



2022 CLIENT FOCUS GROUP

Tobacco Use Reduction in People Living with
HIV/AIDS

ABSTRACT

Michigan held 3 virtual focus groups with people living with HIV/AIDS (PLWHA) who use tobacco products, generating 17 responses from 7 ASOs during July-August, 2022. The purpose of the focus groups was to generate qualitative data on tobacco use behavior that will inform best practices to increase quit attempts.

Michigan Department of Health and Human
Services, Tobacco Section

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Background and Purpose

Tobacco use is the number one cause of preventable death within the United States as a whole and in Michigan. An estimated 16,200 adults die from smoking each year in Michigan. This is more than the deaths from alcohol, AIDS, car crashes, illegal drugs, murders, and suicides *combined*, with more dying still from other tobacco-related causes (Campaign for Tobacco-Free Kids, 2022). However, the burden of tobacco smoking is not shared equally across Michigan. Data from the Behavioral Risk Factor Surveillance System (BRFSS 2021) shows that tobacco use disproportionately falls upon people based on their socioeconomic status, race and ethnicity, mental health, ability, insurance status, and sexual orientation.

In Michigan, about 17% of adults smoke. But when stratified to look at only People Living with HIV/AIDS (PLWHA), that statistic rises to a bit over 41% (MDHHS, 2021). This means that PLWHA are more than *twice* as likely to be smokers compared to all adults in Michigan. Due to advances in medicine, particularly combination antiretroviral therapy (ART), HIV has become a manageable chronic disease for PLWH in continuous care, allowing them to live long, fulfilling lives. However, smokers living with HIV are still dying sooner than their non-smoking counterparts. According to one study modeling life expectancy of people entering HIV care at age 40, smokers living with HIV die more than 6 years sooner than their non-smoking counterparts; this is more than the estimated effect that HIV itself had on shortening life expectancy when HIV was being optimally treated for (Reddy et al., 2016). Smoking with HIV is especially harmful, as both the risks of smoking related illnesses is higher for PLWH and the risk for HIV-related infections is higher for smokers with HIV than nonsmokers with HIV (CDC, 2022).

The Michigan Tobacco Control Program's (TCP) mission is "to reduce morbidity and mortality and alleviate the social and economic burden caused by commercial tobacco use in Michigan" and has made "the identification and elimination of tobacco-related health disparities a primary goal" in achieving this mission (MDHHS, n.d.). PLWHA are a part of a vulnerable and at-risk group with high rates of death and disease due to tobacco use compared to their small population. The TCP, with funding from Michigan's HIV Division, developed the Tobacco Use Reduction in People Living with HIV Project (TURP) to work with multiple statewide AIDS Service Organizations (ASO) to help them assist PLWH who smoke and use tobacco to quit. In July-August of 2022, the TURP team conducted 3 virtual focus groups with PLWH tobacco users representing 7 AIDS Service Organizations (ASOs) across the state in an effort to generate qualitative data on tobacco use behavior that will inform best practices to increase quit attempts. Specifically, the focus group questions were based around assessing knowledge regarding smoking related disparities facing PLWHA, what people do to try to quit smoking, awareness of media messaging around tobacco use, and the impact of COVID-19 on tobacco use behavior. For the full question list, see Appendix D.

Methodology and Sample

7 participating ASOs notified participants of the opportunity to participate in focus groups regarding tobacco use and living with HIV. In order to be eligible for participation, participants must have been: PLWHA clients living in State of Michigan, willing to participate in a focus group, current or former tobacco users, and age 18 years old and older. Participation was incentivized with a \$10 gift card as well as food and Tobacco Quit Kits. All incentives were paid from ASOs tobacco reduction budget for the FY 2022. A total of 14 participants were recruited.

Three focus group sessions were conducted virtually through Zoom by members of the TURP team. ASOs hosted conference rooms for multiple participants to attend the focus groups together while other participants video called in by themselves. A consent-confidentiality form and an anonymous demographics survey were used for all focus groups. Each participant signed the consent-confidentiality form and completed the demographics survey before participating in the focus groups.

Demographics

Across the 3 focus group sections, there were 17 total participants from 7 ASOs. The age of the participants ranged from 35 to 73 years old with an average and median age of 55.9 and 58 respectively. By gender identity: 52.9% of our participants identified as female, and 47.1% identified as male. By race: 70.6% were Black, 23.5% were White, and 5.9% were Asian. For sexual orientation: 52.9% identified as straight, 23.5% identified as gay, and 23.5% elected to not respond to the question.

In terms of highest level of education achieved: 41.2% had completed high school, 35.3% had some college experience, 11.8% completed their bachelor's degree or hold a higher degree, and 11.8% elected to not respond to the question. For annual household income: 64.7% said they made up to \$20,000, 17.6% said they made between \$20,000 and \$30,000, 5.9% said they made more than \$50,000, and 11.8% elected to not respond to the question. And for employment status: 76.5% were on disability income, 11.8% were unemployed, 5.9% were self-employed, and another 5.9% were employed by someone else.

The average amount of time that participants have been living with HIV is 17.7 years, and 87.5% of participants have been living with HIV for a decade or longer. The average number of years that participants have been using tobacco products is 25.5 years, with 93.8% of participants having had used tobacco products for a decade or longer and half of participants having used tobacco products for 3 decades or longer. Barring 1 outlier, participants made 3.1 quit attempts on average this year. More than 82% of participants attempted to quit using tobacco products at least once this past year. When asked to rate their own health on a scale of excellent, good, fair, or poor: 11.8% rated their health as excellent, 41.2% rated their health as good, 35.3% rated their health as fair, and 11.8% rated their health as poor. See Appendix C for the full table of all demographics data collected and graphical representations of this data.

Discussion: Major Themes

Stress and Stigma

One of the most prominent themes that emerged from these focus groups is that PLWHA are under a considerable amount of stress, and that this stress plays an important role in their smoking behavior. Stress was commonly identified as a reason for participants to start smoking, and as a reason for participants to continue smoking. PLWHA face many stressors unique to their circumstances on top of the other stressors of everyday life, including the stigma and discrimination associated with HIV/AIDS and the burden of obtaining and managing their medications. For many, smoking acts as an outlet for their stress.

"Well, I personally was dealing with a lot of stress. And on top of that stress there was this stigma, you know. So, it made me not ... even want to quit smoking because that was my outlet."

Obtaining and managing HIV medications can be a significant stressor in the lives of PLWHA. Prior research has shown that many barriers exist to obtaining HIV treatment such as financial barriers (including lack of insurance coverage), barriers in getting access to doctors (including trouble getting appointments and lack of transportation), ongoing drug use, and the fear of stigma if someone finds them receiving HIV medications (Dombrowski et al., 2015). Once obtained, managing several medications required to suppress HIV acts as another stressor in and of itself.

"You're wondering how you're gonna get you next medicine. You're gonna wonder if you're gonna die, if you're gonna live."

PLWHA face stigma surrounding their HIV status, which is often compounded by negative assumptions surrounding their smoking behavior. This stigma often leads to discrimination towards PLWHA, or unjust differential treatment of PLWHA based on their HIV status. This stigma, discrimination, and the fear of stigma and discrimination acts as a significant stressor in the lives of PLWHA, and also contributes to multiple negative mental health outcomes and social isolation, including depressive symptoms, anxiety, and poor sleep quality (Fekete et al., 2018). Stress was also often tied to relapse among PLWHA who had managed to quit smoking for a period of time. Particularly stressful life events often lead to relapse.

"I didn't want the disease. Who could I tell?"

"This is a disease that I don't wanna share with everybody. Everybody's opinion is different, especially today about it."

"I lost my oldest sister, and I lost it...And I started smoking with it."

Social Influence

Many participants described their smoking behavior being related to the social influences in their life. While there were participants who began smoking across the age spectrum, more

often than not, participants began smoking as a teenager or young adult. Some participants began even younger. Many of these individuals began smoking for social reasons, such as to fit in with their peers. Others noted that smoking caused others to view them in more favorable ways, such as making them seem more cool or more serious.

"My name's [respondent's name] and I started [smoking] around 12-13."

"It makes your point come across better if you can wave a cigarette at them."

"For me, like I said, I was in the nightclub business. And I was just around [smokers] a lot. It was more social."

"That's like so distinct in my brain of being like, 'Oh, this is where the [cool kids smoked] - hanging by the side steps to the library'. And that's where the cool kids did it."

For some people, the social influence on smoke came from people in their inner social circle. Some participants explained that they began to smoke after being around family members or close friends who would smoke. Often times, they would even get their first smoke from these individuals. However, this relationship seemed to go both ways, as many of these participants also noted that they first attempted to quit smoking following their friends or family members attempting to quit.

"What I did in order to stop smoking... me and my cousin, who I started smoking with, who I got my first cigarette from, we decided to do the e-smokers... we just didn't want the nasty habit of smelling like smoke every time we got in the car."

While many participants indicated that societal factors played a role in their smoking initiation, many also reported social factors playing a role in why they wish to quit. In about the last 60 years, the social perception of tobacco use in America has been shifting to be more negative (Cummings & Proctor, 2014). Subsequently, social acceptability of smoking has been decreasing since. Some of the participants indicated that this social unacceptability of smoking is a reason why they want to quit.

"So, I will say that that - that is something that I'm cognizant of - where I am, the social acceptability of it, where it wasn't how it was like when I first started, you know."

"I have less and less people in my social circle that are smokers. Also, those that have quit are very much like, 'You need to quit smoking'"

Desire to Quit Smoking

Another extremely prominent theme that emerged from these focus groups is that most participants are actively trying to or at least contemplating trying to quit. In the terms of the Transtheoretical Model (TTM), a behavioral change model devised by Prochaska and DiClemente that was originally created to explain smoking cessation behaviors as a continuous cyclical process with distinct stages, most participants had already progressed past the precontemplation stage. The precontemplation stage is usually marked by unawareness or indifference to the negative consequences to one's behavior, and subsequent lack of intent to change this behavior. As such, most interventions aimed at people in this stage of change tend to focus on raising awareness or education regarding the negative consequences of a behavior. As this group seems to largely be past this stage of change, messaging and tools used to encourage this population to move through the stages of change towards the stage of maintenance of healthy behavior (in this case, not smoking) should be focused on building capacity and self-efficacy in quitting as opposed to raising awareness of potential harms of smoking. To this end, understanding the motivations to quit smoking and barriers to quitting is essential.

While other motivators such as cost, injury or death of loved ones, and general disdain towards the smell of tobacco smoke were brought up by participants, by far, personal health was the most common motivator for an individual to attempt to quit smoking. Some individuals indicated that smoking adversely impacted their health such that they cannot engage in some activities that they used to enjoy, and they wish to quit to get back to doing those activities. Others were suffering from diseases (smoking related or otherwise) and wanted to quit smoking to prevent the exacerbation of those diseases or the hampering of its treatment. Some individuals recently recovered from life threatening diseases and wish to quit smoking to improve the quality of the remainder of their lives. Yet others have yet to experience any major health problems from smoking but are aware of the potential impacts down the road and wish to quit before their health gets worse. Overall, many participants seemed to have an understanding that regardless of what stage of disease one is on, or how many years one has smoked, quitting smoking can help to improve health or at least prevent worse health outcomes.

"I quit cold turkey, and the reasons I quit: cost, health, and just smelt like an ashtray."

"My cancer wasn't tobacco related. But quitting makes a whole world of difference when you're trying to rebuild [tissue]...You know smoking is poisoning your body."

"I have congestive heart failure. And that was a contributing factor – was definitely a factor in me trying to give up smoking and stuff."

Many individuals associated their smoking behaviors and quitting behaviors with their other, non-tobacco related, health behaviors. Some individuals have indicated that their quitting behaviors have mirrored their overall efforts to get healthier, such as attempting to quit smoking while or immediately after trying to get clean from other drug use, or attempting to quit smoking while trying to get into the habit of exercising again. Some people have also expressed an optimism about their ability to quit based on experience in other, non-addiction related, diseases. There seems to be a pervasive wholistic view of both health and personal strength, in that being strong or healthy in one way means being strong or healthy in every way.

"I would get clean from the drugs, and I would quit smoking, because I kind of associated the smoking with the drugs."

"The reason why, I'm more serious about quitting now is because if I can beat HIV, I can beat COVID, I can definitely beat smoking."

"I beat cancer. And beating cancer and still smoking doesn't make sense at this age."

"I can't work out and be healthier with the lungs that I have and it's like I can't be healthier and continue to smoke, and I can't get healthy if I continue. It's like - it's just the one begets the other."

A number of people mentioned a sense of guilt driving them to try to stop smoking. This sense of guilt can come from a number of sources, including potential judgement from friends and family and knowing that smoking is harming their health and continuing to smoke. These individuals tended to also mention how feeling accountable to another person for their smoking behavior helps them stick to their quit attempts because they do not wish to feel like they let this person down.

"She's [a support group member] always on me about, you know, about my smoking. Which is okay, because I feel guilty every time I come to group and I say I'm still smoking."

"I kind of like, used as like a mini kind of attempt [to stop smoking] over last weekend because I'm like, 'Am I gonna be that person that's gonna constantly be like, 'Wait, hold on,' or 'I'll catch up with you guys,' or 'Let me take 10 minutes to run downstairs and go do this.'"

Individuals who have talked about trying to quit typically have attempted to quit using tobacco products multiple times. Some participants have even mentioned that failing to quit has made them feel demotivated and feel at the mercy of tobacco. It is important to provide support to these people and encourage them to keep quitting. Relapse is a common and normal step in the quitting journey, with most former smokers experiencing relapse in their quitting journey at some point. The last stage of the TTM is maintenance instead of completion or recovery,

because very few people lose the desire to quit smoking entirely. Instead, most individuals simply learn to cope with their cravings, but continue to battle the addiction.

"As you guys know I have tried to quit before and I finally feel like I've gotten there. But like I said, it took - I can't even tell you how many times I broke. 5 on the paper, but it's probably has been more times than 5. In fact, I know it's been more than 5."

"I still feel vulnerable to maybe going back [to smoking], but I'm determined not to start back up, because I feel a lot healthier."

Participants showed varying degrees of susceptibility to external factors impacting their smoking behavior. One's beliefs about to what degree one's own actions and thoughts, as opposed to external forces, control one's life events is referred to as their locus of control. There are two major categories of locus of control: internal locus of control and external locus of control. Those with a strong internal locus of control believe their own actions and thoughts have a direct and important role in dictating the circumstances of their lives. Those with a strong external locus of control believe that forces outside of their own control determine the trajectory of their lives (Lassi et al. 2019). Individuals with a strong external locus of control often feel at the mercy of their circumstances and their stressors, and subsequently use tobacco as a coping mechanism. On the other hand, individuals with an exceptionally strong internal locus of control may discount the effectiveness of outside tools and resources in their quitting journey. A number of participants in this focus group talked about how external influences has no effect on their smoking behavior. Instead, they attribute their smoking behavior to their own personal strength and drive (or lack of) to quit.

"And none of that [media messaging and policy changes] makes a difference to me. What makes the difference is my own personal health, my own personal past."

"The only thing that is affecting [me] about quitting smoking is me."

Tools and Strategies to Quit

Participants talked a lot about the various strategies and tools they used to try to quit smoking. A few participants said they quit or attempted to quit cold turkey, or abruptly without the usage of medications or other replacements. However, studies have shown that attempting to quit cold turkey has low rates of lasting quits, with about 95% of people attempting to quit cold turkey unable to quit for longer than 6 months. People who attempt to quit cold turkey tend to believe that willpower alone is the most important aspect of quitting smoking. In reality, willpower alone is rarely enough to overcome nicotine addiction. This is because addiction alters brain structures, particularly those that influence decision making, behavior control, learning, and other high-level functioning, thus undermining one's ability to control impulses through their decision making (willpower) alone (Truth, 2017). Thus, it is important to remind

people who overly emphasize personal strength and willpower as the keys to quitting smoking that addiction is a disease and that using medications or other support structures is an acceptable and viable way of quitting smoking.

"I stop smoking for one day, I do breathe better, and it seems like that should be enough to make you want to quit. But it ain't. And that's weird."

A number of participants talked about their experiences using medications or nicotine replacement therapies (NRTs) in their quit attempts. Participants had mixed experiences with their medications and NRTs, with many saying they tried and switched between which medications and NRTs they used until they found something that worked for them. Participants also talked about how they worry about how their medications may interact (including their HIV medications), and what effects tobacco or nicotine may have on their medications. Many participants also described having trouble with using NRTs, and assistance from TTS helping them learn how to use their NRTs. Participants mentioned that having a tobacco treatment specialist or a recovery coach has been immensely helpful in the quitting process. A TTS can help with answering the questions that one might have about what their medication does or how to use it. They can work with their TTS on creating plans to quit and get tips on how to deal with cravings. Participants also mentioned that their TTS keeps them accountable to their quitting plans, which further motivates them to quit.

"I used - the patches seem to help out a little bit, and then the throat lozenges or things you put in there? That seemed to help me with my craving for it."

"Also, in the past, I tried nicotine patches and the gum. So, I don't know if I was doing it wrong or whatever, but it just seemed like it wouldn't help for me."

"But that nicotine gum was nasty. Every time it got hard and rubbery, so what it was, I was doing it wrong. So, you know, when I go through here [healthcare organization], they explained to me how I was supposed to do it."

"But [tobacco treatment specialist] does give some pretty good candy [NRTs]."

"I found it [using a tobacco cessation coach] to be very beneficial for me. Like I have gone from being like a pack a day, like a half a pack in between, to like, maybe like 3 to 4 a day. And just the last like 2 months that I've been even utilizing the coach, and kind of being more mindful and making, like, an active, like, intention and part of my day."

Besides using medications and NRTs, participants also talked about other ways they tried to curb their smoking. A number of participants have mentioned a number of techniques to attempt to delay access to cigarettes or otherwise fight craving that do not involve using medications. These include leaving cigarettes at home when going out, using caramel suckers when craving cigarettes, distracting one's self with their phone when feeling cravings, and even

notes on packs of cigarettes. Mindfulness techniques (such as meditation or yoga) were also mentioned. Mindfulness techniques are known to not only be effective in coping with cravings but also reducing stress, anxiety, and depression, all of which participants had identified as being drivers of their smoking behaviors (smokefree.gov, n.d.).

"Well, what I'm trying to do is [when] I go out somewhere, I leave my cigarettes at home."

"Like I have sticky notes, that'll be like I put on the pack of my cigarettes, because I am still smoking, that's like, 'Do I need the cigarette or do I want a cigarette'"

"I was always grateful to finish up a project so I could smoke a cigarette, but now I don't - now I find another way to take care of that."

"There are a couple of things that I have tried in the past, like to do that, where like utilizing straws. And even like those caramel apple suckers ... it does help to kind of, you know, cut down on that like hand-to-mouth and oral kind of fixation thing."

Media

When discussing media messages, the negative, fear-based messages were what most people remembered. In particular, TRUTH and the Tips from a Smoker campaign were mentioned most often. Often, the disease shown in the ad was what people used to identify the ad itself, showing that the graphic imagery is what was most memorable, often even more so than the message to stop smoking.

"I've seen the commercial that comes on about the lady. She shows – she loses her toes."

"The images I've always seen was like when you see them on TV. You know, they always say with the tracheotomy and then I've seen the lady with the foot amputated, you know, and stuff like that."

Despite being the most memorable kinds of ads, several participants talked about how these fear-based messages were ineffective for them because they were a “turn off”. These people disengaged from the messaging as soon as they recognized what it was, and actively avoid media messages surrounding smoking cessation.

"Some of the social media messages and television commercials just give me time to go to the bathroom and grab a snack."

"I mean some of the commercials are really extreme. Like I know they have to get your attention, but they could be more sensitive towards people that don't smoke, or more ... friendly towards like people that do smoke."

"They think that using shock value is going to, like, persuade someone not to smoke."

Another reason participants noted for some of the media messaging they have seen to be ineffective for them is that they find media messages regarding smoking to be difficult to connect with. Often, the consequences shown for smoking seem like they are down the line, making the need to stop smoking seem less urgent. Others talked about how messaging around smoking doesn't connect to things that are important in their lives, and subsequently doesn't feel relevant.

"I will say for me personally, those commercials never [were effective]. Because again my brain is like, 'Okay, that's down the road'. It's like it's something that may happen like later in life, or as I get older."

Yet other participants talked about distrust of the media messages they saw being a reason why they were ineffective for them. One participant talked about how the advertisements she saw didn't provide any citations for their claims. Others talked about how the media messages were incongruent with their own lived experiences. Media messaging should be wary of reactance, or the "unpleasant motivational arousal that emerges when people experience a threat to or loss of their free behaviors." Reactance will drive an individual to engage in behaviors or adopt ways of thinking to reestablish their freedoms, often by engaging in the very activities that is being forbade (in this case, smoking). One way reactance manifests is in the form of anger and counterarguing against the message, at which point the message loses all persuasive effect. Research has shown that messaging that focuses on benefit instead of loss, uses less forceful/compulsory language, and is short and concise elicit less counterarguing and reactance (Steindl et al., 2015).

"You know, cause how I can relate to that? Because my dad, he smoked for years and years and years and years. I mean years. He died. He – how can I say – he passed away in 2018. He smoked until the day he died; you know? So, and he didn't have no health issues ... So, that's what I'm saying, half the time I believe it [media messages about smoking], but half of time I don't believe it."

"That image of the lady who had lost her toes; they didn't put any kind of medical link to prove what they're saying. So, I don't believe it, you know. Because Buerger's can come from another source. They don't know where it comes from."

Still, despite most participants saying that media messaging around smoking had little or no effect on their smoking behavior, some people did say that media messaging was useful. A few participants noted that, to them, the media messaging was relevant and did stick with them. Usage of humor or strong storytelling elements were common aspects of messaging that

participants mentioned stuck with them and played a role in them trying to quit smoking. However, all of these participants had also mentioned other reasons for them trying to quit smoking unrelated to the messaging, which may indicate that the media messaging they received acted only as another reason to quit rather than acting as a primary motivator.

"I think that one [Truth ad] sticks in my head because I thought it was funny."

"The lady that has the tube, she's saying, 'Be careful what you wish for because it might not be what you want.' They're pushing the tube up through her lung in order to drain the fluid off. You're seeing this. And you're listening to what she's saying. Both of them together you can't deny."

"Like, first off, health wise I was getting a cough that was horrible from it [smoking], and so that had a big impact on me as well. And then watching the commercials of, you know, we've all seen it, the lady smoking through her, you know, neck. And that was a big impact on as well as far as to not smoke."

[Desire for More Information Surrounding Smoking, Disparities, and Medications](#)

While overall, participants showed they understood that smoking has negative health outcomes, participants were less aware of the health disparities that exist around smoking. In Michigan, 17% of adults smoke overall. But looking specifically at adult living with HIV, that rate goes up to 41%. In other words, the smoking rate of PLWH is more than double that of those who don't have HIV. Many participants showed surprise at learning that PLWHA smoked at more than double the rate of people who don't have HIV/AIDS, with one participant even showing distrust of these statistics. Despite this, participants routinely expressed a desire for more information about smoking among PLWHA. Some even talked about how there is a need for more awareness regarding the smoking disparity among PLWHA.

"I don't know anything at all about people living with HIV or AIDS compared to people in the general population."

"Like logically I can connect the dots to where I see why that is, but I just didn't realize it [the smoking rate of PWHA vs. the general adult population] was, you know, almost double in comparison."

"I'm not saying your facts are a lie. But half of that, I think are a lie... Because I know a lot of people that don't have HIV, they smoke at least 2 to 3 packs a day."

"That question [about the smoking rate of PLWHA compared to not living with HIV] really has to be talked about."

Throughout the focus group sessions, many participants had questions regarding interactions between medications, smoking, and their own bodies. Some people had also heard

misinformation regarding their medications and the effects they had on their bodies. This can lead to misuse of medications, which can make medications less effective or even harmful, and to individuals feeling a loss of control over their quit journey, which can be demoralizing. As mentioned above, a tobacco treatment specialist available can help people navigate the confusing and often overwhelming path to quitting smoking.

"The rate [of smoking among PLWHA], I think, is very high, because the chemicals that go into your body really ain't communicate with your blood cells more than what you want to do because of the medications we're on. Does that sound right?"

"So, I heard Chantix really is for like – I'm trying to think of the word – for depression people."

COVID-19

COVID-19 had varied effects on participants' smoking behavior. Some participants noted that COVID-19 didn't really have a significant effect on their smoking. Participants noted that the lockdown didn't hamper their ability to get a cigarette, because the places they would go to get a cigarette were still open. Others talked about their habit of smoking and how COVID-19 couldn't shake that habit, for better or for worse. Yet others referred back to their conversations about how nothing but their own personal strengths have any impact on their smoking behaviors.

"So, it [COVID-19/lockdown] didn't affect me [in my smoking behaviors]. The only thing that is affecting about quitting smoking is me."

"As far as COVID-19, I don't think I smoked more or less during that time, because I didn't have a problem getting cigarettes when I needed them."

"I've been a pack a day smoker most of my life and I don't think COVID did anything to increase it."

"Okay, the lockdown didn't bother my smoking because I live in a low-income area, and all the liquor stores were still open. And as long as the liquor store is open, you can get a pack of cigarettes"

For some participants, however, COVID-19 negatively impacted their smoking behavior. A number of participants noted that COVID-19 and the lockdown caused a lot of stress which, as discussed above, is a primary reason participants smoked. A few also talked about how the lockdown caused them to feel bored. Yet other mentioned that the pandemic caused them other mental health problems, such as depression. As a way to cope with the stress or as something to do to relieve the boredom, some participants talked about turning to smoking. For these people COVID-19 increased their smoking rates, or in some case, caused people who were quitting/had quit to start up again.

"Well, during COVID-19 it was more difficult to quit because you really couldn't go anywhere. You know, when you can't go nowhere, you're like fumbling with like 'What the hell can we do?'"

"Couldn't do nothing. Couldn't see nobody. And I was just depressed and so I started smoking again, but I'm still trying to quit."

Beyond creating an environment where people's mental health suffered, causing them to turn to smoking to cope, the lockdown and pandemic also impacted people's access to smoking cessation tools and services. Participants talked about how it was difficult to get to a treatment specialist or doctor to get help. Others talked about how the tools they used to curb their smoking were being sold out and were unavailable for purchase.

"With the lockdown situation, it was hard for anybody to get anything to help with their, you know, smoking stuff."

"Like those [air filters used as a replacement for cigarettes] were on like back order of back order of back order."

The shift to telehealth had mixed effects on people's healthcare utilization. For some people, the shift to a virtual setting was an easy transition. A few people even mentioned the shift to virtual being positive because it is more convenient and more comfortable to talk about their health in their own home, or because they can get to a device to have their meeting more easily than getting to the doctor. A few people also mentioned that by the time the lockdown began, they had dealt with any major health care needs they had, so the switch to telehealth didn't play a large role in their health care. Others talked about how the lockdown and COVID precautions caused doctors to cancel their appointments. Others experienced the shift to telehealth negatively affecting the quality of their visits. Of those who experienced a negative impact from the shift to telehealth, video calling fatigue was the most prominent reason cited for this. Some participants talked about how they grew weary of communicating with people through video calling, including that they didn't want to use telehealth because they were so tired of video calls.

"The introduction of telehealth affect my treatment... definitely! Because I'm on different committees and orgs throughout the city, and I was getting – I'm so zoomed out, I don't even want to do Zoom stuff anymore."

Many people expressed some degree of frustration with the COVID-19 pandemic. This frustration came from not only being under lockdown, but with the inconsistent messaging around the disease that they received and with what they found to be insufficient policy changes that followed. A few people also expressed that the pandemic is ongoing, and its effects can still be felt.

"We didn't do anything right with COVID. I mean, look at our healthcare system, it's still a big cluster of ridiculousness."

"And to make a fight out of people living or dying or eating or getting kicked out of the places was just a - It was all just a mess."

"I still won't ride in no – I won't ride on no bus, and I won't take no Uber or a Lyft, because with my anxiety and everything going up right now still with COVID... And you know, Kalamazoo is high rate again, you know."

Conclusions and Recommendations

Tobacco use is a complex issue that requires multiple approaches to the many facets the problem presents on. In efforts to reduce tobacco use, it is just as important to understand the people using tobacco as it is to understand tobacco and its effects on the person. People living with HIV represent a diverse array of races, gender identities, and sexual orientations. But still, there seems to be commonalities in the issues faced by PLWH in reducing their tobacco use borne from the unique challenges of being a person living with HIV. Understanding the needs of PLWH in reducing their tobacco usage to help them in their quitting journey is essential to the success of the TURP program. Below are a few recommendations to address the burden of tobacco use among PLWHA, informed by these focus groups.

Tobacco Treatment Specialists and Support Groups

Many participants expressed that peer support groups are helpful to them and a desire to attend more of them. Support groups provide a sense of comradery and accountability to group members. The sense of community and belonging may drive an individual to attend groups while the desire to avoid disappointing one's group members due to not sticking to one's quit plan may act as another piece of motivation to quit one's tobacco use. In addition, groups offer a chance to share one's experiences, tips, and struggles, thus offering a space to both be vulnerable but also to learn from peers. This helps establish feelings of self-efficacy and allows the individual to take control of their own smoking behavior. Importantly though, these peers should be current or former tobacco users who live with HIV, as they would better understand the circumstances of current tobacco users living with HIV who are looking to quit.

The presence of a specialist can also be helpful in many of the same regards. Tobacco treatment specialists (TTS) can provide expertise and assistance to PLWH looking to reduce their tobacco use. TTS can provide advise based on both evidence-based practices and personal experiences, including tips that may not be common knowledge and would not come up in a peer support group. Additionally, in the focus groups, participants spoke to how helpful and supportive their TTS was, suggesting that having a TTS can also provide a central figure to seek support from if one is unsure they may find it with their peers or social network. New or continued funding to host support groups and employ specialists through program funds would allow these benefits to persist/be achieved. Ensuring that these services are sustainable and

remain available in crisis situations (such as a global pandemic) would help alleviate stressors that would otherwise lead to relapse.

Offer NRTs and Medications Throughout the Year

Participants described having more or less success with different forms of medications and NRTs and experimenting with different forms until finding one that works best for them. ASOs should continue to offer education regarding how to use different forms of medications and benefits and disadvantages of each one. Offering this education can help clients build self-efficacy. Furthermore, clients should not be penalized for discontinuing usage of treatment. People tend to attempt to quit multiple times before successfully quitting. Additionally, it may take a few tries before someone finds the medication or treatment plan that works for them. Given that so many participants have noted access to medications as a barrier to quitting and that so many participants have shown a strong desire to quit, it is reasonable to assume that making these resources available throughout the year and at low cost will encourage more people to try to quit.

Limit Negative Media Messaging

Participants overwhelmingly recalled negative “fear-based” messages when trying to recall media messages related to tobacco use. This suggests that these negative media messages are memorable. Unfortunately, negative media messaging also appears to be largely ineffective, as participants mostly noted that these media messages were ineffective at creating behavior change. Many participants even noted actively avoiding these messages. As many participants showed awareness that tobacco use is unhealthy, and showed a strong desire to quit, messaging that simply attempts to raise awareness of the harms of tobacco use may also be unhelpful. Participants identified storytelling elements, humor, and more immediate relatability as traits of effective message. Prior research on the subject also indicates that messaging that reduces the capacity for reactance and uses less forceful language also tend to be more effective (Steindl et al., 2015). Instead of scare tactics, messages should revolve around missed or recovered opportunities for enjoyment or self-fulfillment.

Combatting Stigma and Raising Awareness

Society and core institutions, such as the healthcare system, stigmatize both PLWH and tobacco users. This stigma is a major stressor in the lives of clients. Given that stress was the most common reason participants gave for why they smoke, eliminating stigma should be regarded as a primary goal to reduce tobacco use among PLWHA. ASOs should adopt strict zero tolerance policies towards discriminatory practices towards PLWHA and seek to eliminate any stigma towards tobacco users or PLWH within their organizations. Furthermore, ASOs, TCP, and other partner organizations should strive to raise awareness for the disparities being faced by PLWHA, and act as leaders in destigmatization of living with HIV.

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Appendix A: TURP Focus Group Consent Form

Focus Group Consent to Participate and Confidentiality Form

- You are invited to be part of a focus group. This focus group will collect information from clients of Tobacco Use Reduction Program (TURP) partners. Questions will be asked about tobacco use, tobacco marketing, the impact of COVID, methods of quitting tobacco, and other topics. TURP and its partners will use the information for internal quality improvement. We will also research themes that come up to improve knowledge about tobacco use by people living with HIV.
- Your participation in the focus group is voluntary. The focus group will take 30 to 90 minutes. You are free to leave at any time. If you decide not to take part or to leave during the discussion, your decision will not affect the services you receive from _____ (the organization you receive tobacco related services from). If you stay the entire time, we will offer you a \$10 gift card.

CONFIDENTIALITY

- Participants are encouraged to keep information discussed in the group confidential. We encourage free sharing of information, and hope participants will respect each other by keeping shared information private. The research team cannot control what other participants might share after the focus groups though.
- Nothing you talk about will be shared by the research team unless all identifying information is removed first. We will record the focus group. A scribe will write down comments based on that recording. The comments written down will not include personally identifying information. We will destroy the recordings after comments are written down.
- We will group your comments with answers from all participants so your individual comments cannot be identified. Any report or presentation made by the research team will not include information that could identify you as a participant.

CONSENT TO PARTICIPATE

- If you have questions about the focus group, please ask a member of the research team before agreeing to participate. If you do agree to participate, you are still welcome to ask questions at any time. If you stay and choose to participate, you are agreeing to be part of this focus group and to be recorded during the focus group.

CONTACT INFORMATION

- If you have any questions about this effort, please feel free to contact:
 - Sheyonna Watson watson4@michigan.gov (TURP Consultant)
 - Farid Shamo shamof@michigan.gov (Tobacco Section Evaluator)
 - Sean Bennett bennetts11@michigan.gov (TURP Evaluator)
 - MDHHS IRB MDHHS-IRB@michigan.gov or (517)-241-1928

Appendix B: TURP Focus Group Demographics Survey

Participant Demographic Sheet

Agency Convening Focus Group: _____ Date of Focus Group: _____

Participants complete below:

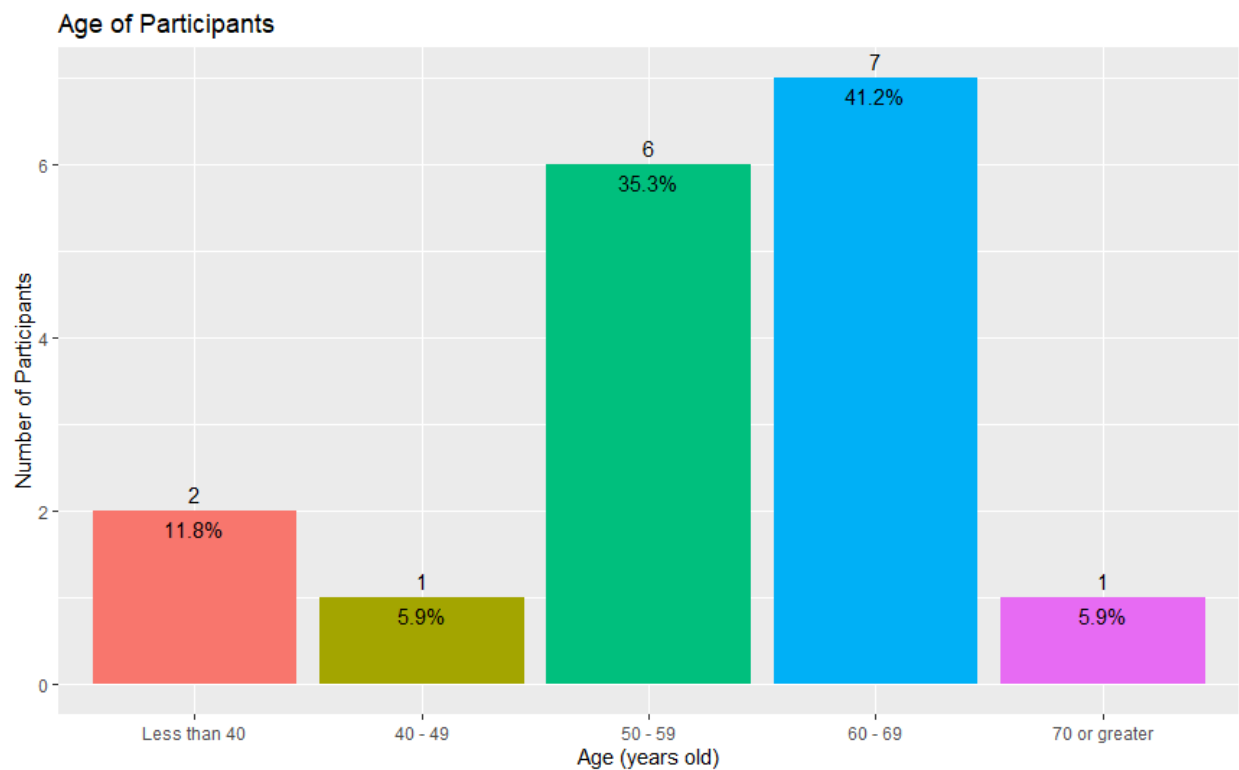
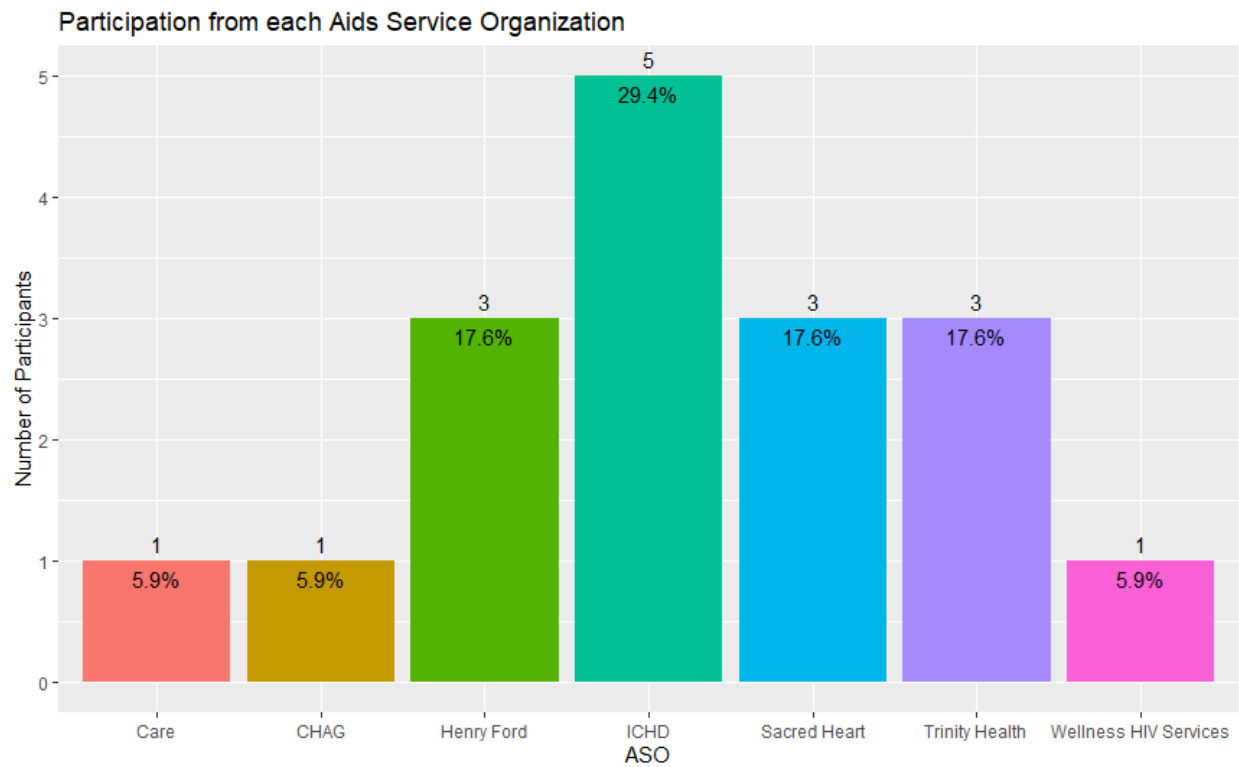
1. Age: _____
2. Gender Identity: _____
3. Race: _____
4. Sexual Orientation: _____
5. Self-assessment of Health:
☐ Excellent ☐ Good ☐ Fair ☐ Poor
6. Educational level:
☐ Less than High School ☐ High School ☐ Some College ☐ College and Above
7. Annual household Income:
☐ up to \$20,000 ☐ \$20,000 - \$30,000 ☐ \$30,000 - \$40,000
☐ \$40,000 - \$50,000 ☐ more than \$50,000
8. Employment status:
☐ Self-employed ☐ Employed ☐ Unemployed ☐ Disability Income
9. How long have you been living with HIV? _____ years
10. How long have you been using tobacco products? _____ years
11. How many quit attempts to tobacco use have you made in the past year? _____

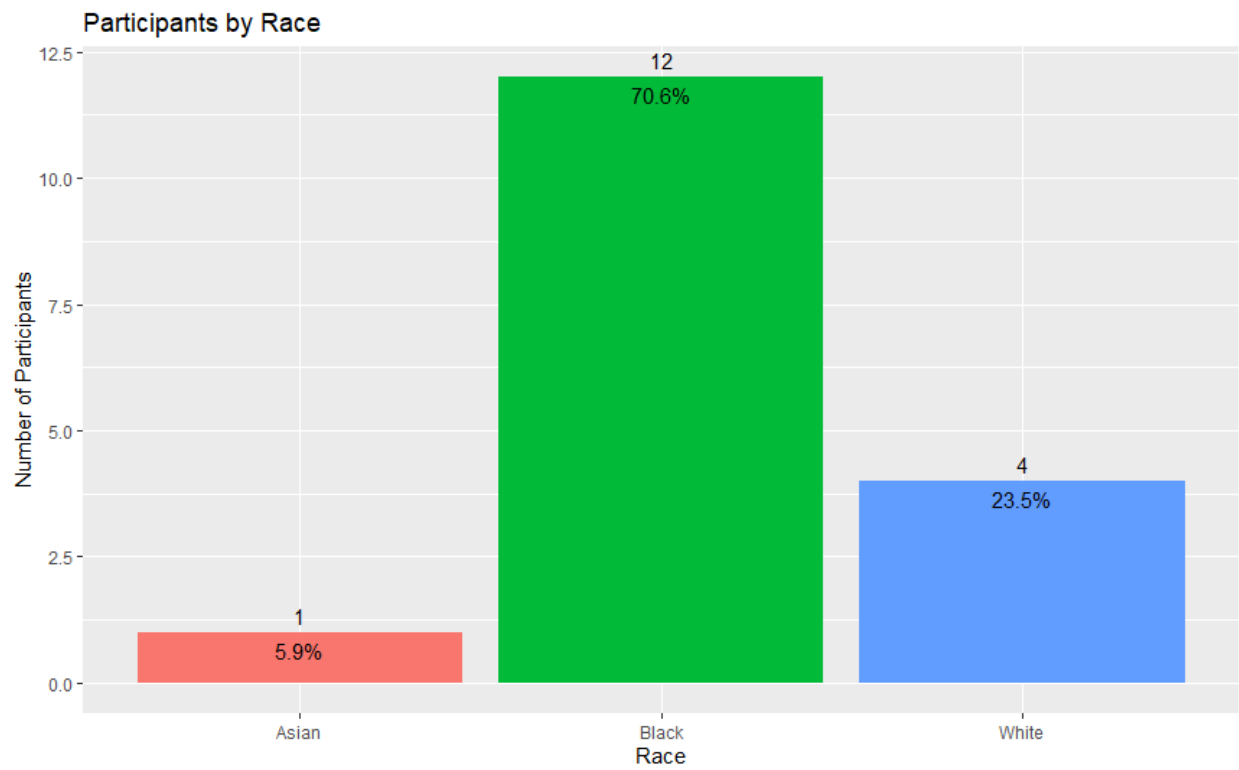
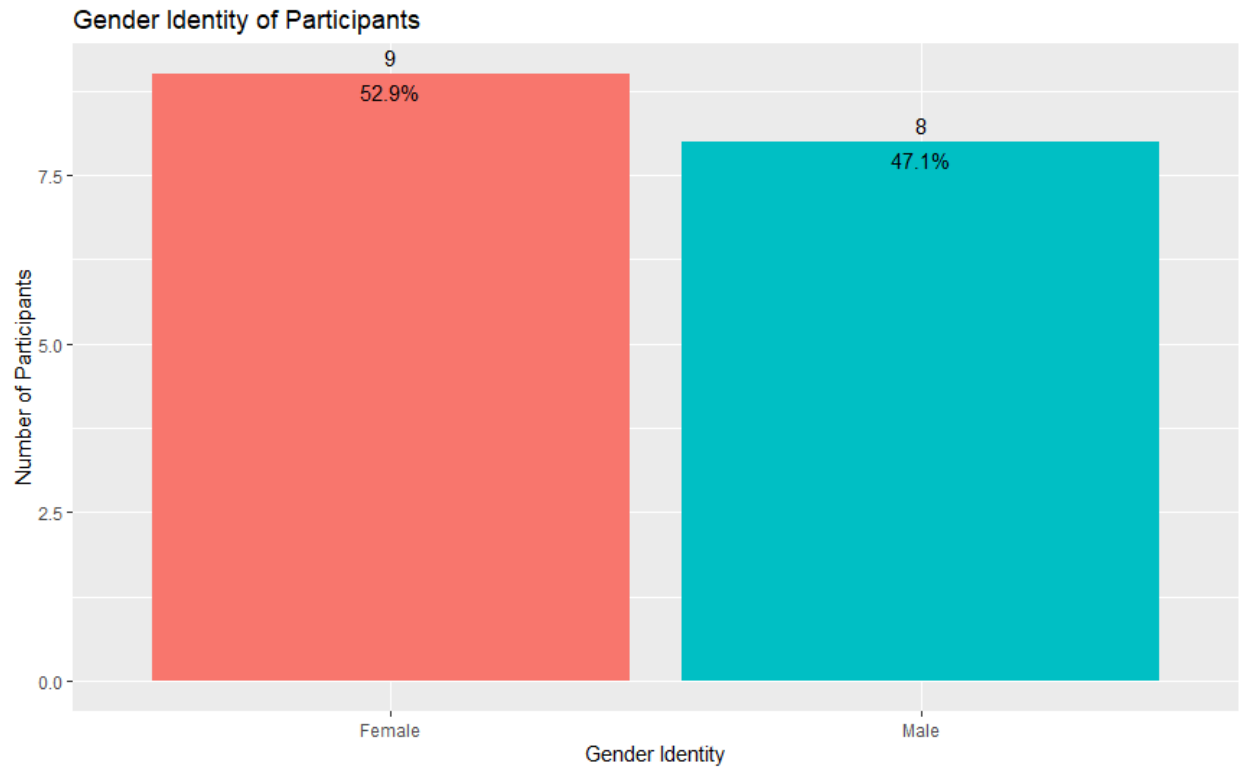
Appendix C: Demographics Survey Data

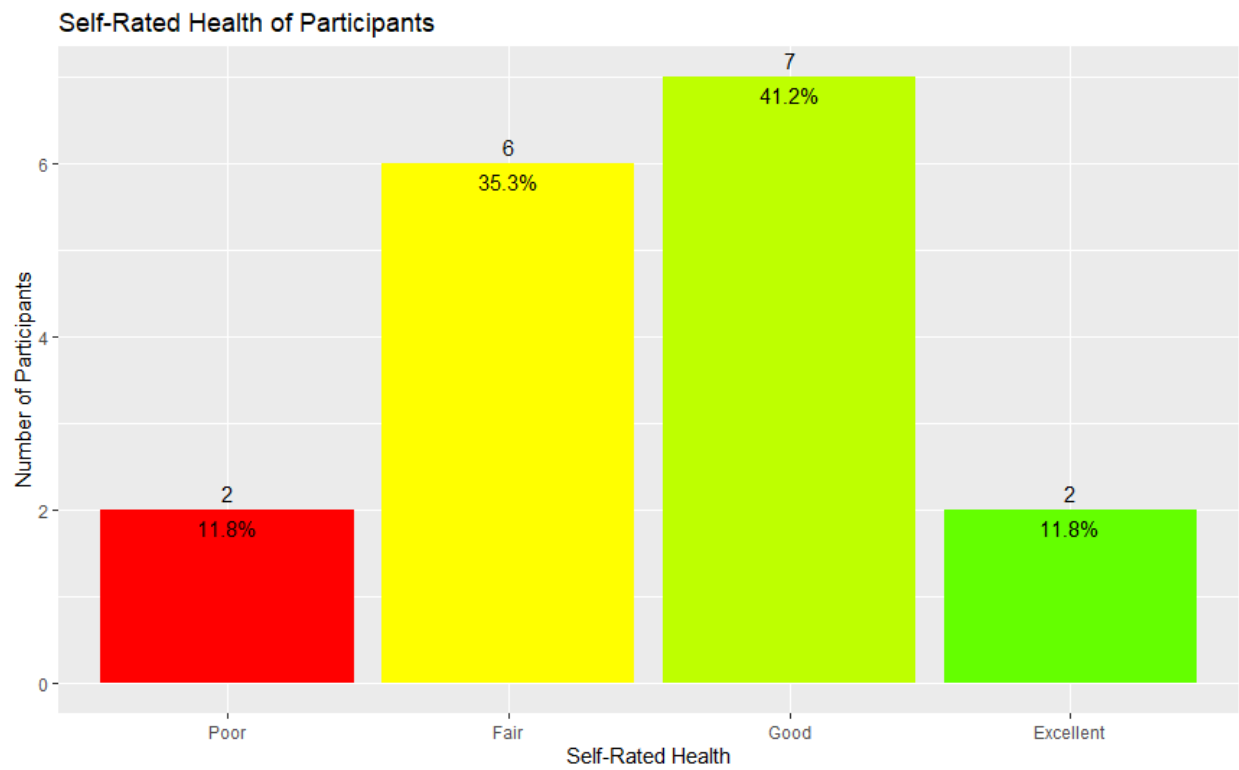
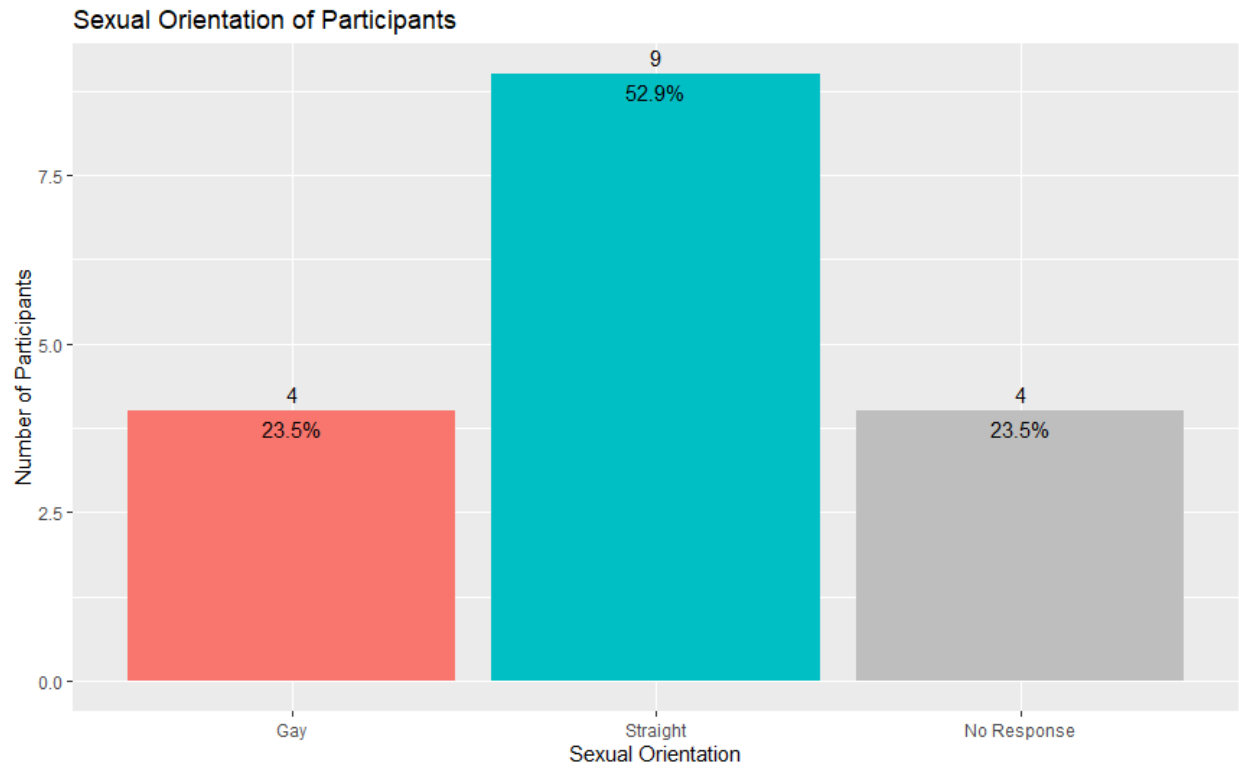
Data Table

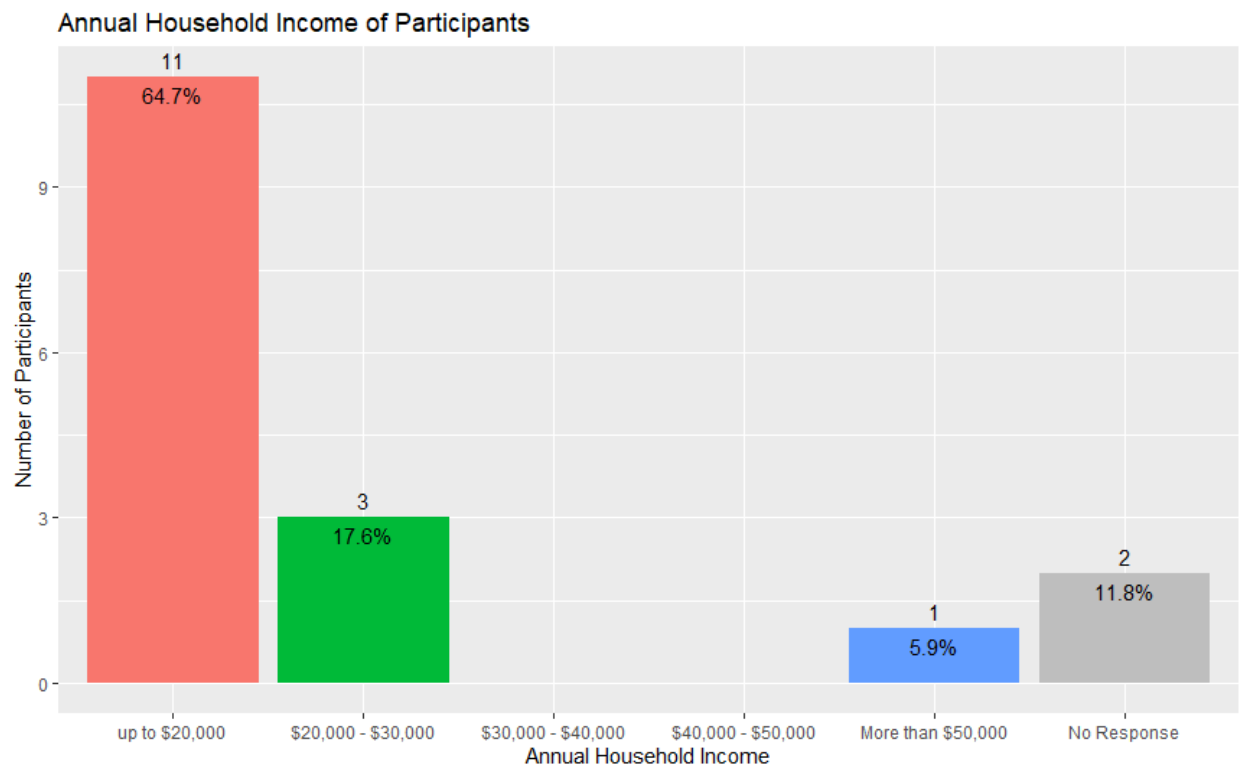
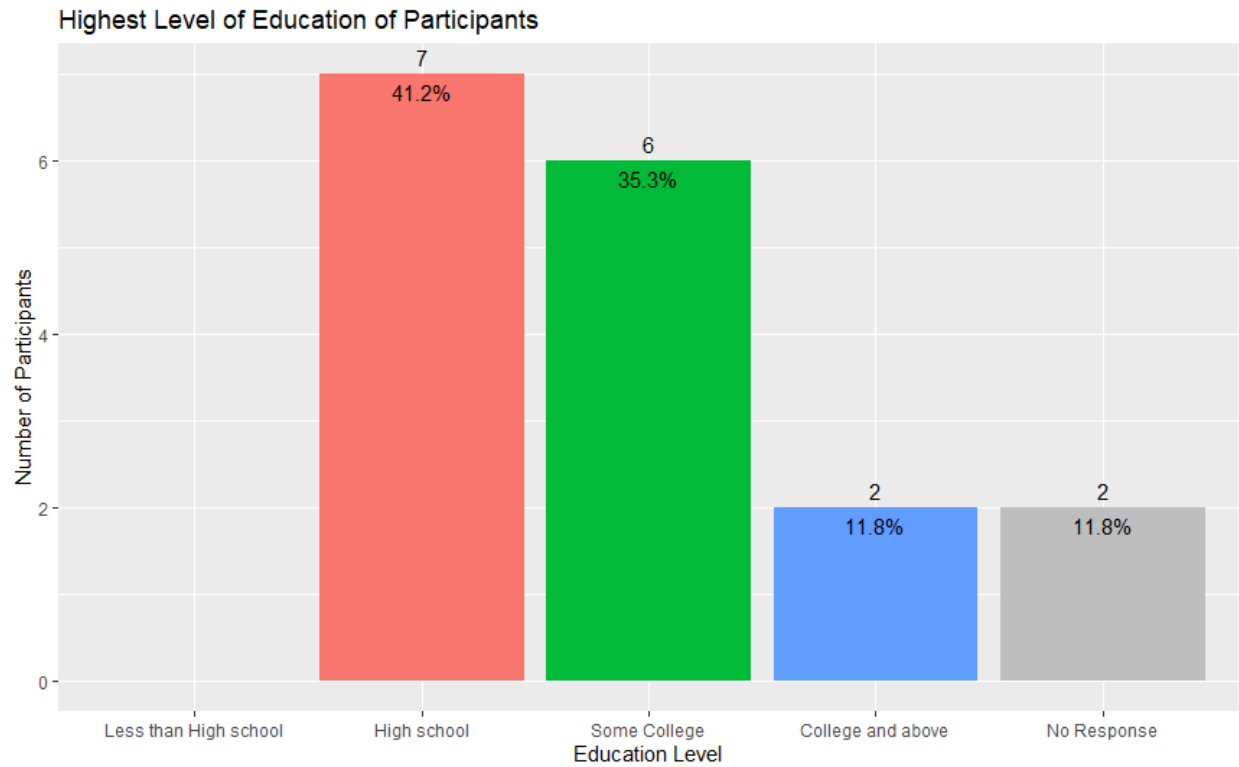
Name of Agency Where You Receive Services	Date of Focus Group	Age	Gender Identity	Race	Sexual Orientation	Self-assessment of Health	Education Level	Annual Household income	Employment Status	How long have you been living with HIV?	How long have you been using tobacco products?	How many quit attempts to tobacco have you made in the past year?
Wellness HIV Services	7/28/2022	55	Male	White	Straight	Fair	High school	up to \$20,000	Disability Income	25	42	7
Henry Ford	8/1/2022	37	Female	Asian	Straight	Good	College and above	More than \$50,000	Employed	10	24	3
Care	8/1/2022	61	Male	White	Gay	Good	High school	up to \$20,000	Disability Income	22	40	29
ICHHD	7/28/2022	73	Female	Black	Straight	Fair	Some College	\$20,000 - \$30,000	Disability Income	12		0
ICHHD	7/28/2022	40	Female	Black		Good			Unemployed	3	10	4
ICHHD	7/28/2022	61	Female	Black	Straight	Fair	College and above	up to \$20,000	Disability Income	12	45	3
ICHHD	7/28/2022	50	Female	White	Straight	Fair	Some College	up to \$20,000	Disability Income	20	15	2
ICHHD	7/28/2022	58	Female	Black		Fair	High school	up to \$20,000	Disability Income	8	30	5
CHAG	8/1/2022	64	Male	Black	Gay	Fair	Some College	\$20,000 - \$30,000	Disability Income	30	30	2
Trinity Health	8/1/2022	56	Male	White	Gay	Poor	Some College	up to \$20,000	Self-employed	15	40	2
Trinity Health	8/1/2022	60	Female	Black	Straight	Good	High school	up to \$20,000	Disability Income	14	20	3
Trinity Health	8/1/2022	68	Female	Black	Straight	Good	Some College	up to \$20,000	Unemployed	17	5	0
Henry Ford	7/28/2022	63	Male	Black		Good	High school	\$20,000 - \$30,000	Disability Income	23	38	2
Henry Ford	7/28/2022	55	Male	Black	Straight	Poor	Some College	up to \$20,000	Disability Income	21	10	5
Sacred Heart	8/3/2022	63	Male	Black	Straight	Excellent	High school		Disability Income	36	40	7
Sacred Heart	8/3/2022	52	Female	Black		Excellent	High school	up to \$20,000	Disability Income		1.5	0
Sacred Heart	8/3/2022	35	Male	Black	Gay	Good		up to \$20,000	Disability Income	15	17	5

Graphic Visualizations

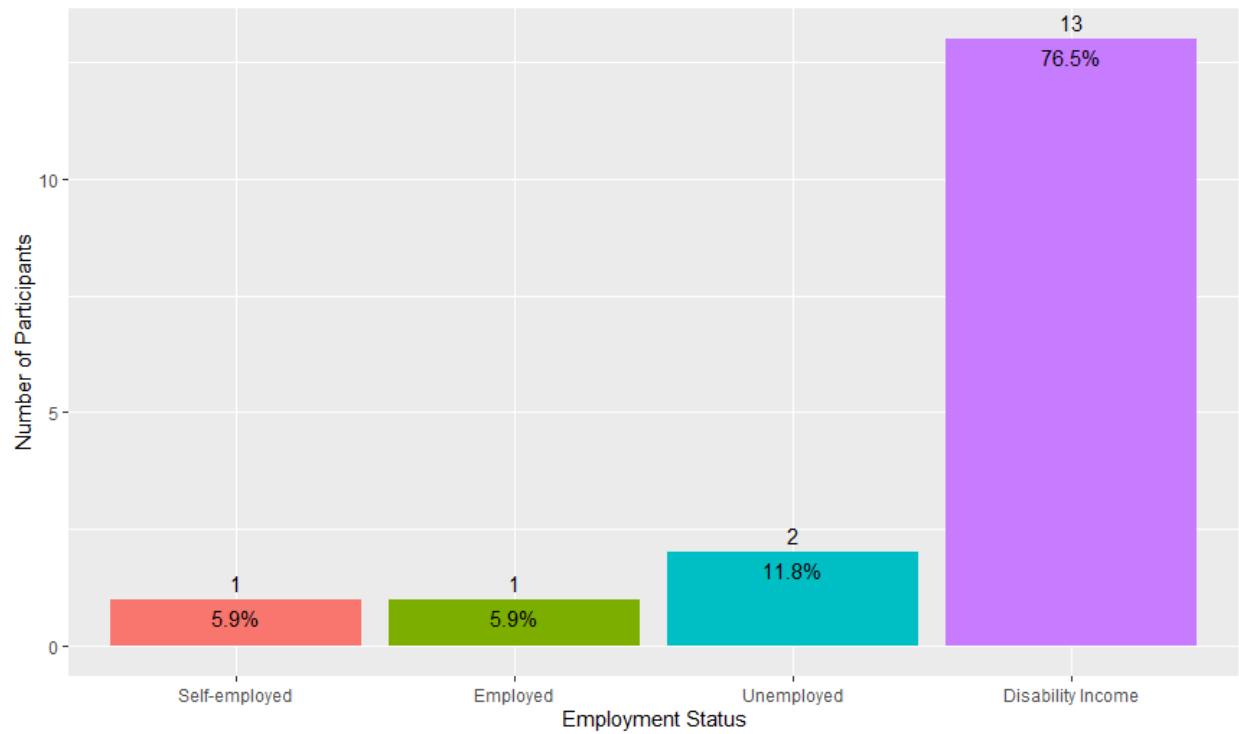




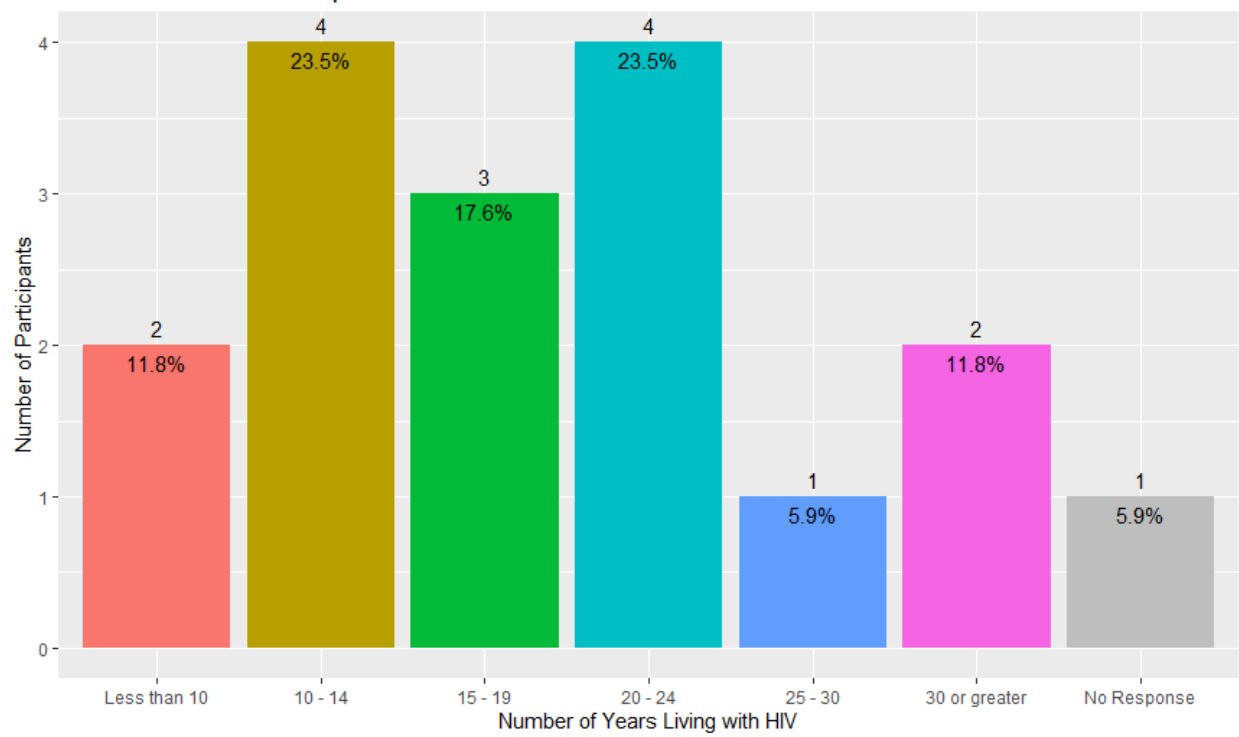


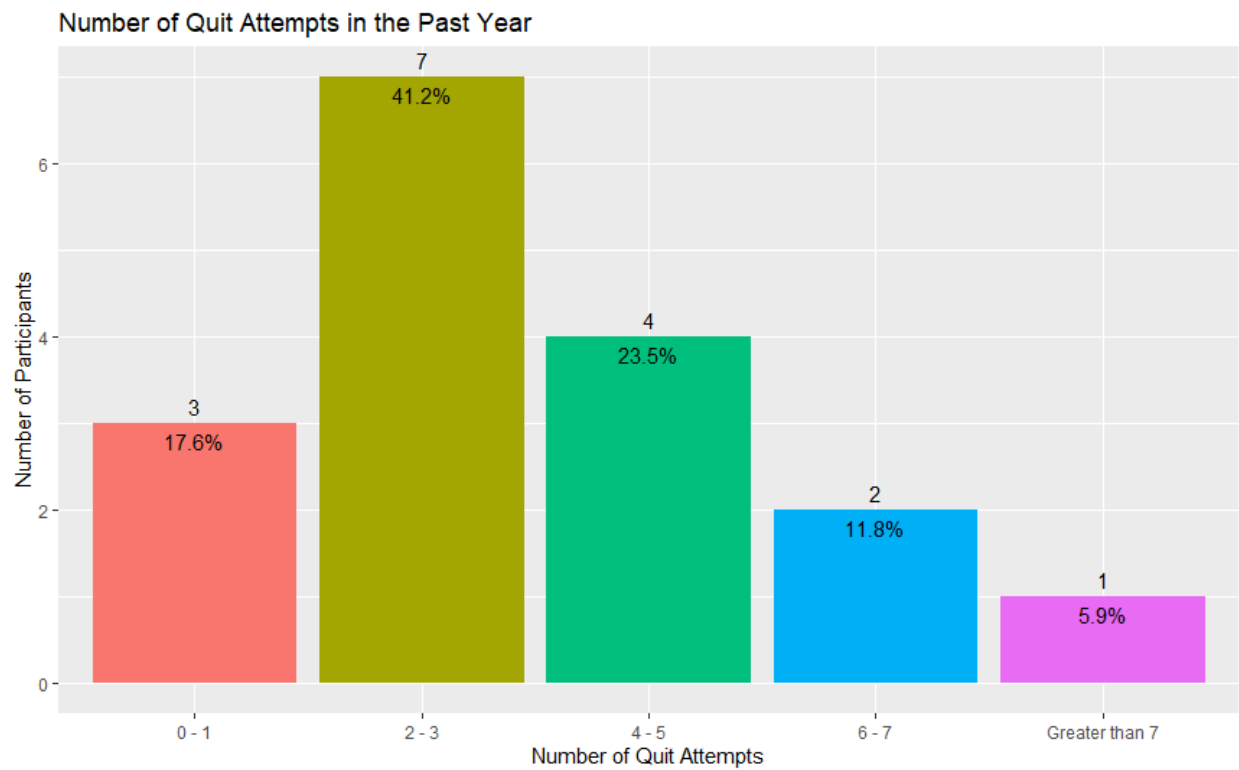
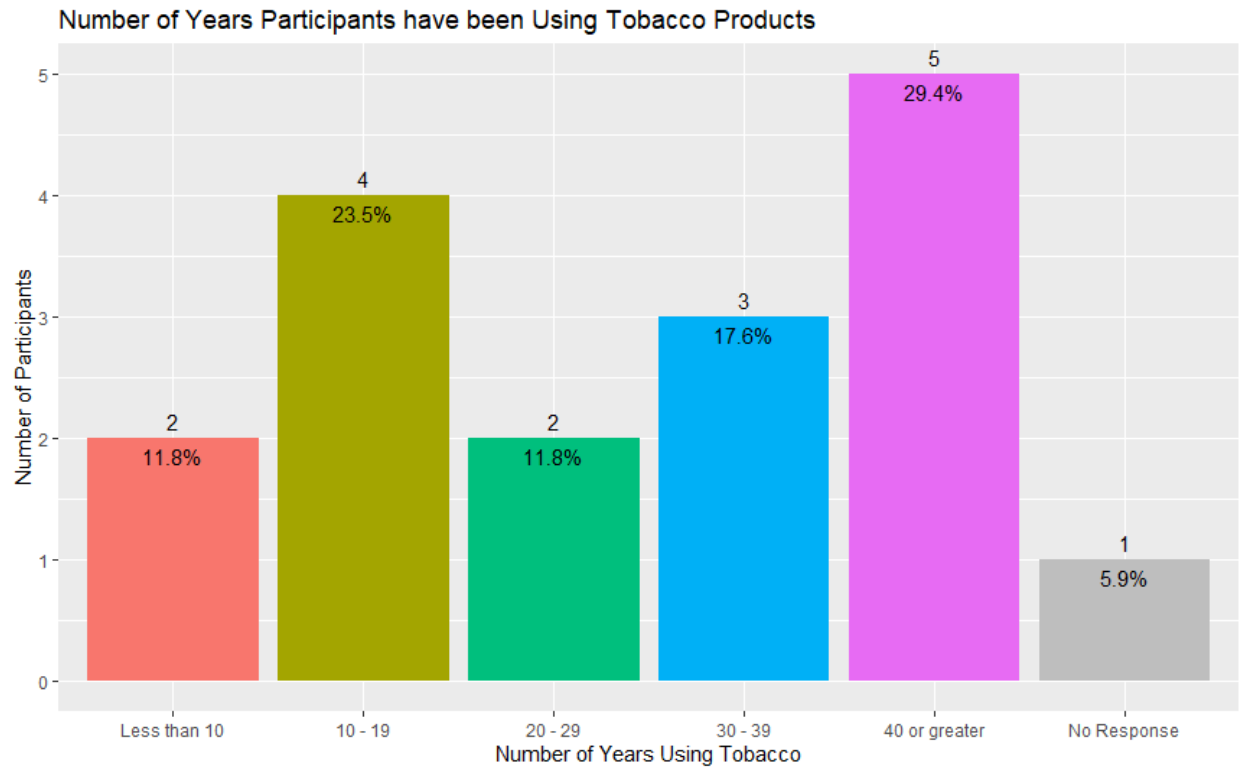


Employment Status of Participants



Number of Years Participants have Lived with HIV





Appendix D: Focus Group Questions

Focus Group Questions

*Agency Instructions: Do not share these **questions** with focus group participant. Read the questions in bold exactly as they are written.*

Topic-1

Theme: Knowledge of smoking related health disparities: Smoking Prevalence among PLWHA

- 1. What do you know about the smoking rate of people living with HIV/AIDS (PLWHA) compared to the general population?**
- 2. Why do you think that PLWHA smoke at a higher rate than other people?**

Topic-2

Theme: Perspective on social behaviors associated with tobacco use

- 1. What have you done or what services have you used to quit tobacco use?**
- 2. What has helped you to quit tobacco use in the past?**

Topic-3

Theme: Expectations for appropriate and sensitive treatment and prevention: Awareness of tobacco use, media messages, and prevention activities

- 1. What specific media images or messages to quit using tobacco that you recall or can identify?**
- 2. Have you tried to quit before? What happened?**
- 3. What health problems have you had related specifically to your tobacco use?**
- 4. What do you think of the following statement: Focusing on changing social norms regarding acceptance of tobacco use will produce an environment that is supportive of non-smoking behavior among people living with HIV/AIDS.**

Topic-4

Theme: Impact of COVID-19 on tobacco use, and health consequences associated with tobacco use and COVID-19

- 1. Has the response to COVID-19 made it more or less difficult to access tobacco treatment services?**
 - a. Probing questions:**

- i. How did the introduction of telehealth affect your treatment?
 - ii. Did your provider cancel in-person visits? If so, how did that impact your routine?
- 2. Did the stress of the COVID-19 pandemic and the subsequent response (lockdowns, canceling of in-person non-emergency medical services, etc.) make it difficult to remain tobacco free or start your journey to quit?