church support groups. These groups would research alternative programs, promote respite care, and offer re-entry support workshops. Another idea was to collaborate with other programs, especially Chrysalis Center and Advocacy Unlimited. Chrysalis Center is a local mental health agency. People see their church as a place of support, and Spottswood wanted to offer workshops to inform others about available programs. Peer Advocacy and building health ministries in the church seemed important to participants.

### Vision of Faith Church

A few people said they were at **“ground zero” with their knowledge about the ACA**. One woman tried to sign up for the ACA and decided it was not worth it. She was told to pay \$500 per year and thought it was too expensive. She wanted to know why she needed insurance, and thought it would be a waste of money if she never got sick. Another woman was on Medicaid but thought she had ACA insurance. She liked her insurance aside from her limits on buying medications.

People found it interesting that **pre-existing conditions cannot preclude people from getting insurance**. They liked that anyone could be covered, regardless of previous conditions. Many moms appreciated that their kids had coverage up to age 26 under their parents’ plan.

The **biggest challenge for people signing up was costs**. The premiums were often more than what people could afford in their monthly expenses. Other challenges included knowing where to sign up, access to enrollment information, finding PCPs and doctors to use in addition to understanding what providers take the plan, whether they qualify, and encountering misinformation and prejudices in the system.

Among all the myths and facts, **penalties struck people the most**. People were surprised at the amount and how much the penalties rose in the last couple of years. They also wanted to know how the penalties would be deducted and how to avoid them.

In terms of what it takes to get people to talk about mental health, people talked about a range of challenges. The first issue is the amount of time with clinicians is too short. People only get **15 minutes with a psychiatrist and this is not enough**. It is hard to talk about mental health issues so people need a community, trust, and an anti-stigma campaign. Moreover, there are not very many Black women providers in the mental health field, which is alienating to Black women seeking clinical care. Participants worry about doctors not understanding or thinking that they are different or crazy. They also do not want to go to the hospital because they think they will just get medications. They want someone to listen.

Concerning substance use, participants talked about how groups like Alcoholics Anonymous (AA) could introduce people to other drugs. One person shared that “people who are weak pull others down. Those people are in the group for the wrong reasons.” Another person pointed out that **most users start abusing due to mental health issues** or because they do not have anyone to talk to. Therefore, everything starts to go downhill once they use drugs to cover up their mental health issues.

Another frustration is in AA meetings people are asked to say, “I am an addict.” For some people, this statement traps them into this identity. Our Peer Health Navigator talked about an alternative group called Double Trouble, which is for co-occurring issues to support both mental health and addiction. People talked about how **being part of the right group helps**. Everyone agreed that having groups with peers is useful. People must have lived experience to be able to help others struggling with mental health or addiction.

For Essential Health Benefits, people talked about how amazing it is that **weight loss programs were covered under the ACA**.

To better educate people, participants talked about **having more small groups like Community Conversations**. They also recommended commercials, passing out fliers to people, inviting people to group meetings, and sharing brochures with relevant information. One woman stated, “In the Black community, people do not want others to know what they do not know” but “knowledge is power!” Everyone agreed it is important to share information.

People appreciated the format of the Community Conversations because it gave them room to talk and to ask questions. They said that insurance professionals only wanted them to sign the papers rather than talk about it and that kind of pressure made them less interested in enrolling.

# Community Conversations: PRO/RCOs

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## Connecticut Community for Addiction Recovery (CCAR)

At CCAR, some people felt tricked by the system. One man was told that the ACA would cover anything and everything, and he could not be cut off for 5 years, which proved to be false. People were not clear about what to expect and felt that they signed up for insurance based on misinformation.

Folks at CCAR felt that the Community Conversation “Myths & Facts” section stimulated a lot of discussion. A myth that stuck out most to people was about **penalties for having no insurance**. People felt that these penalties were too high. Others felt that there should be penalties for doctors who do not accept the ACA insurance. Ultimately, people felt that it is up to a person if they want insurance or not.

Challenges with the ACA included the fact that some people’s premiums increased and some **people were dropped from their insurance, probably due to documentation issues** during the transition. Another challenge was potentially not being able to stay with their doctor through health coverage transitions.

Many shared **problems with Access Health CT losing paperwork**. Access Health reportedly does a poor job at filing and receiving paperwork. According to some people, Access Health CT asked for original documents, which they reportedly did not return. Some people wondered whether Access Health had enough people doing the job of enrollment.

Many people had **questions about ACA’s insurance coverage**. It was unclear to many why some doctors do or do not accept certain insurance. People appreciated that Obama recognized that people did not have insurance, and now the legislation is in place to ensure that everyone can have insurance. Because of this, people thought the ACA is important. Nonetheless, there was a lot of confusion about how to learn about the ACA and access it. People did not even know dates for the application deadline.

People liked that the ACA made health insurance affordable, that people cannot be denied benefits, and that insurance must cover the 10 Essential Health Benefits. In particular, people appreciated prescription benefits. These benefits were especially helpful for older people. They also liked coverage for wellness programs. People had concerns about doctors having their updated medical records and prescribing something that interacts with their medications that

may hurt them. People also did not want to see multiple doctors. They just wanted their primary care physician to help.

In terms of language and cultural competency, people perceived a **lack of interpreters**. Access Health CT reportedly does not offer phone support for people speaking different languages. Once enrolled, people found that healthcare providers still struggled with cultural background differences and language barriers. People complained that in seeking primary care, they are not told that providers can offer an interpreter. Some people felt that patients should not have to ask about interpreter options. This added to distrust of the system.

To improve access to care, people suggested that we should post information in inner cities and other places so people understand what to do. People believe that cultural barriers play a role. “If you don’t have access to the information, you wouldn’t understand what to do.”

People wondered whether future elections would affect the ACA. They are concerned that Obamacare will cease after Obama leaves office.

In terms of mental health and addiction, people shared that they do not want to be a zombie and sleep all day. One person shared that her doctor prescribed meds with side effects she does not like, so she does not take them. People agreed that there was more than one way to deal with mental health and addiction.

People do not get mental health treatment because of the labeling and the stigma. There needs to be more education about mental health and education to help recognize the signs of crisis. People with mental health issues also need to know how to access health care. People acknowledged that the public thinks you have to look a certain way to be mentally ill but this is not the case. **Anyone can suffer in silence**. People also think that locked doors at treatment facilities feed into stigma. There was an interest in teaching people not to treat folks in recovery in discriminating ways.

People felt like they needed to **stop negative talk about mental health and addiction**. Confidentiality, peer support, addressing trust issues, putting a face on mental health, and overcoming comfort issues all help people talk about mental health. What prevented people from talking about mental health included criticism, shame, fear, lack of support, nightmares, and ignorance. As for addiction – it was difficult for people to discuss this issue because some people felt that addiction is a “choice.” People need to understand addiction and be compassionate. Activities that helped people talk about addiction include meetings, peer

support, finding help from someone who cares, and therapy. One person had medical issues that prompted them to seek medical care, and this helped them address their addiction issues.

Some people were thankful to have the ACA because it offers **continuous coverage regardless of employment status**. People said, “COBRA is limited, the ACA is not!”

There is still a lot of confusion about the ACA. Many people **think they have Obamacare but they actually have Husky D (Medicaid)**.

Most people treat insurance similar to the way they treat a car alarm system – they only find it useful in cases of emergency. However, one person said we needed to make health insurance use into a movement. We need to take our health into our own hands. People also talked about the importance of self-advocacy. They say that doctors do not tell patients this information.

Many wanted to have more Community Conversations to discuss healthcare access issues and to learn “what does this do for me?” Many folks said we needed to go to the communities in churches, at libraries, at soup kitchens, in halfway houses, in community centers, at doctor’s offices, and at Intensive Outpatient Programs (IOPs) to organize conversations. At the DSS office, people often have to wait a long time for their appointment. Hence, this could be a good place to pass out information. People wanted to walk around neighborhoods and give others information on street corners or via word of mouth. The group felt there needed to be more grassroots movements and education from a community level. People want to offer sweat equity or volunteer time to this effort.

In terms of improving mental health and addiction services, people agreed that we needed **more (inpatient mental health and addiction treatment) beds in the state**. There is a lapse in resources for adolescents. We need to shorten the length of time to see a psychiatrist.

### **InterCommunity (IC)**

At this peer recovery organization, we heard from many people with lived experiences. These folks talked about how their **recovery affected their access to health** and their various perspectives on the ACA. One person said insurance via the ACA is too expensive. Another person said the ACA is working, but people who do not qualify based on income continue to struggle. Others believed that mental health issues were helped only by providers who accept insurance from the ACA. Somebody talked about how she was denied coverage three times for unclear reasons. One person has had both Husky (Medicaid) and insurance under the ACA, and she has not had a problem with either insurance. She has had regular checkups.

People also talked about how **different providers offered different levels of care**. One woman described how she had different experiences with providers in East Hartford than in New Britain.

Some challenges people discussed included **confusion about what to do for a 26-year old** in terms of insurance. Some people felt that staff and healthcare insurers do not listen. In the community, people were **afraid of losing Obamacare when Obama leaves office**. There was a perception that the ACA will not help certain women or seniors.

One man went to Access Health CT and waited over 2 hours to talk to a Navigator. Finally, he filled out his paperwork, only to have someone tell him that there was no appropriate plan for him. This man's social worker had encouraged him to get health insurance via the ACA. Therefore, when he came back without enrolling, the social worker rejected him as a client.

Another woman shared that even though she was insured, she felt the use of Emergency Departments (EDs) was easier than using a primary care physician. She said EDs offered the fastest service, that the walk-in clinic takes too long with an average 2.5 hours wait time, and that it was better for her to go to the ED once a month than go to her primary care physician. This clearly demonstrates that **more work needs to be done to help people understand and utilize the preventive system of care, or people will continue to rely on EDs**. This woman uses the ED monthly for dialysis because even though she has health insurance, she believes EDs are the most efficient use of her time and insurance coverage.

Talking about mental health was difficult due to discrimination at work, embarrassment, or feeling self-conscious. The day program at InterCommunity was helpful for people in recovery to socialize and learn new skills. However, outside of that, people struggled with confidence.

### Toivo

This conversation was comprised of entirely Black people who had lived experience. They were all taking a recovery skills class with our Peer Health Navigator. People talked about their many struggles with the ACA. Among them, one formerly homeless man **struggled with the website for enrollment**, so it left him with a bad vibe about the ACA. Other people asserted that the **website was down a lot**. A woman who was a pharmacy technician shared her frustrations with the broken website and how that affected her work. Another problem is when people are in between transitions, they have no money for prescriptions and insurance does not cover this.

Another person found a troubling loophole in the system. She discovered that **Access Health CT does not talk to the Department of Social Services (DSS)**. When she sent information to DSS, it

did not go to Access Health CT. One woman tried to sign up but they lost her paperwork. The run-around with DSS, Husky, and Access Health CT was difficult for people.

One person who has been on Medicaid does not feel like anything has changed. She continued to feel limited in terms of providers she could use. While the ACA expands Medicaid so more people can be enrolled, the **ACA does not seem to provide more health access options for people on Medicaid.**

**For young adults, information needs to be more accessible** and sending information to Access Health CT needs to be streamlined. Otherwise, people believe this group will not use health insurance.

Finally, one person recovering from addiction stated that he struggled with homelessness, and when he came into the hospitals, he was given opioid drugs, which he wanted to avoid. **Health providers must understand how to better help people with addictions.** Just because someone is sober does not mean his addictions have vanished. When a person with addiction seeks help in a hospital, they are especially vulnerable to relapse. Hence, doctors should be sensitive to offering these clients medications.

People were impressed with the ACA discounts at pharmacies. Folks also discussed the possibility of “doubling up” on insurance or enrolling in the ACA to cover certain issues as well as enrolling in another insurance to cover other health conditions.

A big **challenge of the ACA is the lack of knowledge about eligibility.** People agree that many folks assume that they are not eligible for the ACA. However, they just need to know more about the ACA. Some people said, “The ACA should be talked about religiously.” However, people do not know where to start, cannot find an accessible computer, need computer literacy, need more information about how to get help, and need to know more about Access Health CT. People also struggled with the **cost of premiums.**

In terms of how people’s cultural background affected their ability to get quality health care, people talked about how **preconceived notions of African Americans affect the way physicians treated them.** When in a doctor’s office, one woman said she felt judged for the way she is dressed. She did not feel heard, and she felt there was a stigma with Black culture. People talked about how **they need people in doctors’ offices to have compassion for Black patients.** They feel that state workers are rude. People also said, “Those who abuse benefits ruin it for the rest of Black people.”

One of the participants was a homeless man in Hartford, and when he was brought to the Hartford Hospital ED, he was given Percocet and Vicodin even though he just needed a place to

stay. He felt offended and thought **doctors stereotyped Black clients, thinking that Black people just want to be medicated.**

People also talked about how it is easier to go to the DSS office than to Access Health CT for help with health insurance. They agreed **that Access Health CT needed to put an office in the North End of Hartford** because many Black people do not have phone or internet in this area, and people needed a physical place to go in this predominantly Black neighborhood. This proposed Access Health CT office would also need a Spanish-speaking and culturally competent staff.

Another problem people discussed was that doctors stocked shelves with the newest samples of drugs. This is not helpful for people who need the same drugs consistently.

When we talked about ACA myths and facts, the myth that stuck out most to people was the one that discussed how **the ACA might be less expensive than employer insurance.** People also remarked on the myth about penalties, and discussed their confusion over Open Enrollment.

Participants were **curious about the communications gap between DSS and Access Health CT.** These are the two state organizations tasked with figuring out how to offer insurance under the Exchange. Many wondered why paperwork got lost between the two agencies. The two agencies also do not seem to share information. Therefore, even if someone had all their paperwork in with DSS, they still have to submit separately with Access Health CT. Several people mailed their forms into DSS and Access Health CT and heard that their paperwork was received at DSS but missing at Access Health. This affects benefits and causes delays in people's ability to access health care.

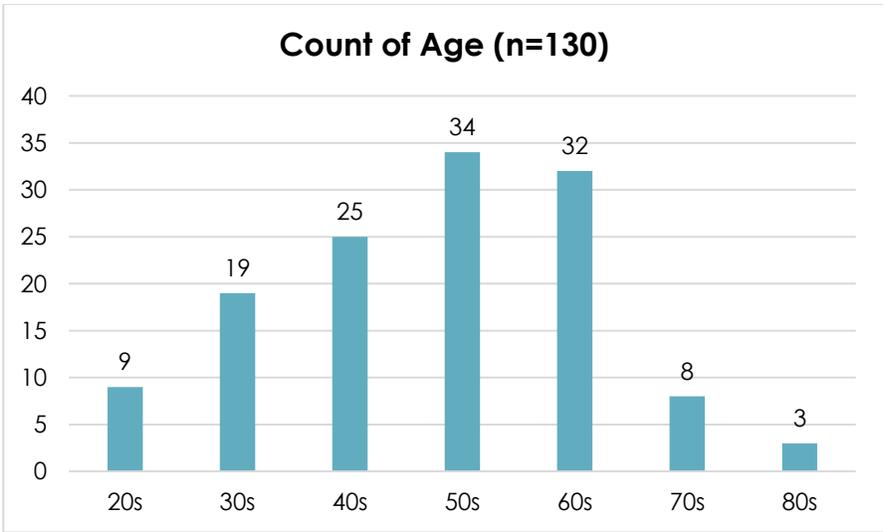
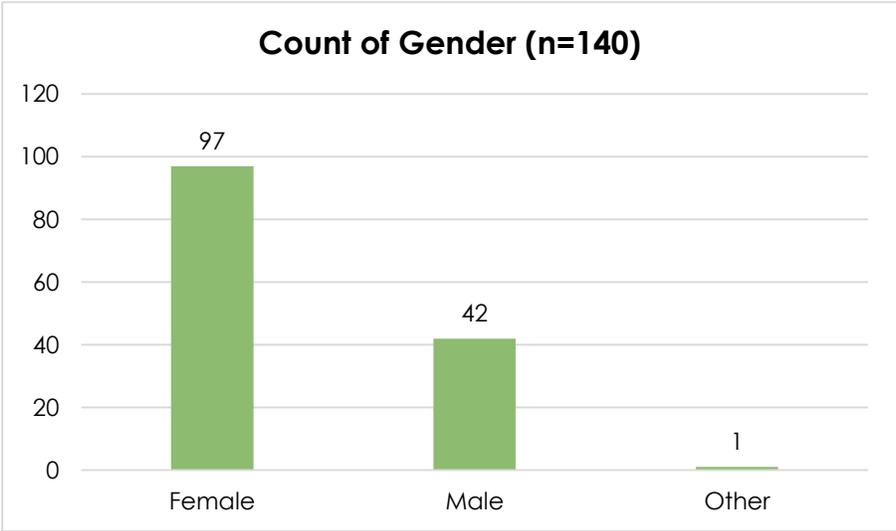
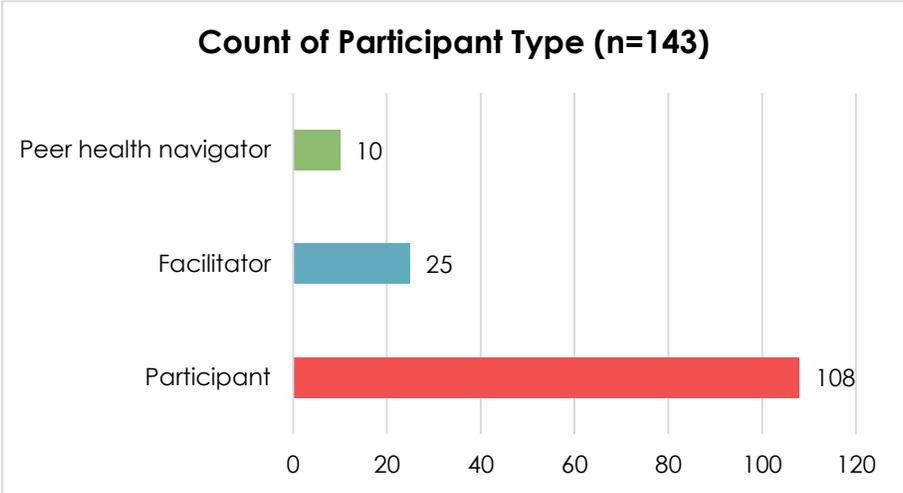
When we discussed mental health challenges – people talked about how someone who looks normal can have issues, but it is difficult to discuss this. In the dating realm, it is **difficult to share mental health issues due to fear of rejection.** One person expressed anguish over knowing when or how to disclose their mental health issue to a new romantic partner. The stigma makes it difficult to share. Ministers try to solve mental health issues with religion. This resonates with some people but not others. People said **Black people do not discuss mental health issues but they might discuss substance use.** Some people found that the “Alternatives to Suicide Group” available at a local mental health agency was helpful. However, outside the group people cannot discuss suicide. Overall, **people needed more advocates with some degree of life experience who feel comfortable with sharing what they have experienced.** People also need more education about mental health and addiction. They agreed that support groups, overcoming boundaries, becoming more self-confident and admitting they need help all

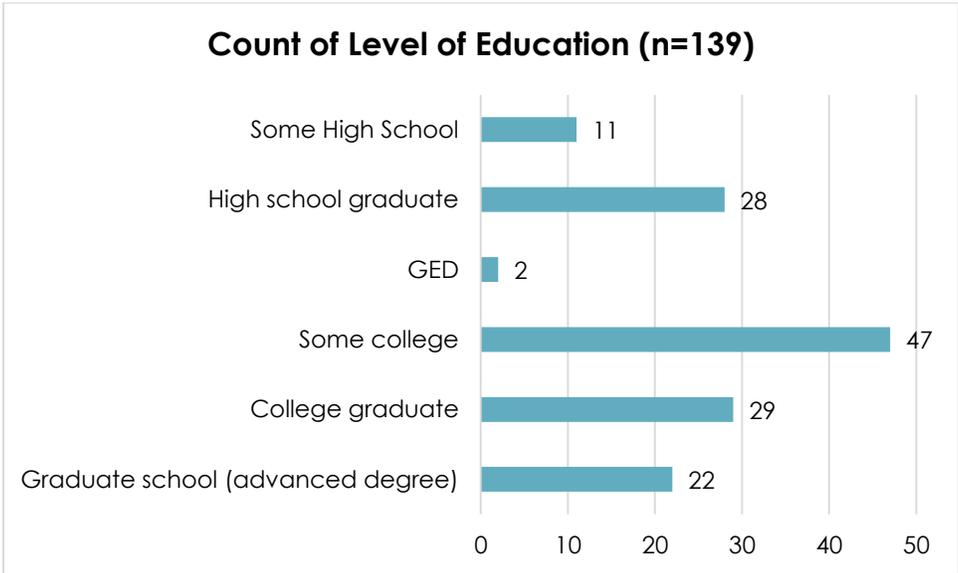
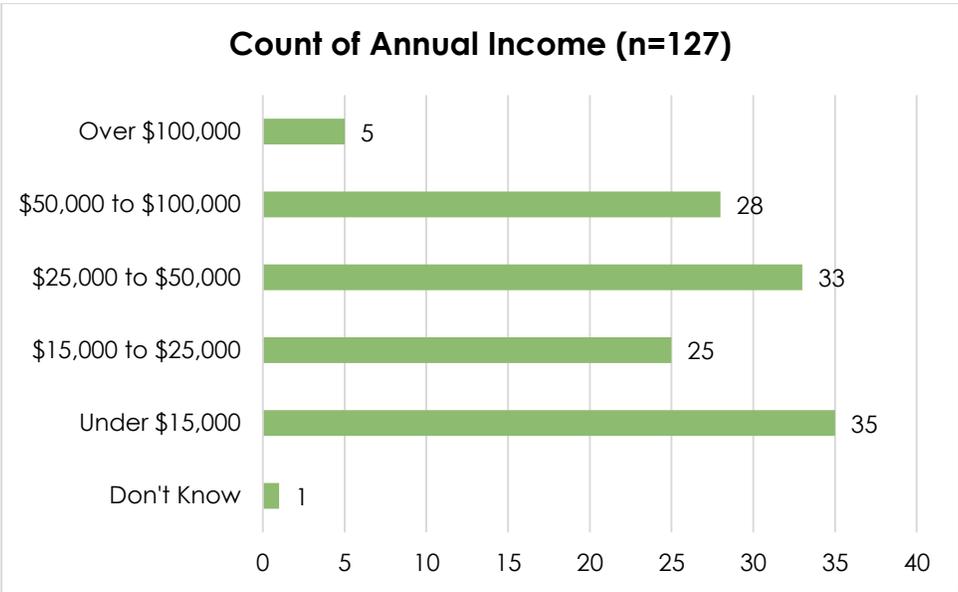
contributed to more open discussions about mental health. People think that self-awareness leads to more self-control over mental health and addiction issues.

With Essential Health Benefits, people said **chronic disease management, including mental health and addiction issues, were most important to them.** In order to help others better understand the ACA, people wanted to share information at clinics and hospitals. They also wanted to **offer more Community Conversations** and give out pamphlets. People really liked the Community Conversations model because it “got people talking” and engaged people. Finally, people thought presentations with mental health and addiction support groups could help. People wanted to address misinformation, find “middlemen” to help people sign up for the ACA, shut down insurance brokers who are not from a qualified agency, and educate people about how the process works. Many people **did not know that signing up for the ACA was free.** Now that they know, they wanted to tell others. Other thoughts included educating people that there is a choice between employer insurance and the ACA. Some folks felt there needed to be better efforts at reaching people with employer insurance, perhaps involving companies to share information about the ACA with their employees.

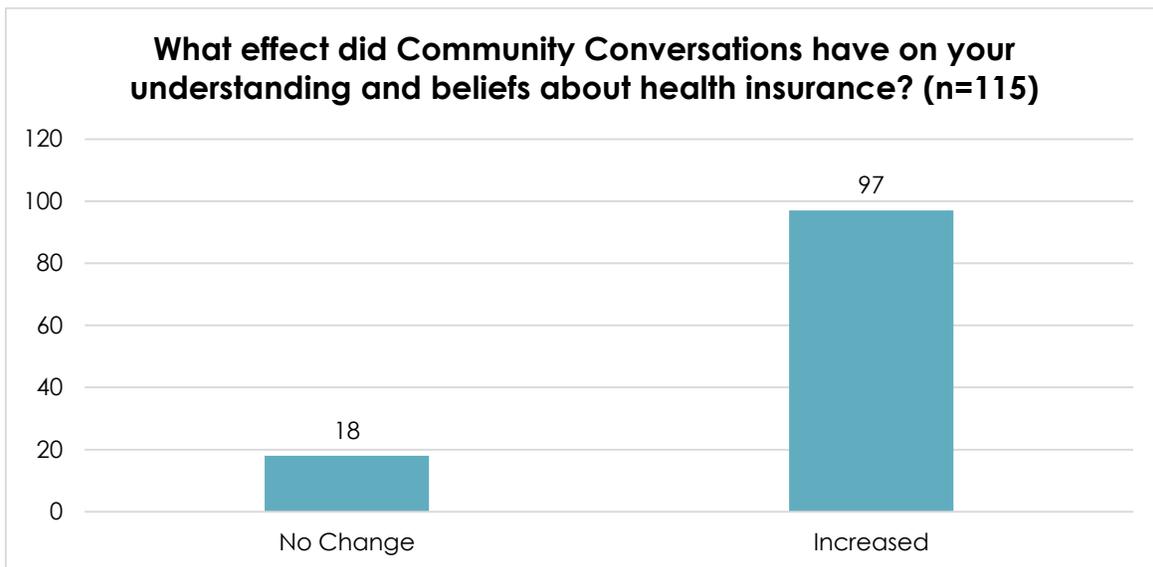
There is a **perception that the ACA is not helping.** People think we need to have better education that empowers people and we need more advocacy for people. They also say that we need to do more public service announcements, reach parents via schools, and maybe even organize a “health walk” to raise awareness. There is a role for churches, the YWCA, and other community organizations to help people access better healthcare.

# Participant Demographics

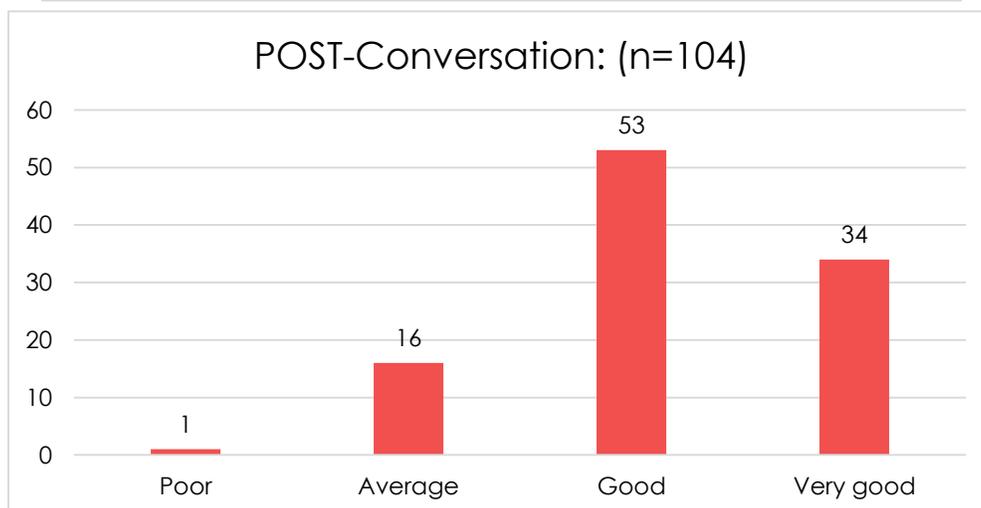
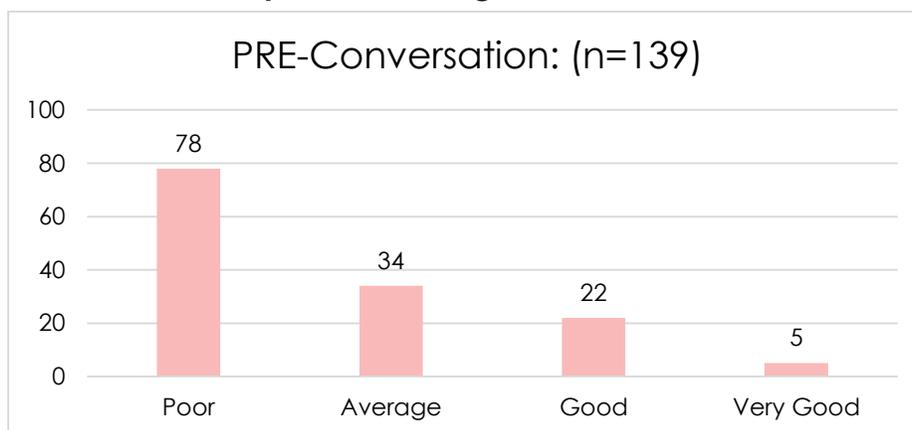


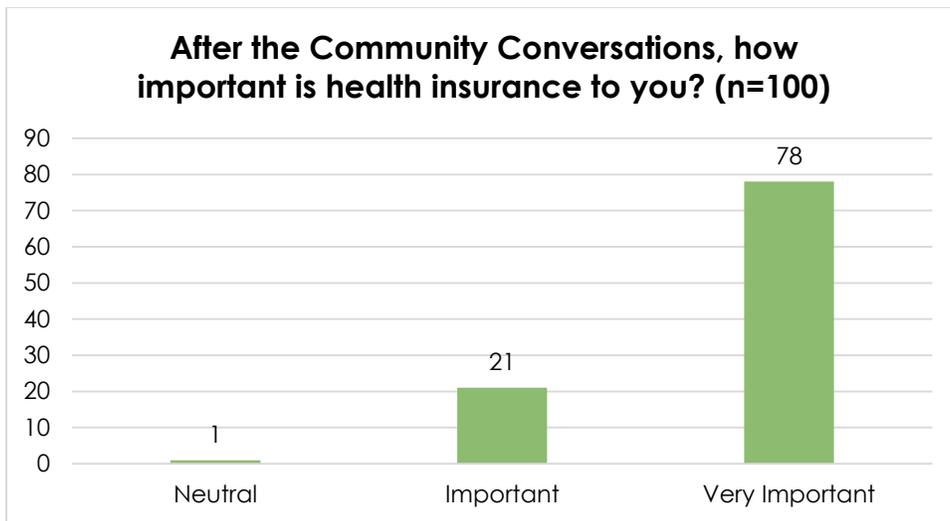


# Survey Results

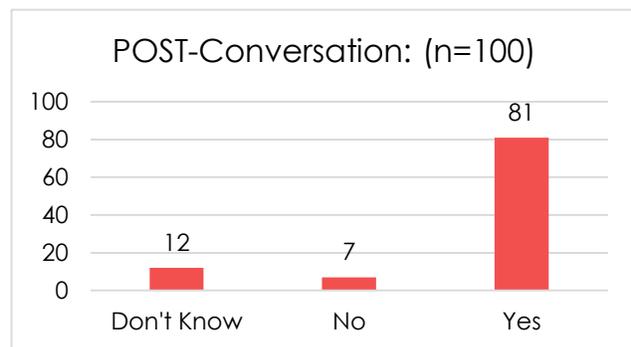
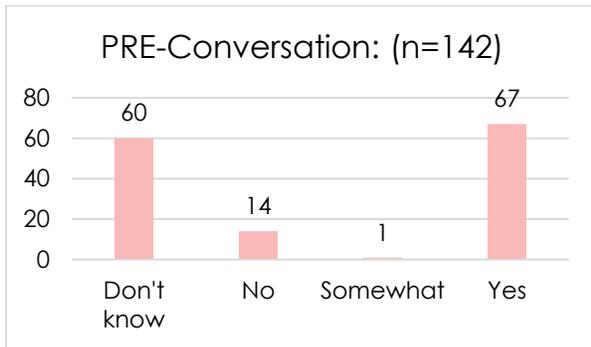


## What is your knowledge level of the ACA?

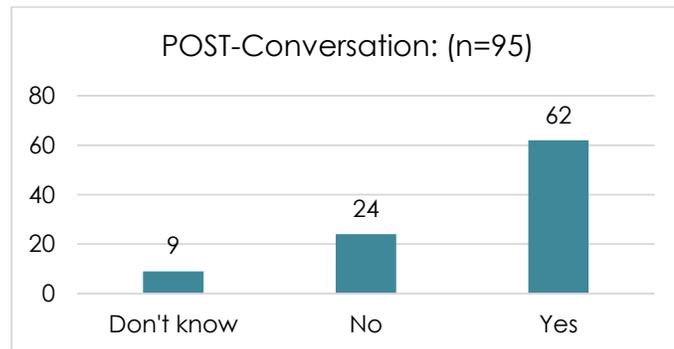
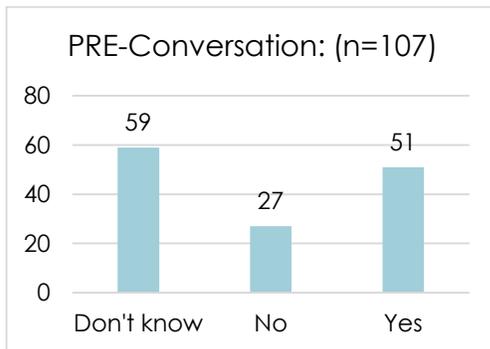




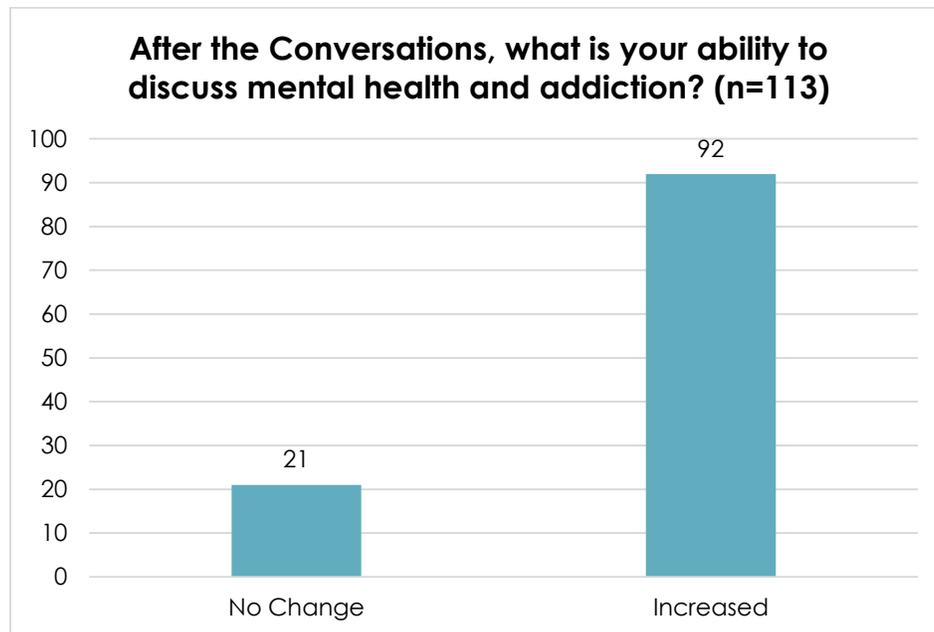
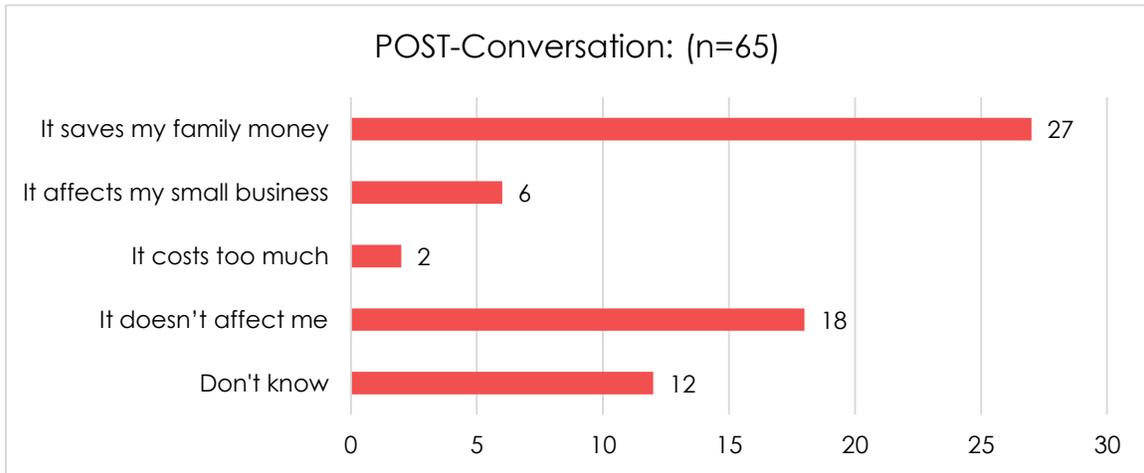
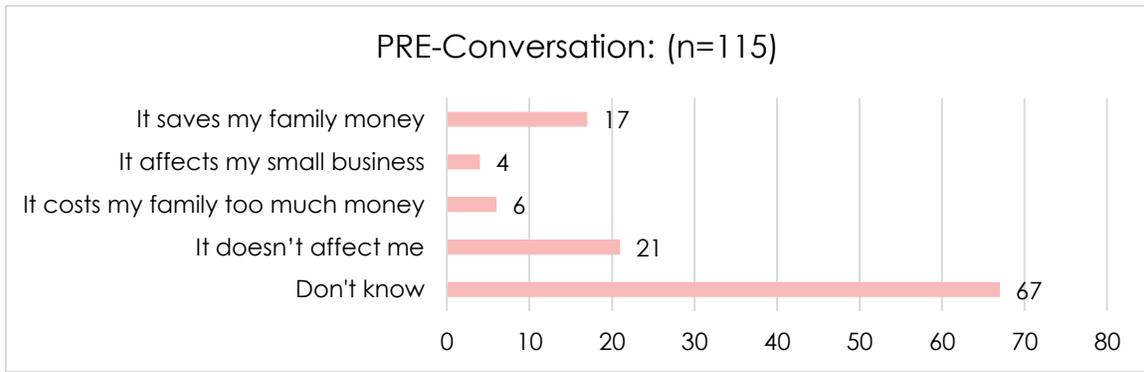
### Does the ACA help solve health problems?



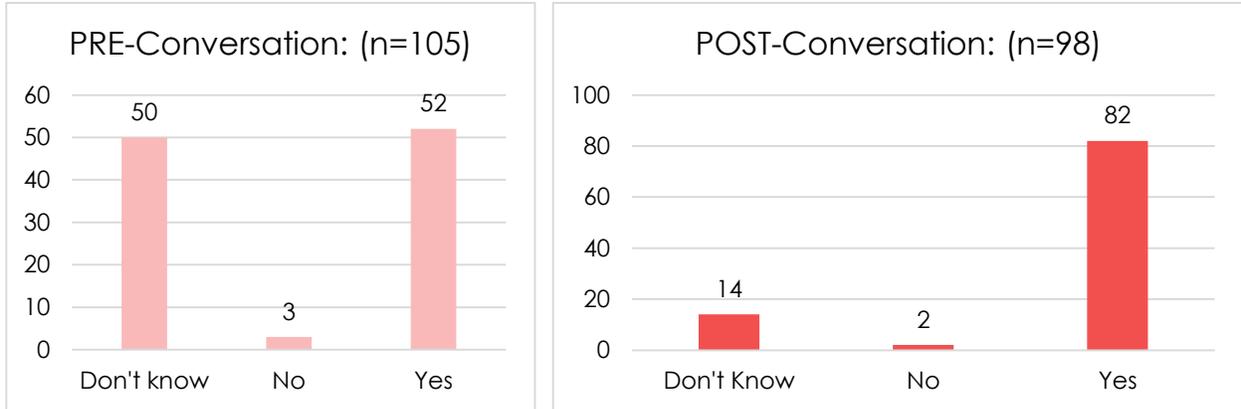
### Do you think the ACA affects you?



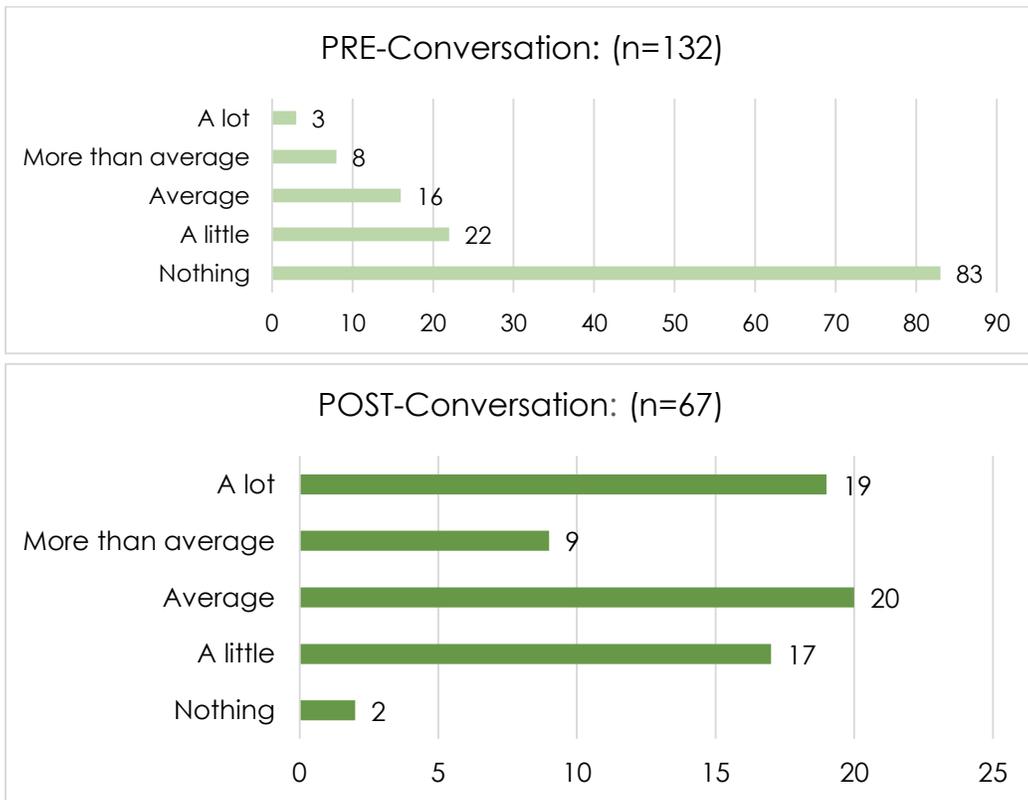
## How does the ACA affect you?



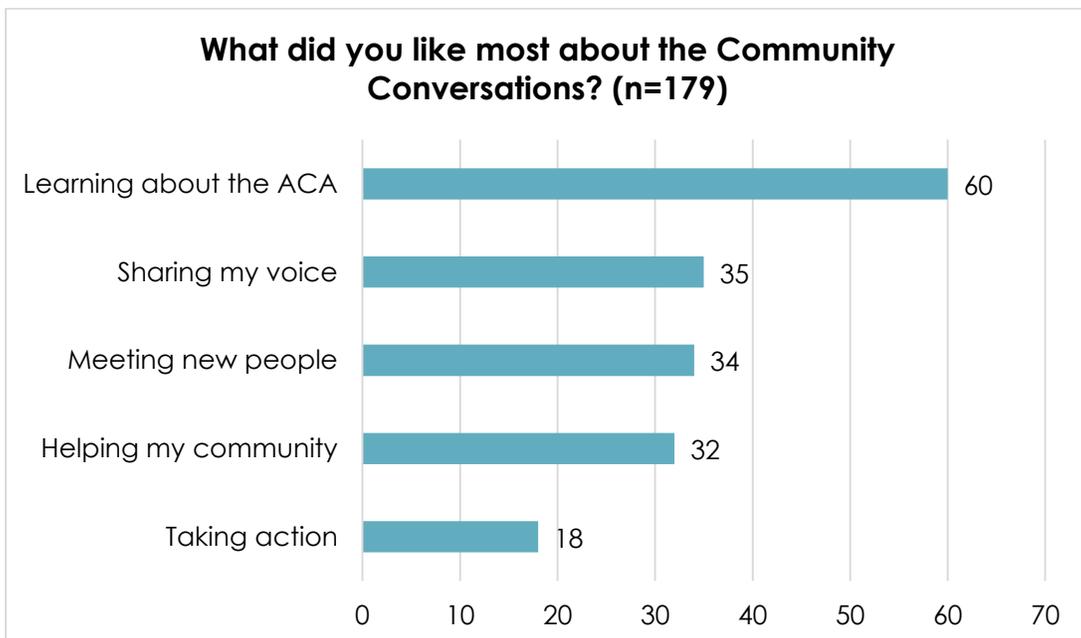
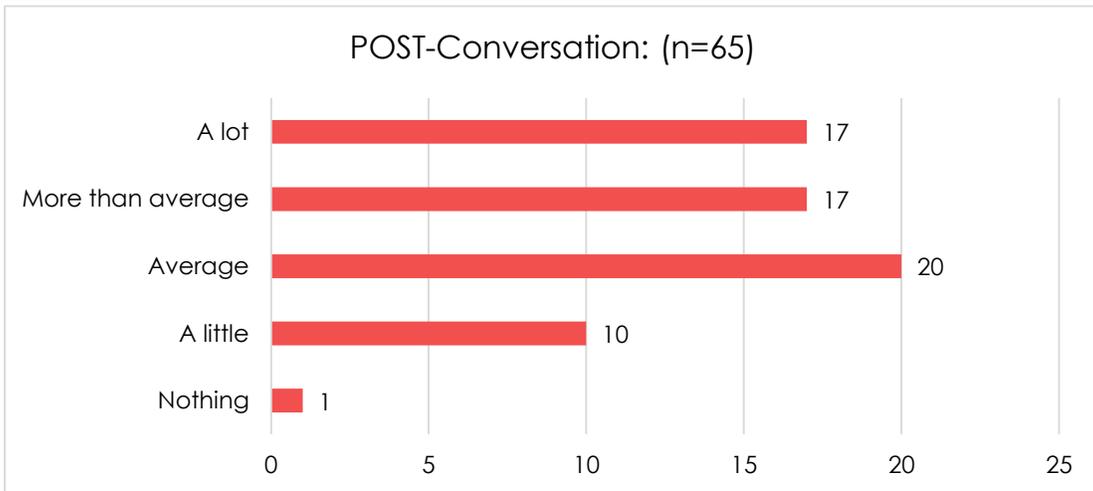
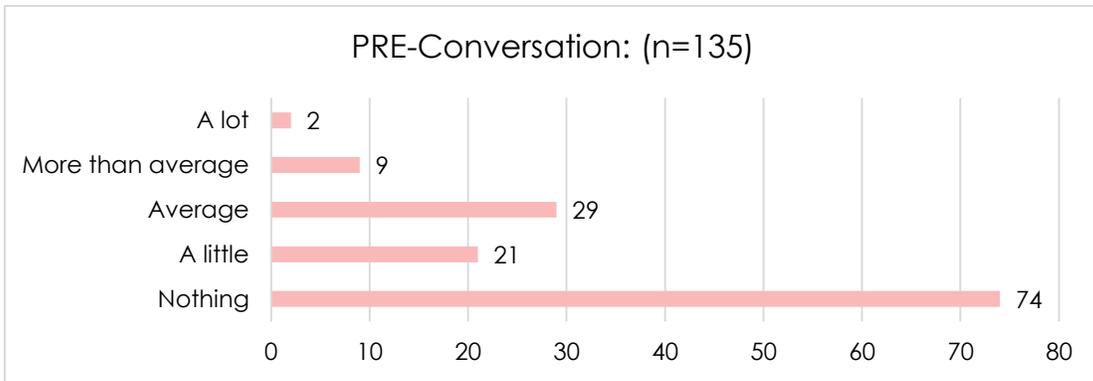
### Does the ACA help with mental health and addiction issues?

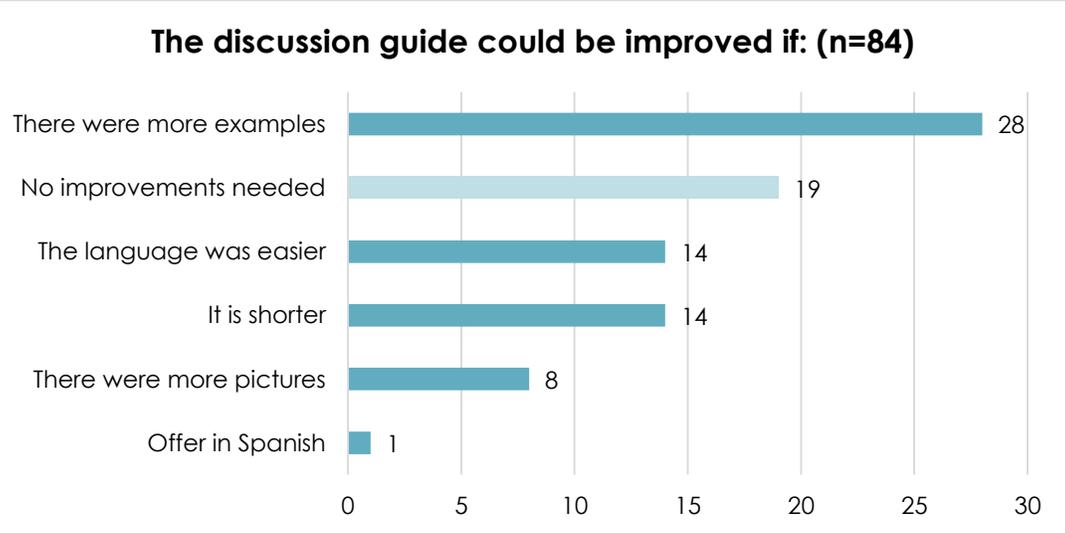
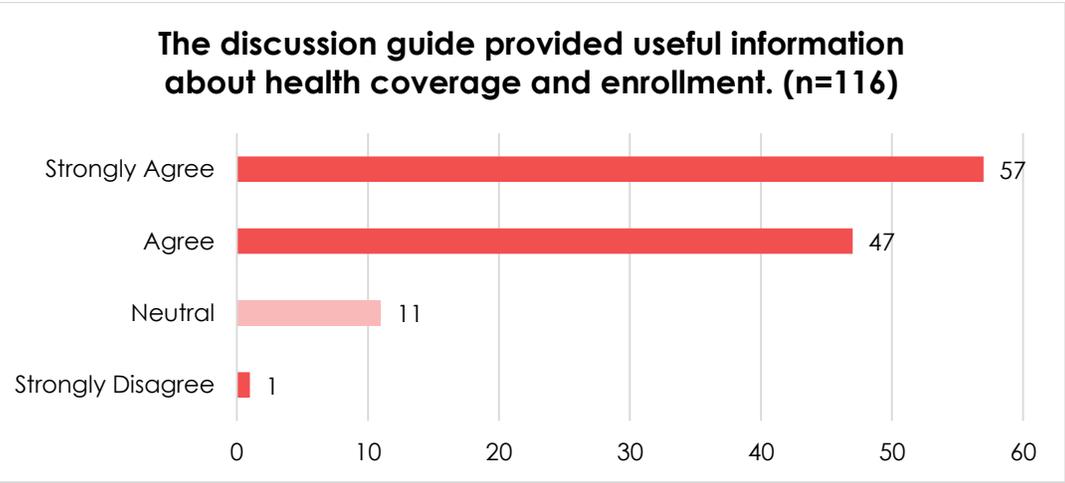
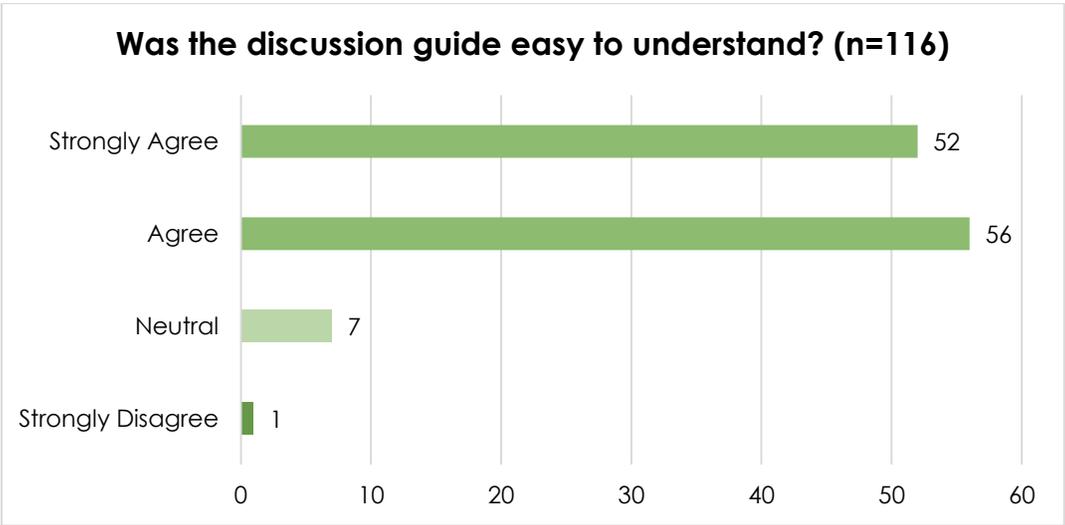


### How much do you know about CLAS Standards?

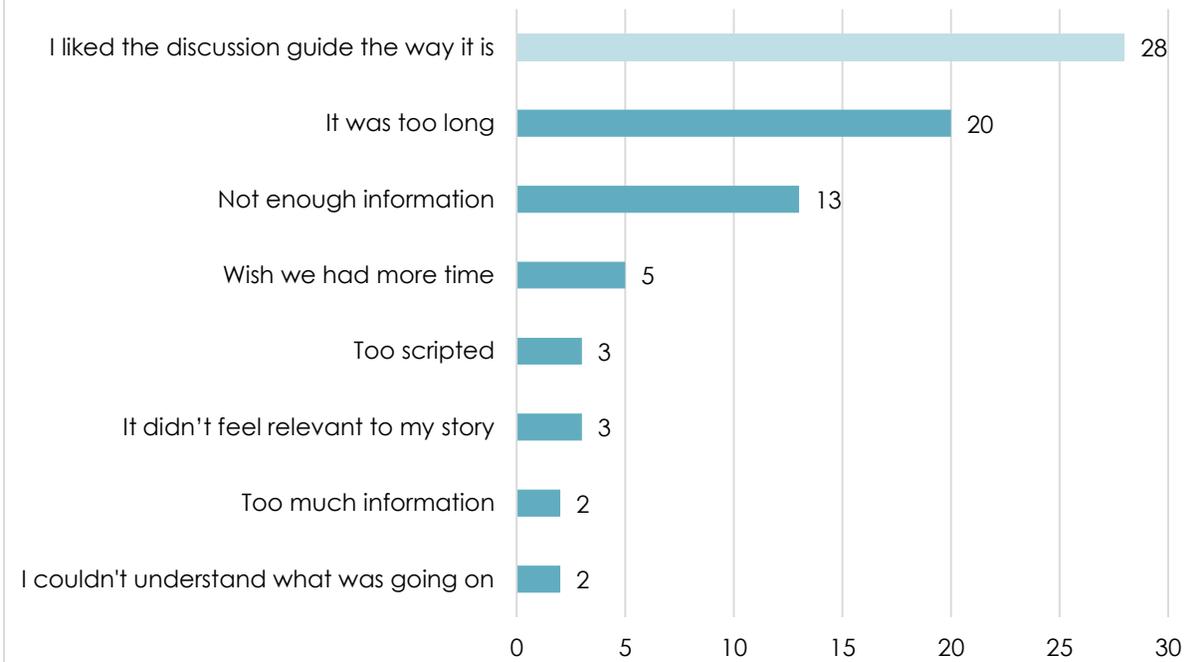


## How much do you know about the Essential Health Benefits?





### What did you like least about the discussion guide? (n=76)



### Overall I would rate the discussion guide as: (n=115)

