

OHS CONSUMER ADVISORY COUNCIL REPORT OF NEW BRITAIN HEALTH FORUM

AT New Britain Community Health Center: January 23, 2020

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EVENT OVERVIEW

On January 23, 2020 at the New Britain Community Health Center – The Office of Health Strategy (OHS) Consumer Advisory Council (CAC) organized the New Britain Health Forum event to understand the community needs of a city most impacted by health disparities in our state. New Britain community members had the opportunity to share their stories and concerns with health care providers about access to primary care and behavioral health services. The event also opened the door to interaction between New Britain community members and the Consumer Advisory Council for future feedback. Dr. Wizdom Powell of the University of Connecticut Health Disparities Institute facilitated the event and centered the conversation around community voices. With her engaging fishbowl forum discussion format, Dr. Powell then asked health care providers to reflect on what they heard from community members. The fishbowl forum concluded with community members and health care providers discussing potential solutions together.



The event was attended by about 60 guests, which included community members¹ and health care providers². The fishbowl forum required community members to volunteer to enter the center circle and share stories as a conversation starter. As the dialogues progressed and people felt more comfortable entering the circle and sharing their perspectives, others sat around the speakers and listened. Dr. Powell then encouraged health care providers to enter the circle to share what they heard from community members, and to reflect on how to improve health care access. Finally, community members, health care providers, and elected officials all joined the conversation to discuss ways to improve health care together. OHS Consumer Advisory Council members were a part of these conversations as listeners. Community members came from diverse backgrounds and represented a range of age groups.

¹ Community members included faith leaders from Spottswood AME Zion and Grace Church and people from partnering organizations such as Connecticut Legal Rights Project and Catholic Charities.

² Health care providers included Vice President of Community Health Center Yvette Highsmith-Francis, Chief Program Officer of Community Mental Health Affiliates Victor Incerti, and representatives from Wheeler Clinic, UConn Health, the Klingberg Institute, the Hospital of Central Connecticut, and Hartford Health care.

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The event began with registration, a pre-event survey, and complimentary refreshments. Terry Gerratana, OHS Senior Adviser, gave opening remarks at the event. She described the importance of community listening sessions to OHS and set a welcoming tone for an engaging discussion. Next, Dr. Wizdom Powell facilitated an interactive discussion around access to primary care and behavioral health services for communities of color. Participants, who comprised of mostly Black and Latino community members, had the opportunity to share their personal health care stories and discuss what can be done to improve patient-provider relationships and address barriers to health care access.





KEY FINDINGS:

- Trust between patients and providers is important to health care access.
 - The historic racism Blacks endured with the Tuskegee experiments and sterilization of Black people broke people's trust in the medical system.
 - Male community members shared that even when they shout or raise concerns, many providers do not listen, and instead treat them as the "angry Black man" if they say something.
 - Black men struggle to find relatable doctors, are caught off-guard by all the questions, and worry that doctors will treat them "less than."
 - o Providers shared that it is easy to lose trust and hard to rebuild it.
- Affordability issues and cost of health care prevent timely access to care.
 - An arbitrary difference exists between health care provided to the wealthy and those without money.
 - However, money does not solve everything some community members had the health insurance and money to pay for health care and continued to struggle with health due to lack of trust or lack of understanding between patient and provider.
- Stigma presents a barrier to accessing preventive care and behavioral health services.
 - Words and language play such a big role in access to health care.
 - Misperception that people of color or Black men have "no pain threshold."
 - If Black people are called "crazy" they will not get seek help.
 - Doctors and community members can have a role in making people fear behavioral health services.
- People's perception of whether they need health care is impacted by their race and gender.
 - o Black men tend to exhibit anger when they might actually suffer from depression.
 - Men might complain about a physical pain when they actually have anxiety.

RECOMMENDATIONS:

- To reach a community that has had a history of mistrust and racial injustice, providers have to be authentic: "You can't come armored and want me to come naked. You have to let me know who you are."
- Providers need to do outreach to people of color, meet them where they are, and treat them with dignity and self-worth.
- We need a concerted community effort to address stigma in patient and provider communities.
- Encourage voluntary use of services instead of enforcing involuntary commitment to health care.
 - We must stop forced treatment, especially with behavioral health services.
 - Involuntary commitment to behavioral health services taught patients not to be honest with a clinician.
- Make Community Health Workers (CHWs) an integral part of the health provider team. For many community members, it is more difficult to open up to doctors than to CHWs.
 - To improve access to care and reduce health inequities, broaden the circle of health care providers: add peer support, recovery coaches, doulas, health coaches, community health workers, and faith leaders.
- Address developmentally disabled issues
- Continue to have conversations about unequal treatment
- Uplift and amplify community voices in the legislature and with policy makers. Ensure that no policy decisions are made without community input: "nothing about you without you!"

EVENT DETAILS

CHALLENGES ABOUT HEALTH CARE:

TRUST

Community members shared a variety of stories that illuminated how trust enabled or hindered their ability to access health care. One person shared how the policies and regulations that determine how doctors treat her hindered her ability to trust the doctors. Interactions and transaction with doctors amplify the importance of communication with doctors. Even when people shout or raise a concern, providers do not always listen and hear people in the way that they want. When other community members hear about these negative experiences, they feel deterred from addressing their health care concerns until a crisis arises.



Citing historic racism and the Tuskegee experiments, a Black male participant shared that he avoided doctors until recently. He shared that his concerns with seeing the doctor also related to his feelings about masculinity – he talked about how Black males are perceived to be strong and capable, so he would ignore what he considered to be minor aches and pains. This community member admitted that he never received a full physical until last year – at the age of 65. When he got bloodwork, he was able to identify health issues that his family chronically faces. He also learned about

the impact of low Vitamin D and how preventive measures like a colonoscopy can prevent many of the issues his family faced. Now he plans to work on prevention rather than only go to a hospital for emergency care.

Community members talked about how building trust requires a mutual exchange. We need to identify our own biases, feelings, and concerns and work on communicating them authentically. One health care provider stated that "our own internal biases can negatively impact our engaging with people to provide care. So we need to not only look at race, gender, culture, orientation and identity issues but how we contaminate the relationship from our hard-held beliefs and opinions about those who are different from us." Community members said they need providers to show up and to be authentic; one person said, "you can't come armored if you want patients to be vulnerable." Providers and patients agreed that there is a concern about the amount of time needed to gain the trust of patients. Providers need to invest more time to build that trust at the beginning of the appointment, but they face a lot of competing pressures on their time. Providers articulated how tragically easy it is to break trust. One doctor expressed his frustration at a colleague doctor who, in a few minutes, broke the trust of a patient that he spent months to build a relationship.

People discussed how we still need to be watchful of health care providers and address concerns about different care quality for patients due to the insurance they carry. An elderly Black woman shared a tragic story about how she entrusted her ailing daughter to health care providers, and her daughter died while unattended in the middle of the night. She talked about how the loss of her daughter's life was a major breach of trust in the medical system and in health insurance. The mother was concerned that the fact that her daughter was on Medicaid affected the quality of care her daughter received. She advocates for improving the Medicaid system.

Advocates said that we also need to separate the criminal justice system from the health care system. People agreed that criminalizing addictions does little to help with recovery efforts, and behavioral health care in jails is not effective. To ensure that our community protects community health, we must be creative to address these issues.





HEALTH INSURANCE COVERAGE

Community members also talked about how health insurance coverage determines the kind and amount of care they can receive. One major concern was that health insurance does not pay for preventive care such as exercise classes, but only for crisis care. Dr. Powell pointed out the arbitrary difference in health care for people with lower and higher

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income. However, cost is not the only barrier. Community members pointed out that even those with money cannot get therapy without being medicated for certain behavioral health concerns. Holistic care generally is not covered by health insurance.

Participants agreed that we focus too much on reactive rather than preventive health care, especially when it comes to exercise and healthy solutions. Community members said, "food is medicine: what goes into the cart goes into your heart." Instead of drugging people or prescribing medications, people advocated for more access to healthy food and exercise interventions.

People also raised issues of behavioral health and preventive care for immigrants. Providers and patients agreed that lack of health care results in worse outcomes and bigger health care issues, so they talked about how we should work towards making health care accessible to everyone regardless of immigration status.

People felt that individual consumers should have more power to negotiate with doctors in the hands, especially with regard to using their insurance. The group recognized that without insurance, patients have very little bargaining power. Overall, people want to understand how profits affect health care — and they want better health over private profits. There was a perception that there were "profits over people's lives."

Finally, community members concluded that Medicaid must be improved and expanded. The current Medicaid system excludes a lot of community members because perhaps the statemandated minimum wage increase disqualified them from Medicaid limits, or because they are undocumented immigrants, or because there is a minimum work requirement and they cannot work due to a chronic health issue. Even if someone has Medicaid, patients report discrimination due to identification as a Medicaid recipient, or waiting longer for a health appointment. People also report a quality difference between being on Medicaid versus private commercial insurance.



STIGMA

Many community members talked about stigma. The most common stigma people faced was around behavioral health concerns, especially as a person of color. People from the African American community talked about the stigma against using health care from the days of the Tuskegee Institute experiments on Black people. Additionally, in many minority communities, talking about a mental health or addiction issue was prohibited. Some people shared that "we dealt with behavioral health problems in our home" but did not know it. The culture of some communities is to avoid discussing behavioral health concerns rather than seek therapy or counseling until a crisis arises.

Stigma against people with substance abuse issues means that sometimes, their underlying mental health was not properly treated. Through stories about how people's substance abuse issues were alleviated when they were finally treated for a mental health issue, people uplifted the ignorance of doctors around co-occurring mental health and addiction issues. People also acknowledged that stigma goes both ways: from patients towards treatment and providers towards complex medical needs – addressing stigma from both perspectives is important to building trust between the patient and provider.

The group also addressed stigma by affirming that a diagnosis is not the definition of one's identity. One health care provider admitted, "I cannot tell you how much I hate being identified as a patient. The word demoralizes me and remands me to a less that equal partner. I am an old man but I did not fall of the turnip truck just yesterday I am not stupid, need to be yelled at or blamed for my ill health." When people are depressed or struggling with a chronic health issue, they need empowerment. Providers should be sensitive to how language can impact stigma. Calling a person a "patient" or a "consumer" may limit them to a particular role, while learning about someone beyond their medical condition can help bridge the trust divide. Moreover, using words such as "use disorder" versus "substance abuse" may unduly create guilt and shame in people who are seeking help to address a disease.

Nonetheless, we can learn skills to address our anxieties and concerns. Treatment should include learning and exercising coping skills. Different treatment modalities such as counseling, group therapy, and peer support can bring strength back to patients. Patients must accept that they need treatment and providers need to be open to the individual needs of people with complex medical histories in order to overcome the stigma together.



Community members acknowledged that

everybody needs some sort of mental health service but maybe do not know they need it. Additionally, people who lack adequate health insurance and are juggling multiple jobs to support a family say that they do not have time for a mental health breakdown. Advocates encouraged us to promote voluntary use of behavioral health services rather than coerced use. People admitted that they have learned how to lie to the system in order to avoid forced medication or involuntary commitment to mental health facilities. Therefore, we should encourage people to be honest and get preventive care rather than promote a system that engenders people to lie out of fear that they will be forced into treatment.

GENDER

Gender differences can pose a challenge to individuals seeking to access health care providers. Men shared their struggle with talking about mental health and admitted sometimes they cannot accept that they even have health issues. One Black man shared concerns about boys and men of color's ability to access health care. He struggles with health care providers when he is trying to be assertive and they perceive him as an angry black man. He also shared his frustration

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regarding the lack of cultural competency in the health care profession, stating, "We've got to get cultural competency. Just because we are Black doesn't mean you can ignore me." Mistrust, bias, and racial discrimination all apply to challenge Black males against seeking health care. People also talked about the criminalization of Black males rather than treatment of their health issues. Dr. Powell affirmed that anger is a legitimate response to injustice, "Anger has a place to live and can transmute something positive." Addressing health care barriers for Black males will help improve health equity in Connecticut.

COMMUNICATION WITH PROVIDERS

Many people spoke to the need for more transparency in communication with providers. Clinicians agreed that they need to meet people where they are at – in the community – to better communicate and understand the context in which people struggle with health issues. Overall, to improve communication between patients and providers, people need knowledge, time, and trust, and community health workers (CHWs) can help with brokering all this. Many people said it is easier to sit down with a CHW than with a health care provider. CHWs can provide the time and flexibility with the meeting location, and focus on listening to people. While people might be fearful of



sharing information with doctors due to the Tuskegee experiments and other historic mistrust issues, people are less worried about sharing intimate details of their health condition with CHWs, who are trusted community members that aim to bridge the divide between patients and doctors.

If a CHW is not available, then doctors can focus on a few tips to improve their communication with patients. People asserted that doctors should let people speak when they first arrive, or ask the patient an open-ended question.

One provider spoke to the importance of the patient-provider relationship in a person's recovery efforts. This psychiatrist said that even the best care can only assure 10% of recovery, while 20% of recovery depends on circumstances, 30% depends on genetics, and 40% depends on the partnership between provider and patient. He made the point that strong communication and a trusting relationship will do a lot more to improve patient health outcomes than the doctor simply drawing on medical expertise.

The doctor also recommended that patients utilize the Choosing Wisely questions with their health care providers to improve communication and trust in the health care system. Choosing Wisely is an initiative that encourages patients to ask their health care providers five basic questions:

- 1) Whether a proposed medical procedure is necessary
- 2) What are the side effects
- 3) Whether there are there simpler or safer options
- 4) What happens if the patient chooses not to do anything

5) How much the procedure will cost, and whether the patient's insurance will pay for it.

To create systems change, people recommended that we build advocates so people can look out for one another and families can navigate the system as a village. Community voices need to be uplifted in the legislature and be visible. We must start with the community voice, and ensure that no policy decisions are made without community input: "nothing about you without you!"

CONSUMER ADVISORY COUNCIL FEEDBACK:

OHS Consumer Advisory Council (CAC) members noted the event was a success. The multitude of people and the many diverse perspectives were in attendance and allowed for an honest, productive and thorough conversation. The discussion was further deepened by many New Britain health care providers, who played an active role in the conversations. After the event, a few health care providers reached out and affirmed the importance of continuing these dialogues between patients and providers. One health care provider said, "The responsibility to provide accessible, client-centered care that develops partnership and collaboration is such a key



component to reducing disparities for people of color and poverty ... the more we move away from the traditional medical model the better as we recognize that the person seeking care is the expert in their care not the professional. I think much of what was shared was relevant to what we need to learn about how to provide behavioral health care better."

PRE SURVEY FEEDBACK

What is the best way of reaching you? (Mark one)

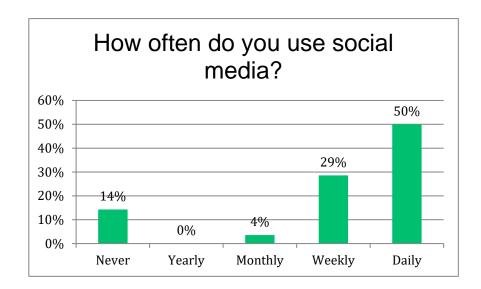
Answer Choices	Responses	
Email	79%	22
Phone	21%	6
Knocking on your door	0%	0
School	0%	0
Reaching you through a trusted friend/family member	0%	0
Other (please specify)		0
	Answered	28
	Skipped	0

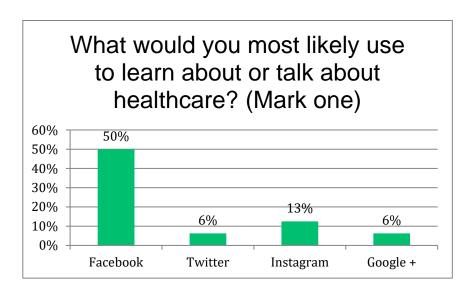
What is NOT a good way of reaching you? (Mark		
Answer Choices	Responses	
Email	0%	0
Phone	11%	3
Knocking on your door	70%	19
School	4%	1
Reaching you through a trusted friend/family member	15%	4
Other (please specify)		0
	Answered	27
	Skipped	1

Would you be able to go to/be a part of: (Check all that apply)

Answer Choices	Responses	
Online forums	48%	13
In person focus groups	59%	16
Social Media campaigns	41%	11
Community Education events	74%	20
Other (please specify)		0
	Answered	27
	Skipped	1

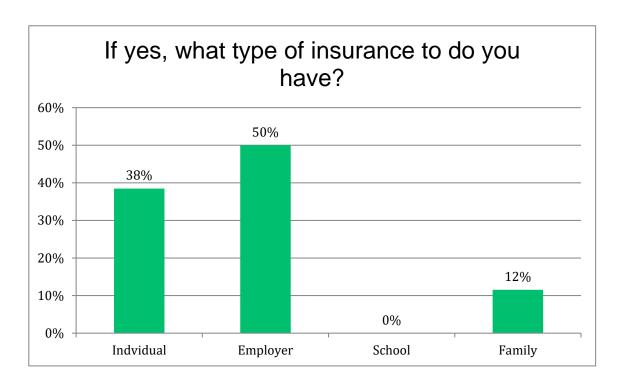
If you attend a forum/focus group/community discussion about healthcare, what do you want to get out of it?		
Answer Choices	Response	S
Listen/learn more	74%	20
Share my story	11%	3
Help my community	63%	17
Become an advocate	33%	9
Connect with people	44%	12
Meet others who need help with getting healthcare	22%	6
Other (please specify)		0
	Answered	27
	Skipped	1



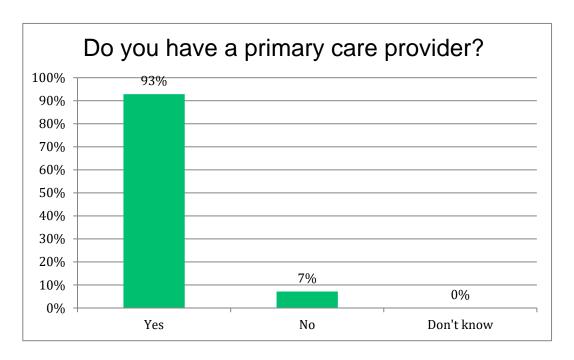


What affects your understanding of healthcar	e most?	
Answer Choices		Responses
Social Media	4%	1
Family/Friends	15 %	4
Religious community	15%	4
TV/radio	4%	1
Your interactions with your healthcare provider	50%	13
School	8%	2
Other (please specify)		
Cell phone		1
	Answered	26
	Skipped	2

Do you currently have health insurance?		
Answer Choices	Responses	;
Yes	96 %	27
No	4%	1
Don't know	0%	0
	Answered	28
	Skipped	0



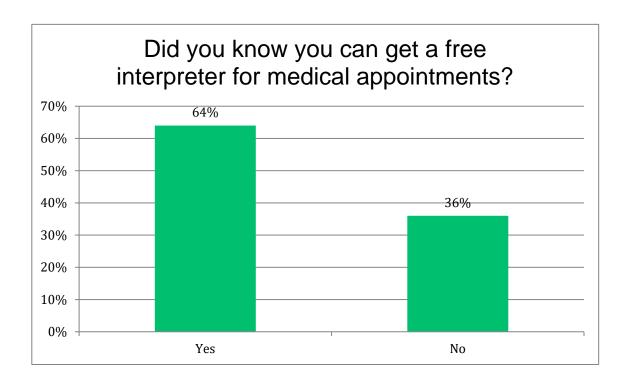
If you don't have insurance, why not?		
Answer Choices	Resp	onses
Too expensive	100%	1
Too complicated to apply	0%	0
Don't think it's useful	0%	0
Other (please specify)		0
	Answered	1
	Skipped	27



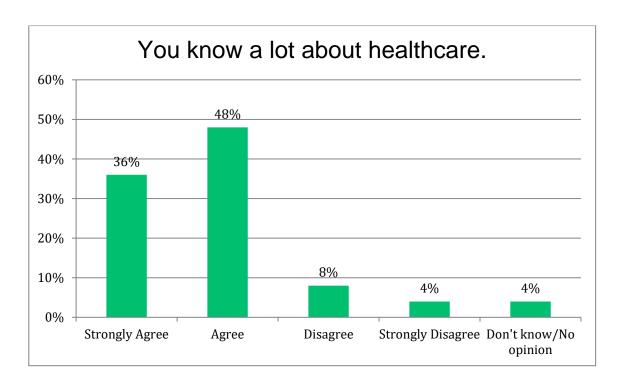
Do you have a relationship with your primary care provider?			
Answer Choices	Responses	;	
Yes	82%	23	
No	18%	5	
	Answered	28	
	Skipped	0	

Are you in charge of your own health insurance?		
Answer Choices	Responses	;
Yes	87%	21
No	13%	3
	Answered	24
	Skipped	4

Is English your first language?			
Answer Choices Responses			
Yes	84%	21	
No	16%	4	
	Answered	25	
	Skipped	3	

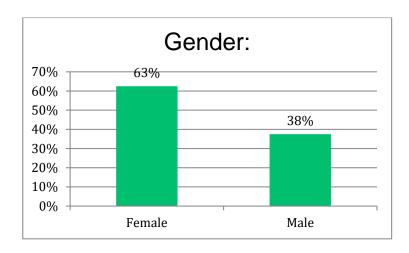


Have you ever used an interpreter for medical appointments?			
Answer Choices	Responses	;	
Yes	4%	1	
No	96%	23	
Don't know	0%	0	
	Answered	24	
	Skipped	4	

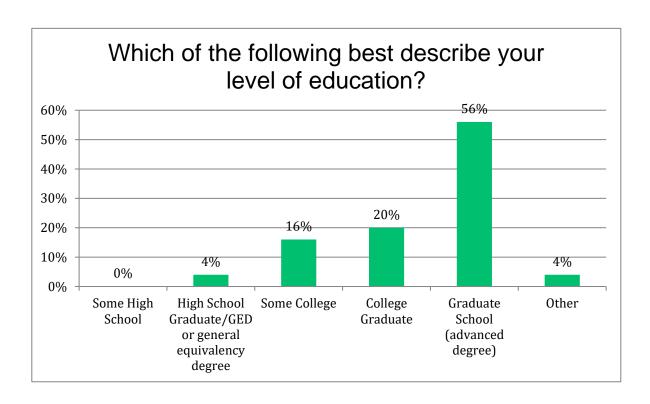


You are comfortable when visiting the doctor's office.			
Answer Choices	Responses	3	
Strongly Agree	58%	14	
Agree	38%	9	
Disagree	4%	1	
Strongly Disagree	0%	0	
Don't know/No opinion	0%	0	
	Answered	24	
	Skipped	4	

You feel that your doctor understands you and where you are coming from.		
Answer Choices Responses		3
Strongly Agree	36% 9	
Agree	60%	15
Disagree	4%	1
Strongly Disagree 0%		0
Don't know/No opinion 0%		0
	Answered	25
	Skipped	3

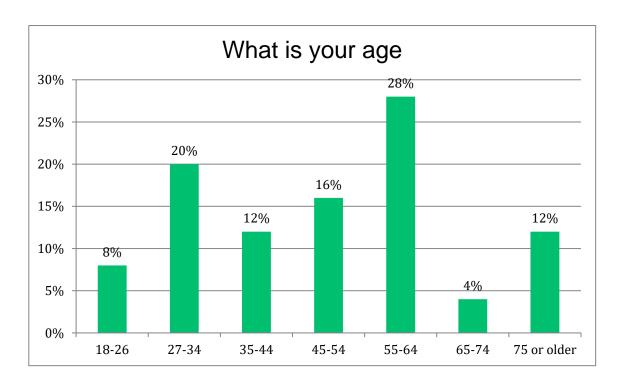


Which of the following best describes you?		
Answer Choices	Responses	
American Indian or Alaskan Native	4%	
Asian / Pacific Islander 4%		1
Black or African American	46%	11
Hispanic / Latino	13%	3
White / Caucasian	33%	8
Multiple ethnicity / Other 0%		0
	Answered	24
	Skipped	4

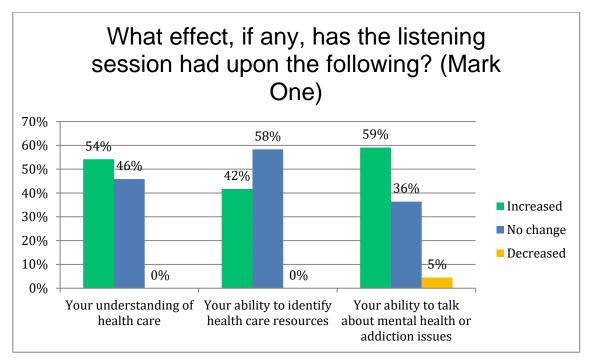


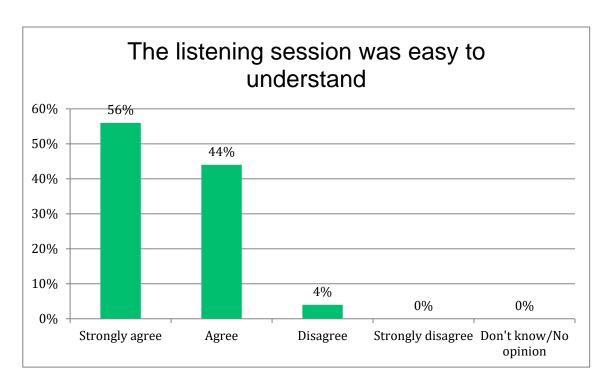
Do you identify with any of the following religions? (Please check all that apply)		
Answer Choices Responses		3
Christianity 79%		19
Hinduism	0%	0
Judaism 0%		0
Inter/Non-denominational	4%	1
Islam	0%	0
Buddhism 0%		0
No religion 17%		4
Other 0%		0
	Answered	24
	Skipped	4

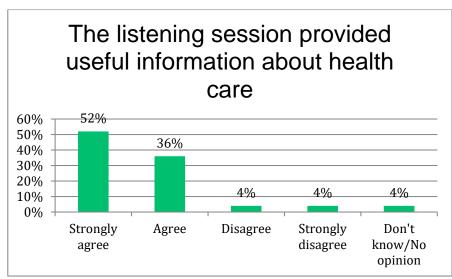
Do you think your religion affects how you view healthcare?		S
Answer Choices Responses		;
Yes	54%	13
No	46%	11
Don't know 0%		0
	Answered	24
	Skipped	4

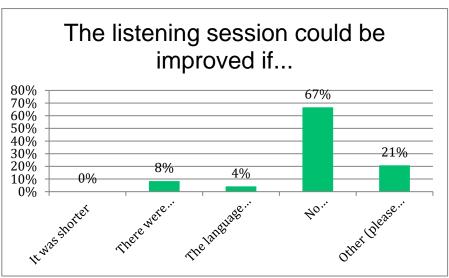


POST SURVEY FEEDBACK

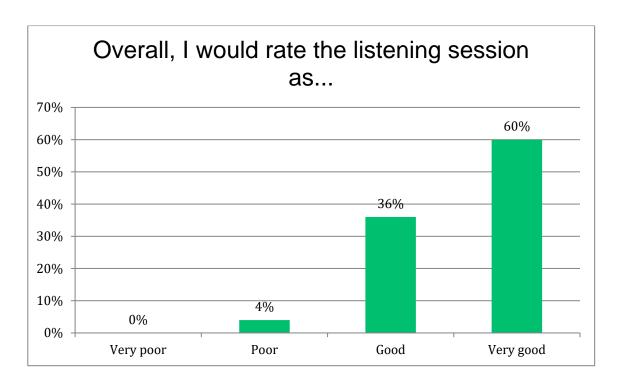








Describe what you liked least about the listening ses (Mark all that apply)	ssion.	
Answer Choices	Responses	
It was too long	0%	0
Not enough information	38%	3
Too much information 0%		0
It did not feel useful to me 25%		2
I couldn't understand what was going on 0%		0
Other (please specify):		
issues too big to resolve		
	Answered	8
	Skipped	17

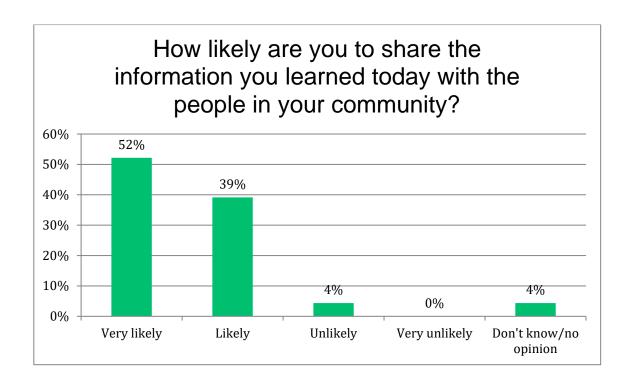


Describe what you liked most about the listening session. (Mark all that apply)		
Answer Choices	Response	es
Meeting new people	35%	8
Learning about this target group	48%	11
Hearing from healthcare experts	43%	10
Sharing my voice	39%	9
Taking action	17%	4
Other (please specify)		
 more opportunities to speak 		
hearing people's experiences		
 learning experiences of others and the impact 		
 hearing perspectives of men of color 		4
	Answered	23
	Skipped	2

Do you think that the listening session was helpful for you? Why?	
Respondents	Responses
1	definitely
2	I got to hear about the experiences that were unfamiliar to me
3	yes it will allow me as a provider to better empathize with patients, build better trust
4	yes. enlightening and informing of true life situations with healthcare
5	yes learned from experiences of others
6	yes
7	yes, it helps me to understand what more has to be done
8	yes, powerful to hear these voices
9	i was able to hear a lot of voices about health care
10	making my voice louder
11	yes, testimonies help to facilitate and motivate change
12	yes people talk about what happened to them and how they were afraid, not comfortable
13	yes, hearing from the community itself
14	yes, helped me hear and understand
15	yes, hearing the barriers to black men, hearing the importance of credibility and trust
16	no

Please share your suggestions for future listening sessions:

Respondents	Responses
1	see below
2	Expand notification methods
3	more voices
4	widen the circle
5	encourage people in the circle to leave to make room for others
6	we need more people who can make a difference in this discussion
7	Keep the same session, the circle works
8	Maybe outline the topics that will be discussed
9	perhaps more promotion, marketing or provide community transportation
10	encourage more voices, do not let the same people talk too many times
11	we need more
12	stay on topic, no straying off



What was the greatest takeaway from this forum?

Respondents	Responses
1	community voices are being heard
2	how beautiful the live energy was
3	all voices matter
4	the system has failed many and continues to do so
5	advocate care
6	importance of others' stories, listening
7	gathering info for what? Go to the board who made the decisions
8	That patients don't have more time with providers
9	listening and advocacy
10	the people in the circle
11	advocacy, speak out
12	the system is badly broken
13	the importance of having culturally informed healthcare delivery system

How can this particular forum be improved?

Respondents	Responses
1	live note taking or vendors of a sort to support and connect talking points
2	more involvement or even rotating people in the circle
3	Background info needs to be on the forum
4	Need more experts, more focus on certain topics