# Connecticut Getting to Zero Commission

# Community Listening Sessions

## Full Report and Community Recommendations

Report written by:

Marcie Berman, Ph.D.[1] and H. Danielle Green, Ph.D.[1]

Listening sessions facilitated by:

Dwayne Jackson[2] and Latoya Tyson[3]

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[1] Institute for Community Research, 2 Hartford Sq., W., Ste. 100, Hartford, CT 06106
[2] Leadership Greater Hartford, 30 Laurel St # 3D, Hartford, CT 06106
[3] AIDS Connecticut, 110 Bartholomew Ave, Hartford, CT 06106

# Introduction

In 2018, the Connecticut Department of Public Health (CT DPH) joined several other states in the U.S. to launch a "Getting to Zero" (G2Z) campaign, with the goal of zero new HIV infections, zero HIV/AIDS deaths, and zero HIV/AIDS stigma and discrimination in CT. As a first step in launching this campaign, the CT Commissioner of Health established the CT G2Z Commission to develop a set of recommendations for how to achieve the state's G2Z goals. To inform these recommendations, the G2Z Commission conducted 19 community listening sessions focused on three groups of people with the highest rates of new HIV infections in CT according to the 2016 CT DPH HIV Epidemiological Report. These included young Black/African American and Hispanic men who have sex with men (MSM), Black/African American women, and transgender women. Listening sessions were conducted in the five cities with the highest number of new HIV infections and largest proportions of people living with HIV (PLWH) in CT, including Bridgeport, Hartford, New Haven, Stamford, and Waterbury. An additional session was held with HIV health and service practitioners who provided medical or other services to PLWH. These practitioners were attendees at the "Front Line Staff Think Tank" conference, held in New London, CT on August 2, 2018.

A facilitator from Leadership Greater Hartford (LGH) and two Research Associates from the Institute for Community Research (ICR) were commissioned to conduct these listening sessions, to take detailed notes, and to compile findings in this report. Additionally, two sessions were facilitated by a G2Z Commissioner from AIDS CT. Listening sessions were held at locations where participants would feel comfortable, including health organizations and establishments friendly to LGBTQ+ (lesbian, gay, bisexual, transgender, questioning, plus) persons. Eighteen of the 19 listening sessions were audio recorded with participant consent, and detailed notes of all the sessions were provided to each G2Z Commission member.

Members of the G2Z Commission along with the LGH facilitator designed the questions for use during these listening sessions. Questions focused on participant awareness of and attitudes toward HIV prevention, specifically pre-exposure prophylaxis (PrEP), HIV testing, HIV care and treatment, and experiences of HIV-related stigma. They also focused on facilitators and barriers to address disparate HIV services for PLWH and participant recommended solutions to address those barriers. The following reports on findings from the 19 community listening sessions of this G2Z effort.

# Methodology

In order to conduct the listening sessions to inform the CT G2Z Commission's recommendations to the CT DPH, members of the Commission from each of the 5 hardest hit cities (Hartford, Bridgeport, New Haven, Stamford, Waterbury) worked with community partners to identify and recruit participants from the three focus populations (young MSM of color, Black/African American women, transgender women). Each city planned to hold one group listening session with each population, with a goal of 8-20 participants per session. Sessions were conducted from July through September, 2018. Participants were generated primarily through community organization referral and recruitment to create a convenience sample from each group and city.

Obtaining adequate sample sizes at some listening sessions was difficult; therefore, some cities held more than one session for a given population group. In addition, Hartford held session entirely in Spanish with young MSM who were monolingual Spanish speakers. **Table 1** indicates

the total number of participants from each city and each population group who attended the G2Z listening sessions.

**Table 1. Number of Respondents Who Participated in CT G2Z Listening Sessions**

| City | Young MSM of Color | Black/African American women | Transgender women |
|---|---|---|---|
| **Bridgeport** | 23 | 21 | 8 |
| **Hartford** | 6 in English & 7 in Spanish | 9 | 10 |
| **New Haven** | 4 | 7 | 12 |
| **Stamford** | 2 | 14 | 6 |
| **Waterbury** | 22 | 19 | 10 |

An opportunity to conduct a listening session with practitioners came from conference attendees at the "Front Line Staff Think Tank" Conference. A total of 24 conference attendees were divided into two groups and responded to the same set of questions to offer their perspectives, highlighting the cities they work in and the three target populations when possible.

Participants in all sessions were asked questions about HIV knowledge (e.g., what do you know or have you heard about HIV in your community), HIV testing (e.g., what barriers are there to HIV testing in your community), HIV prevention through PrEP (e.g., has anyone ever heard about pre-exposure prophylaxis or PrEP), HIV care (e.g., what have you heard about HIV care), and HIV stigma (e.g., please describe HIV stigma within your community). (A copy of the full set of listening session questions is included as **Appendix 1** at the end of this report.)

The following reports on the listening session data organized by population group for each of the key HIV G2Z themes (prevention and testing, care, stigma), followed by a summary of findings by city. Following this is a summary of cross-cutting themes and participant recommendations across groups and cities. These were used to inform CT G2Z Commission recommendations to achieve the state's G2Z goals.

# Listening Session Findings by Population Group

## Young MSM of Color

The men in these listening sessions spoke about their respective cities, but some also highlighted that the major cities in Connecticut differ in the care they provide for diagnosis, treating, and dealing with HIV. They also referred to their community (MSM) as complacent about HIV, despite having HIV knowledge. This attitudinal barrier to prevention, created by the overall perception that HIV/AIDS is no longer a death sentence, especially affects the younger generation and leads some to believe that they do not have to protect themselves. Groups from Bridgeport and Stamford both described the general apathy towards others in the community because some individuals do not care to test and are not concerned about hurting others. Several participants believe that unity over topics involving HIV within the gay community is difficult because everything is so segregated by the different cities in Connecticut and different groups, while others believe that separating into groups leads to more awareness of the differences.

HIV Prevention and Testing

Many participants were aware of how HIV is contracted (sex, drugs, blood) and how to prevent HIV (celibacy, condoms, and PrEP). Participants from Waterbury, New Haven, and Hartford mentioned the lack of HIV education among school-aged youth. Hartford monolingual Spanish participants indicated that the school systems offer condoms and birth control methods but they do not offer any information about condom use and why they should be cautious when having sex. Two groups also stated that the lack of education is related to schools limiting the amount of health education about HIV allowed in the school systems, which may be because the teachers provide sex education in schools rather than informed advocates. Groups from Stamford and Hartford also addressed the issue that there is a lack of "wanting to know more" about HIV in their community, indicating some people only take information about HIV seriously when they are personally affected. They also indicated that individuals are fearful about risk and educating themselves on potential risks.

Participants reported that the predominant issue regarding HIV testing was fear, which included the fear that they would be recognized when entering a space to get tested, fear of a positive result, fear that a positive test result will not remain confidential, and fear of rejection. Other barriers to testing were related to the types and locations of testing sites. Bridgeport participants indicated that the majority of clinics are only open from 8am to 4pm, and that men do not always feel comfortable walking into a Planned Parenthood clinic for testing. Waterbury participants also expressed a need for more discreet testing location options. Additional issues regarding HIV testing include mental health, substance use, and insurance issues (e.g., on parent's insurance, lack of insurance). Some participants were aware of where they could receive free HIV testing. Hartford and Bridgeport participants reported provider barriers to HIV testing, which include the lack of non-judgmental doctors and being afraid to ask their doctors for an HIV test. New Haven participants also described getting tested as a scary process every time because they really do not know if their partner(s) are telling the truth when they talk about risk.

Participants were mixed regarding their awareness of PrEP and how to obtain PrEP prescriptions. Some had known about PrEP since 2012, and some had only heard of it very recently. New Haven, Stamford, Hartford, and Bridgeport participants all raised concerns about how PrEP is marketed, because it is advertised in ways that exclude straight people, lack diversity (only showing ads of stereotypical gay men), and limit viewership (e.g., advertised in gay bars, late-night commercials, in medical settings). Hartford monolingual Spanish participants also stated that part of the issue is that more information needs to be made available to PLWH, not just those who are HIV-negative. Participants who knew about PrEP also discussed misconceptions about it, including reduced condom use and some apprehension about taking PrEP due to the unknown risks associated with the medication. Some participants from Hartford also reported that they had asked their medical providers for PrEP and those medical providers denied them a prescription because the provider did not believe the person was at risk. Participants noted that doctors are unaware of PrEP, and PrEP is more widely known and available among white MSM.

HIV Care

All MSM listening session participants discussed where they could obtain local HIV treatment, including clinics, health departments, infectious disease specialists, and primary care doctors, but the groups varied in their level of knowledge about HIV care. Hartford, Waterbury, and Stamford participants indicated that there is a need for more widespread information about HIV

treatment. The following barriers to obtaining HIV care were discussed: fear, lack of insurance or other financial issues, judgement from the gay community and doctors, denial of HIV status, shame for engaging in risky activities, mental health, substance use, HIV stigma (e.g., not wanting others to see you take a pill every day), and not being provided with linkage to care information after testing positive at their doctor's office or through urgent care. Waterbury and New Haven participants mentioned the need to re-educate doctors, nurses, and other healthcare professionals on their sensitivity to individuals who are diagnosed with HIV to ensure that their interactions do not show their biases, or appear homophobic or germ-phobic when discussing HIV.

In terms of HIV adherence, some participants focused on the need to educate physicians about HIV because some PLWH would like the option to go to their primary care providers for HIV treatment. Some of the New Haven participants indicated that having only one infectious disease (ID) location nearby can affect adherence to HIV treatment because most of the time, people are afraid to go into their ID location because they do not want to be seen. They also stated that some people only go once, and then say they feel fine. Stamford participants emphasized mental health support as an important component to initiating and adhering to HIV treatment and that it should be introduced into care upon diagnosis to address fear and denial. Participants in these groups who were HIV-positive indicated that when they felt good (healthy) and supported by friends or family, it encouraged them to adhere to their HIV care.

HIV Stigma

Young MSM participants reported that HIV stigma was a barrier to HIV prevention, testing, and care. HIV stigma was related to homophobia and stereotypes of gay men (promiscuous, substance use), which was greater with regard to MSM of color. Participants in New Haven provided the rationale that most of the issues surrounding HIV revolve around a lack of HIV education and its greater impact on communities of color rather than white communities. Religion is another factor because homosexuality is looked down on by some religious institutions. Additionally, groups from Stamford, Waterbury, and Hartford noted that HIV was thought of as a "gay disease" in the heterosexual community, and negative preconceptions of PLWH still exist, such as that only gay people get it or "you deserve it," especially in Latinx and Black families. A Bridgeport participant indicated that the stigma of letting the families know of an HIV-positive status is bigger than anything else.

Participants across different MSM listening sessions discussed the stigma associated with idea of including HIV tests in routine blood draws. New Haven and Bridgeport men indicated that doctors contribute to the stigma associated with HIV testing when they only test at-risk populations or neglect to ask sexual health questions of everybody. This is particularly difficult for gay men, who often do not feel comfortable telling doctors they are MSM and about their sexual health history. In Hartford, participants were younger and reported that they were afraid of what their health care provider would think of them if they asked for an HIV test, which suggests the need for HIV testing to be automatically incorporated into blood work. Additionally, participants reported that they preferred the HIV home test kit, even though it is expensive, due to the fear of stigma.

Several groups mentioned how the general public does not hear enough about PLWH, so it's difficult for them to relate to people living with HIV, and this division contributes to stigma. Stamford and New Haven groups commented on how some PLWH are not comfortable letting others know they have HIV, so it comes back to normalizing HIV and educating the public on what it means to be undetectable (i.e., U=U, or undetectable = untransmittable). Waterbury and New Haven participants commented on the lack of safe spaces for the LGBTQ+ communities in

Connecticut. Participants in New Haven also mentioned that the support group system tends to cater to older people because of their time flexibility, which often does not adapt to the availability that young MSM need.

## Black/AA women

When discussing the prevalence of HIV among Black women, women in each of the listening sessions drew links to the continued misconceptions about HIV that persist throughout the Black community. These misconceptions include that HIV is a “gay man’s disease,” that people in monogamous relationships are not at risk, and that one could tell if an individual is infected with the virus simply by looking at them. These myths about HIV are perpetuated whenever false information spreads throughout the community and goes unchallenged, which some of the women believe is maintaining the stigma.

Prevention and Testing

While all groups mentioned HIV education as a crucial component to prevention, Black women focused on the populations most in need of the education. Women from Stamford, Bridgeport, and Waterbury suggested that the school-aged youth and senior citizens are groups most in need of education, as these two groups are likely the individuals of unknown status. For youth, they suggested that this education needs to take place in the schools where youth may be more open to the information, and at an early age because, as women in Bridgeport stated, most kids are only concerned about avoiding pregnancy rather than protection against HIV. The older generation needs to be re-educated about HIV because they influence how information about HIV is transferred to the younger generation, along with their beliefs about people with HIV. Women from all cities mentioned a need for an increase in HIV awareness and education throughout churches, and that the message needs to be reinforced that everyone, regardless of the socio-economic status, is still at risk for HIV.

Fear was raised in almost every session as a common barrier to getting tested. Women from Waterbury and Bridgeport characterized the fear as being afraid to find out one’s HIV status, which contributes to a delay or avoidance in getting tested. Some even mentioned that people do not want others to see them getting tested, which suggests that the perception of a lack of privacy could further affect their decisions to get tested. Women from Stamford, Hartford, and Bridgeport also described fear about what would occur after getting tested, a fear of their lives would change because of a positive test result. This was also linked to a fear of being alone, because they assumed that a positive test result would negatively affect the relationships in their lives. Another discussion point about testing occurred regarding who is responsible for initiating an HIV test with medical appointments. Women from Hartford and Bridgeport both mentioned that it is the responsibility of the women to take the initiative to ask for an HIV test during annual exams when needed; however, some women from Bridgeport also suggested that it should be the doctors' responsibility to offer HIV tests each time, in the same way they do for prenatal care.

The groups of Black women differed in the degree to which they had heard of PrEP. Women in Hartford knew less about PrEP and believed that it is in need of better marketing, most women in Stamford only heard about it recently through the TV commercials, and most women in Bridgeport and Waterbury already heard about it through different media outlets. All groups focused on the marketing for PrEP and the barriers to taking it. Among groups that stated that PrEP marketing needs to improve, they suggested that PrEP needs to be advertised in more widespread ways because not everyone has access to the same sources of information and agencies for products. Women in Hartford suggested that PrEP needs to be marketed in a way

that is easier to understand, similar to how birth control was marketed. Women in Stamford suggested that advertisements should normalize taking PrEP in relationships as a way for couples to take care of each other, and in general for any sexually active person. Among the groups that focused on the barriers to taking PrEP, they highlighted concerns about the cost of the medication (even with insurance) because it's not easily accessible to everyone, and stated other barriers that also deter HIV testing (e.g., disclosing to a doctor).

HIV Care

The consensus across groups of Black/African American women was that HIV treatment has changed for the better. Some women knew of the medication and how often PLWH need to take it, some women admittedly knew fewer details about the medications. Particularly, Black women in Waterbury discussed how not knowing enough about the medication's side effects or reasons why a doctor advocates for a patient to change her medications, could affect a patient's adherence to the medication.

A common reoccurring theme across groups centered on the difference in the quality of HIV care from doctors in clinics compared to doctors in private practices. Most women in Bridgeport stated that they are more comfortable with a specialist treating HIV rather than a general practitioner. Some women in other cities, such as Stamford, stated that clinics are better at managing HIV care than private practices and they would want to be able to seek care from primary care doctors rather than having to see a specialist. With regard to barriers to care, women in Bridgeport identified guilt and shame as reasons PLWH do not seek HIV treatment when they know they need it. Women from different cities talked about how to overcome barriers and promote adherence among PLWH.

HIV Stigma

Discussion about stigma and its effect on getting tested were associated with distrust for medical providers and beliefs embedded in the Black community that influence how Black women perceive getting tested for HIV. Most women across cities had not seen or heard of mistreatment towards people who want to get tested in medical settings, but they have a general distrust for health care workers, more specifically a concern that people providing the test could share the results with others. Women from the Hartford group also suggested that the inconsistency in the way that doctors offer HIV testing during appointments can be stigmatizing and shows a lack of connection to their patients. Regarding Black women's perceptions of getting tested for HIV, women from Bridgeport suggested something needs to be done to combat the shame of talking about sex and safe sex practices. Women need to be empowered to insist on safer sexual practices with their partners and to overcome the fear of being alone.

When the impact of stigma on staying in care and the quality of life for PLWH was addressed in the groups, the women focused on the need for PLWH to feel more accepted within the surrounding communities. They felt strongly that medical providers should be professional at all times, so their personal biases do not affect the way they treat patients. Women in Waterbury shared that some physicians can make a woman feel like it is her fault that she has HIV, when they have no knowledge of how it was transmitted. They mentioned that misconceptions about PLWH lead people to reject them, so efforts need to be directed at combating these beliefs in public venues when these moments occur.

## Transgender women

HIV and transgender stigma were discussed in each of the listening sessions with transgender women. They identified several common beliefs with regard to HIV that generate stigma toward transgender women. The first is a general assumption that all transgender women are infected with HIV, and that by contrast, cisgender and heterosexual people are not at risk. They also perceived that HIV is being spread to transgender women by heterosexual cisgender men, though blame for the spread of HIV is placed on transgender women themselves. These stigmatizing beliefs about the association of transgender women with HIV are perpetuated throughout society and often go unchallenged, even though transgender women report they are more likely than heterosexual cisgender individuals to be more knowledgeable about the HIV continuum of care, including where to obtain free testing and care services, and more likely to obtain an HIV test.

HIV Prevention and Testing

All transgender women groups were well-versed in HIV prevention strategies. When abstinence was discussed, participants in Bridgeport and Stamford noted that that is an unfeasible expectation. One participant in New Haven was very adamant regarding the need to use condoms with every sex partner. A common theme in all transgender women's listening session groups was the need for increased education as a method of HIV prevention. Participants themselves were knowledgeable about HIV, including that it is now a chronic illness, that anyone can be infected with HIV, and about the risk factors associated with contracting HIV (unprotected sex, drug use, blood transfusion). Many participants were also aware that PLWH who were undetectable are unlikely to transmit HIV through sex, and were familiar with the phrase "Undetectable = Untransmittable." Many were aware of where they could receive an HIV test (rapid and blood), that an HIV test is unable to detect a recent HIV infection, that HIV can lay dormant in one's system, and that HIV tests are available for free at local clinics. However, some participants believed that PLWH who were undetectable would appear HIV-negative if tested.

Fear was discussed in every listening session as a barrier to HIV testing. Hartford, New Haven, Stamford, and Waterbury participants' characterized fear as others knowing their status, including family, friends, sex partners, and medical staff. This fear would lead to rejection and isolation for the PLWH. Participants in Bridgeport and Waterbury discussed fear in relation to mental health, including depression or thoughts of suicidality if they were to have a reactive test result.

Hartford and Stamford transgender women discussed lack of knowledge about HIV and where to obtain an HIV test as a barrier to getting tested. Bridgeport, Hartford, New Haven, and Stamford participants reported that medical providers who provide testing are barriers to obtaining an HIV test, including that the providers lack compassion or do not provider transgender-affirming spaces within their clinics. Stamford participants discussed a lack of insurance or not knowing where to obtain a free HIV test as a barrier.

Many transgender participants at all listening sessions were well versed in HIV prevention. They were aware of the risk factors associated with contracting HIV, including unprotected sex, injection drug use, sex work, and blood transfusions. All participants were aware that celibacy, PrEP, and condoms would protect them from contracting HIV.

Transgender women in all listening sessions knew about PrEP, and a few were taking PrEP at the time of the listening sessions. A participant in Bridgeport knew she was taking a medication to prevent getting HIV but was unaware of what that medication was called. However, many participants were unaware of PrEP until very recently; two participants in Stamford had not

heard of PrEP until the listening session itself. Transgender women participants in all five cities discussed barriers to PrEP, including lack of knowledge (what it is, where to get it, long-term side effects), lack of PrEP marketing, and lack of health insurance. Additionally, some participants in Stamford disclosed that they were not amenable to discussing HIV prevention, including PrEP, due to high levels of HIV stigma within their communities. Many participants in all transgender women listening session groups believed that access to mental health services, increased education, and increased outreach services would increase PrEP awareness and HIV prevention, particularly among all individuals who are HIV negative regardless of sexual orientation or gender identity/expression.

HIV Care

A few participants in each of the transgender women listening sessions openly reported that they were living with HIV. In the New Haven listening session, one of the transgender allies who participated told the other participants living with HIV that they looked "good" and that no one would ever know they were living with HIV. All participants, including those not living with HIV, discussed the need to take their antiretroviral medications every day as prescribed by their health provider and to obtain blood work as necessary to have an undetectable viral load. Participants in Stamford and Hartford discussed that they delayed taking antiretroviral medications for several years because when they were diagnosed with HIV the only treatment available was AZT. These participants only began receiving treatment within the past few years, as AZT made them and others living with HIV have bad reactions.

Throughout all listening sessions, transgender participants reported that they were aware of where to obtain HIV care (primary care doctors, infectious disease specialists, clinics) if they were to become infected with HIV. Several barriers were discussed regarding HIV care. New Haven, Stamford, and Waterbury reported medical mistrust, particularly among transgender women of color, as a common barrier to receiving HIV treatment. Transgender women in Waterbury in particular discussed the overlapping issue of transphobia within medical care settings as an added barrier related to medical mistrust. Fear and lack of knowledge were discussed among New Haven and Waterbury participants, and one participant in Stamford also discussed the fear of medication side effects. New Haven and Waterbury transgender women reported that isolation and rejection were other barriers to medical care. New Haven participants reported that individuals with multiple diagnoses and immigration status were additional barriers to receipt of care. Additionally, Waterbury transgender women discussed lack of health insurance as a reason why some people do not seek HIV treatment. A few Hartford and Stamford participants who had witnessed the impact of AZT were particularly uncertain about taking HIV medications.

HIV Stigma

Discussions about stigma in these sessions heavily intersected with transgender identity, including people assuming that because they are transgender women they have HIV. This was the primary, and often the only aspect of stigma discussed, as listening group participants believed that they had experienced more stigma as a transgender individual than anything else. One participant in Bridgeport reported that she had experienced more discrimination as a transgender woman in the gay community than among any other group. One individual in Stamford reported that transgender women are viewed as promiscuous as well, which linked transgender stigma with HIV stigma.

Additionally, Bridgeport and Stamford participants reported that transgender women were often associated with HIV, even though they are not the group contributing to the spread of the virus.

Participants reported that many cisgender heterosexual men were often the individuals who were spreading HIV to their primary and secondary sex partners, including spouses and transgender girlfriends. Participants believed that cisgender heterosexual men need to have their own listening and educational sessions to address their participation in the proliferation of the HIV epidemic.

### Practitioners

Through the two listening sessions at the Think Tank conference, practitioners provided their perspectives on PrEP, barriers PLWH face when engaging with medical providers, and the unity of the network of HIV providers. One group discussed the need for PrEP advertisements to be directed at all populations, rather than just the LGBTQ+ community because women and people of all ages need to feel that PrEP is an option for them. In contrast, the other group emphasized that PrEP is not for everyone, and it is being treated as a “one size fits all” method of HIV prevention. They also talked about how there are misunderstandings about PrEP, including that it prevents other STIs.

Both groups of practitioners focused on medical providers and their willingness to treat patients with HIV and prescribe PrEP. They discussed how there are barriers if the doctors are uncomfortable discussing sexual risk or prescribing PrEP to their patients. One group discussed how stigma and discrimination are still rampant throughout the service communities, with general misconceptions about HIV and how to work with people from different backgrounds. The other group also suggested that there is a need for more training on sensitivity, and guidelines for delivering test results and information to people who test positive across agencies in different cities. Another issue mentioned is that providers are less likely to go over sexual health topics because there is minimal reimbursement for them, which suggests that a financial component needs to be addressed to fully integrate sexual health screenings and HIV testing as standard practices.

One group also talked openly about the differences in the service capacity of agencies that are centralized versus decentralized in the provision of services, and the need for universal practices in the delivery of care. They suggested the need for more collaboration among agencies (rather than competition) and more leveraging of resources, universal practices for testing and linkage to care between the state, hospital, and private medical settings. The group also highlighted the need for universal messaging and practices for testing, talking about PrEP, and connecting people to care, especially among agencies that are decentralized.

## Listening Session Findings by City

### Bridgeport

Listening sessions in Bridgeport were well-attended. Participants in all groups knew about HIV, HIV prevention methods, and where to obtain an HIV test and HIV care. MSM participants of color discussed the overlapping existence of HIV stigma and homophobia, including people believing that if one is gay they are also infected with HIV regardless of HIV status. Participants noted that there needs to be an integration of gay communities to increase HIV awareness and reduce stigma and to increase education in the home, in schools, and in religious organizations.

Black women participants seemed to know each other or know of each other, and overall, the group was knowledgeable about HIV and had heard of PrEP through different media outlets.

When asked for places where people could go to get tested, several of the women suggested GBAPP (Greater Bridgeport Area Prevention Program) at the same time. They focused on the issue of suspicion in monogamous relationships. They explained that there is a fear of getting tested because they may be in denial about their relationship; getting tested may confirm their suspicions about their partner, and then they would worry about how life would change after a positive test. This group was also really concerned that school-aged youth do not have the right information about HIV prevention. Unlike other groups, most of the women in this group stated that they are more comfortable with a specialist treating HIV rather than a general practitioner. They also stated that the older generation is contributing to stigma repeated among the younger generation. Parents and grandparents only knew HIV as this "scary thing" and they were also never truly informed of the facts about HIV.

Transgender participants in Bridgeport discussed the impact of transphobia and how that impacts the transgender community. Participants noted that other groups need to be educated about transgender individuals to decrease transphobia. Some of the transgender participants reported that they were on PrEP - one was taking PrEP but was unaware of the term "PrEP". One participant became emotional during the session, discussing the need for increased transgender cohesion in the community. Additionally, participants believed they were being blamed for the spread of HIV when they believed that HIV was being spread through heterosexual men. Many reported that their relationships were mostly with married heterosexual men. Participants believed that HIV stigma could be addressed through increased education and transgender advocacy.

## Hartford

Two MSM listening sessions were held in Hartford - one in English and one for monolingual Spanish speakers. The English speaking group was more fearful of HIV and less likely to know someone living with HIV. Participants were aware of how HIV is contracted, about HIV prevention, and about HIV testing. Fear of testing and an inability to obtain PrEP when they asked their primary care provider for a prescription were considered barriers to prevention. Participants reported that they had seen information about PrEP and that they believed they would be referred to a specialist if they had a reactive HIV test result. Many reported fear of getting tested due to judgment about sexual activities from their doctors. To address the HIV epidemic in the MSM communities, participants reported a need for increased dialogue in the gay communities.

The Spanish speaking listening session group was also aware of HIV prevention, testing, and treatment. Participants were aware of where they could receive HIV treatment in the Hartford area. PrEP was well-known, but it was noted that many people who are not infected with HIV are unaware of PrEP. HIV stigma was discussed as it overlaps with homophobia, and if someone sees someone with a person who identifies as homosexual they will automatically think that they are homosexual and infected with HIV. Stigma was also discussed as it relates to cultural norms among Latinx cultures. Participants reported an increased need for education, educational materials (pamphlets, posters) to be distributed in Spanish, and sex education and HIV to be discussed in the school system.

The Black women present for this Hartford group stated that they had not seen or heard anything about HIV recently through any form of media, PSAs, or brochures. In terms of testing, the group focused more on the funding and financial responsibility of the patients as reasons for why doctors do not always offer tests. Most of the women also agreed that marketing for PrEP needs to improve, and HIV campaigns need to be relatable for a broader spectrum of Black women (e.g., show Black women who were educated and in normal circumstances). They

shared that Black women are often seen as at fault in situations that put them at risk for HIV, and they spoke of addressing stigma by emphasizing that people with HIV need to be approached with messages that show empathy and reduce the blame.

The Hartford transgender women were aware of how HIV is transmitted, where they can get tested for HIV in Hartford, how to protect themselves from HIV (including PrEP), and where to obtain HIV treatment. Participants reported HIV stigma as an issue among transgender women, particularly against transgender women of color. HIV care is not discussed within the community often. Stigma was also associated with not having transgender-affirming medical providers and fear of rejection if infected with HIV. Addressing barriers to prevention, treatment, and stigma included increased education and transgender advocacy.

## New Haven

Two MSM listening sessions were conducted, one with a single participant and one with three participants. All participants were knowledgeable about HIV prevention, testing, and care. Fear was discussed as a barrier to HIV testing and that the anxiety when getting tested never disappears. PrEP was well known among these New Haven MSM, with one participant reporting that he was on PrEP and had to teach his medical provider about it. HIV stigma, particularly among communities of color, was a concern, indicating a need for increased HIV education in the school system and advertisements in neighborhoods with high HIV prevalence rates.

The Black women group in New Haven, consisting of women from a Black sorority, did not speak about New Haven specifically, though the session was held in New Haven. They focused on the issue of Black women's persistent vulnerability to HIV, and even after knowing that Black women are at higher risk for HIV, most Black women still believe that they are personally exempt or excluded as someone who could be affected by HIV. Whereas the women in this group had general information about HIV and testing options, they reported they often hear that other Black women do not know general information about HIV, such as how it is transmitted. They expressed concern that the younger generation's apathy toward protecting themselves and discussing sexual health with their partners is contributing to prevalence among Black women. Like other groups, the fear of getting tested is related to the concern for the outcome, but they also explained that the decision to get tested is based on their readiness to hear the outcome (e.g., the environment, who's around, their appearance). They also emphasized that current PrEP commercials are misleading and lack relatability for Black women. They also focused on the funding available to support women's health, which is not enough to address the current level of need, and the programs that are currently available (such as the Husky Health programs) have not integrated HIV education in their services.

Transgender women in New Haven were also knowledgeable about HIV prevention, testing, and care. Many knew about PrEP as a method of preventing the spread of HIV. HIV was still highly stigmatized and PLWH were described as fearful of being rejected from their communities. Some misconceptions about HIV were apparent among participants, including one person believing that if a person living with HIV has an undetectable viral load she would have a non-reactive HIV test result. Fear was considered a major barrier to HIV testing, including fear of rejection. Some believed that people were unaware of where they could obtain an HIV test. Barriers to PrEP included lack of health insurance/financial constraints, lack of transgender-affirming doctors, and immigration status. Participants believed that HIV stigma could be alleviated through increased education within community settings and HIV advocacy.

## Stamford

Both MSM participants in the Stamford group stated that they did not have a lot of knowledge about HIV prior to getting tested. They indicated that testing is a fairly easy process. It is the fear of the results that creates the barrier to getting tested. They also believe that PrEP marketing needs to be more widespread, specifically by word of mouth and social media. They suggested that there is a mental health component to moving forward with care (adherence), which improves when the individual with HIV feels good (healthy) and supported. They also talked about reducing the stigma by creating more opportunities to educate society about HIV. Essentially, more people need to know that a person cannot get HIV from an HIV positive person who has an undetectable viral load.

Black women in Stamford were aware of the different types of HIV tests available, and they were informed about the circumstances in which a person should get tested more often. When discussing HIV medication, accessibility to treatment, and quality of life for PLWH, some of the women focused on how much medications have improved over the years, based on what they knew existed in the past. It also appeared that most of the women only recently started to hear about PrEP because of the TV commercials, but upon further discussion, some of the women stated that PrEP is a good option for any sexually active person. Many agreed that the lack of knowledge about HIV and fear creates the stigma. They also believe that people in the church are not doing enough to help people with HIV, and if anything, they are contributing to the stigma.

Transgender women in Stamford were well-versed in how HIV is contracted, HIV prevention methods, and where to get tested for HIV. Participants were aware of where they could obtain HIV care and noted that HIV stigma intersected with transgender identity. However, many transgender participants were unaware about PrEP, even though some had reported seeing a commercial about it. Transgender participants in Stamford were particularly adamant on the lack of cohesion among the transgender communities in their city. Two transgender listening sessions had to be conducted, since the first session contained only one participant.

## Waterbury

MSM participants in Waterbury were knowledgeable about HIV prevention, testing, and treatment services in their city. Fear was related to HIV testing and care, including fear about lack of confidentiality and rejection. Some participants believed that many were apathetic toward HIV because they had not seen the HIV epidemic unfold in the 1980s. Most participants were aware of PrEP, but many believed that it is not well marketed. HIV stigma was reported as being highly prevalent, and needed to be addressed through education (re-educating medical professionals, teaching about HIV and sex education in high schools) and increased inclusivity of the MSM communities.

Black women in Waterbury were well-informed about HIV and prevention options. They initially focused on the discrimination they experienced as a PLWH or witnessed toward PLWH in the past. Much of the conversation focused on medical practitioners and their treatment of PLWH, and how this needs to be improved. They discussed the need for women to advocate for themselves in medical settings. There was a lot of focus on the need for the community to rally behind PLWH, including not being afraid to be associated with others living with HIV even if others will assume that they, themselves, have HIV. A large focus was on the church itself, and including churches in efforts to increase HIV and AIDS testing and awareness.

Transgender women in the Waterbury listening session was also aware of how HIV is transmitted and where to receive HIV testing and care in the Waterbury area. Many were informed about PrEP and reported the need for increased PrEP marketing. Participants reported barriers to HIV testing and care, including fear of rejection if they had a reactive result from family/friends/partners, issues with mental health and depression, and HIV stigma. HIV stigma was associated with transphobia and could be addressed through increased education (doctors, forums) and a need for transgender-specific groups to help increase education related to transgender women's needs.

## Cross-Cutting Themes from Listening Session Participants

These group listening sessions provided participants with the opportunity to share their personal experiences with each other and provide insights that could inform future directions for Getting to Zero. Here, we provide some of the language they used to describe to their experiences or observations of gaps in services for PLWH and ongoing HIV stigma.

One of the practitioners' groups highlighted the point that there is a lack of scattered site housing options for people with HIV. There are advantages and disadvantages to housing all PLWH in one location versus integrated throughout different areas in a city. In cities where PLWH (receiving housing assistance) are housed in the same building, they benefit from the sense of community and close proximity to resources, but it can also create barriers with the surrounding community and lead to further stigmatization if others in the surrounding communities identify it as housing for people with HIV.

Two of the Black women's groups mentioned the importance of having more non-traditional testing sites in the community. People are less likely to get tested if they suspect that their privacy could be compromised. HIV testing sites should be integrated into locations that are still easily accessible, but also in locations that serve multiple purposes.

Transgender women's groups discussed the need for increased education surrounding what it means to identify as transgender. Incorporating educational aspects within secondary school education would impact transphobia within society and improve transgender individuals overall health.

In one MSM group, a participant, who also identified as an activist, provided advice to others in the room who wanted to take a role in providing HIV education to the public and having open conversations to dispel some of the misconceptions. He stated that people with HIV need to be aware of their hurt and their anger when they approach other people with the intent to provide information because they could inadvertently push others away. Even if they are approaching people who have hurt or stigmatized them in the past, they have to approach these conversations with openness and positivity. It is also the role of advocates and activists to be fully educated about HIV prevention first, before venturing out to talk to others.

Two of the Black women's groups discussed the issue of accountability, relying on yourself rather than your partner to protect your body. They also suggest that empowerment leads to behavior change. One group made the argument that the facts about HIV have not changed, but it needs to be presented in ways that highlight the medical progress that has occurred in more recent years. As one woman stated, "education + medical progress = empowerment."

One participant in the MSM group mentioned that HIV awareness materials need to address microaggressions, intentional or unintentional insults or snubs that communicate negative messages towards marginalized populations, such as using the terms dirty or clean when referring to a person's HIV status. In addition to having posters that provide facts and statistics, we need to have posters that provide examples and identify these microaggressions.

Two transgender groups discussed the need to address cisgender heterosexual men's contributions to the spread of HIV. They believed that transgender women were often blamed for the HIV epidemic in the U.S., when they are not the ones who are spreading HIV.

A Black women's group and an MSM group both referred to a concept that one group referenced as negative preconceptions, which are the negative beliefs or opinions people form before they have enough information. There is a stigma associated with just talking about HIV, and as stated with the Black women's group, there is hesitation even to talk about HIV or provide information because people automatically assume that you have HIV or start recalling the negative thoughts they have had about people with HIV.

A participant within one of the MSM groups mentioned that the message that undetectable equals untransmittable (U=U) need to be more prominent throughout all communities. This message should be circulated to the same degree that HIV prevention materials are promoted because it helps to combat the stigma against people with HIV. He also mentioned that since this message is less prominent, he second-guesses if it is true.

One of the MSM groups and many of the transgender women's groups discussed how health classes in schools lack inclusivity for LGBTQ+ students. Some of these students feel that they cannot participate or ask questions in their health classes because LGBTQ+ sexual health has typically been excluded from the materials and conversations. The group made the suggestion that whenever sex education is taught in the schools it should be taught by a person from a health department who is more informed about the information that LGBTQ+ students require.

# Listening Session Participant Recommendations

## Young MSM of Color

HIV Testing and Prevention: MSM participants reported that barriers to HIV testing could be addressed through increased education (e.g., in schools, with families), outreach organizations, HIV-related forums, legislation, and mandatory HIV testing. Some participant feedback suggests a need for HIV testing to be automatically incorporated into blood work because doctors appear to test gay and straight people for different things. They also recommend more mobile vans to do testing and increased access to LGBTQ+ friendly providers for younger individuals. They also recommend that doctors provide all patients, not just high risk groups, with information about PrEP and that PrEP ads should include each step in how to get started on PrEP.

HIV Care: Recommendations for addressing barriers to care included increasing the availability of health clinics to people who cannot afford HIV medications, support group availability, and mobile van clinics. Some participants suggested that marketing of HIV treatment is still needed so that PLWH know options for where to access treatment, possibly through posters on the walls in doctor's offices. Bridgeport participants indicated that facilities need to expand hours to see clients, and include some Saturdays. Waterbury participants indicated that patients need to

be reminded to give their doctors some feedback about what they did right and wrong regardin how they treat them to ensure quality care.

HIV Stigma: To address HIV stigma, young MSM suggested including “high risk” communities in educational opportunities and forums and increasing HIV and sex education in schools, in community settings, and in the home. To combat barriers to HIV testing, prevention and care, Bridgeport participants suggested that people within the gay community need to be informed of how to educate everybody about HIV and learn how to overcome the judgement they may receive in return. New Haven participants suggested normalizing HIV testing by making it routine in annual physicals and including standardized education on HIV in schools. It was also recommended that the message that PLWH are living longer and healthier lives should be distributed widely into the community along with other HIV-related information.

## Black/African American Women

HIV Testing and Prevention: Some of the women recommended that the state do more to encourage routine HIV testing at all clinics and to alleviate patient concerns about the lab costs for HIV tests. Women indicated that HIV testing campaigns need to be relatable, show everyday women and women of different ages, and relay messages that reduce blame for individuals who have HIV. They also suggested that more conversations about HIV need to be held with everyone so that anyone with a partner knows they are at risk and that they need to get tested more than once. HIV testing and PrEP options need to be advertised in more widespread ways and more accessibly in neighborhood locations throughout the Black community.

HIV Care: Multiple groups provided the recommendation that there be more standardization of practices so that PLWH can receive the same level of care no matter where they seek services (community health centers, hospitals, private practices). Women in both Hartford and Waterbury discussed solutions that require legislative change, such as providing more incentives for primary care providers in CT to treat for HIV. At the individual level, women suggested ensuring that PLWH have support systems to reinforce and encourage treatment because sometimes information is easier to digest through peer-to-peer dialogue. They also suggested promoting care as a lifestyle change, rather than just taking medication, because some people do not manage their medication if they are active substance users.

HIV Stigma: Black/African American women from different groups suggested that more needs to be done to ensure that PLWH feel supported, especially in church. Participants from the Waterbury group recommended that information about local statistics should be distributed throughout churches and social media to encourage conversations, and invitations should be extended outside of the church to attend HIV awareness groups (or community forums) so people can learn more about the virus. To correct some of the negative beliefs about PLWH, these women suggested that people in general need to be encouraged to interject when they hear someone stigmatizing another person or group. They also recommended that community and local governments need to take a more active role in pushing preventative messages, such as U=U.

## Transgender Women

HIV Testing and Prevention: Transgender women participants believed that education and advocacy would help alleviate barriers to HIV prevention, testing and care. All listening session group participants believed in the need for increased advocacy, in which transgender advocates could hold audience-specific forums to increase HIV awareness. Bridgeport, Stamford, and Waterbury transgender women believed that increased HIV advertising and school-based

educational programs which focused on increased student and teacher education would improve HIV knowledge. Several transgender participants in Bridgeport, New Haven, and Stamford believed there was a unique need for increased medical provider education and sensitivity. New Haven participants discussed the need for incentives to address HIV testing, including gift cards. Bridgeport, Stamford and Waterbury transgender participants believed that addressing HIV stigma in faith-based communities would increase HIV testing and care and reduce stigma. Additionally, Stamford participants believed mentorship for younger transgender women would help increase overall health. Transgender participants also believed PrEP needs to be more widely advertised and targeted for at-risk groups.

HIV Care: To address barriers to HIV care, transgender participants in Stamford and Waterbury discussed a need for more providers who are transgender-affirming and knowledgeable about HIV. One participant in Stamford reported that she began to receive HIV treatment by being introduced to a health provider who was transgender affirming and knowledgeable about transgender people's needs. Additionally, Waterbury participants reported a need to increase HIV care education among those living with HIV to link and retain them in HIV care.

HIV Stigma: Transgender participants discussed the need for transgender-affirming spaces (particularly doctors' offices) and education, as well as increased cohesion in the transgender community. While HIV stigma was considered a major issue, participants noted that increased education in schools and within communities, including those that do not identify as transgender, could help address the combination of HIV stigma and transphobia. In particular, participants noted that transgender-related discrimination needs to be addressed first and foremost. Additionally, these participants discussed the need for educational groups (transgender-only and groups with transgender and other at-risk groups). Participants reported that stigma could also be addressed with increased numbers of transgender individuals as doctors, particularly increased opportunities for transgender women of color.

# Conclusion

Findings from this report were used to inform the CT G2Z Commission's proposed recommendations for moving the state's campaign forward to achieve its G2Z goals. Additional information about the CT G2Z campaign and Commission recommendations can be found in the December, 2018 "Comprehensive Report on Ending the HIV Epidemic in Connecticut," prepared by the Connecticut Getting to Zero Commission. This report can be retrieved and additional information is also available on the CT G2Z website, gettingtozeroct.org.

# Appendix 1

# CT G2Z LISTENING SESSIONS – QUESTIONS

## SECTION I

*Now I am going to ask you about your general knowledge about HIV or AIDS in your community.*

1. What do you know or have you heard about HIV/AIDS in your community?

## SECTION II

*Now I am going to ask you some questions about HIV testing*

2. What do you know or have you heard about HIV testing in your community?

3. What are your feelings about being tested for HIV?

4. What hesitation do people have about getting tested and what are some these? If so, what are they?

## SECTION III

*Now I am going to ask you some questions about HIV Prevention*

5. What do you know, or have you heard about how to prevent getting infected with the HIV virus?

6. Has anyone ever heard about pre-exposure prophylaxis or PrEP? This is when an uninfected person takes a pill every day that can prevent HIV infection.

7. What do think about uninfected people taking a pill daily to prevent them from getting infected?

8. Do you think PrEP has value within your community?

**If no one has heard about PrEP, ask question 8 and skip questions 9 to 12**
**If they have heard about PrEP, then skip question 8 and continue to 9**

9. Why do you think that you have never heard about PrEP?

10. What do you know, or have you heard about access to PrEP in your community?

11. What person or organization in your community comes to mind regarding PrEP access?

12. Do you feel that there are the barriers for accessing PrEP, and if so, can you describe what those barriers are?

13. Based on what you know or have heard about PrEP, would you change anything about access to PrEP in your community?
    a. IF someone says “YES,” then ask,
        i. What would you change?

    b. Would you change how PrEP is promoted within your community?
        i. IF someone says, “YES,” than ask,
            1. What would you change?
            2. How can PrEP be best promoted in your community?

## SECTION IV

*Now I am going to ask you some questions about HIV Treatment*

14. What do you know or have you heard about HIV treatment in your community?

15. What do you think prevents people from going to the doctor and taking HIV medication?

16. What do you know, or have you heard about access to HIV or AIDS treatment in your community?

17. Based on what you know or have heard, would you change anything about access to HIV or AIDS treatment in your community?
    a. IF someone says, “YES,” than ask,
        i. What would you change?
        ii. Do you feel that there are the barriers for accessing and enrolling into treatment, and if so, can you describe what those barriers are?

## SECTION V

*Now I am going to ask you some questions about HIV Stigma*

18. Do you feel people with HIV in your community are treated differently?
    a. IF someone says, “YES” then ask them.
        i. What evidence of stigma and discrimination do you see in your community?
        ii. What do you feel can be done to help address HIV or AIDS stigma and discrimination that is affecting your community?