

Ending the Epidemic

Beyond 2020



Department
of Health

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Ending the Epidemic: Beyond 2020

Introduction

New York State has been laying the groundwork for ending the AIDS epidemic since the disease emerged in the early 1980s. New York's response to the HIV/AIDS epidemic has involved the development of comprehensive service delivery systems that evolved over time in sync with the evolution of AIDS from a terminal illness to a manageable chronic disease. This strategy enabled the state to implement new technologies as they were introduced, including new treatments, new diagnostic tests and, more recently, pre-exposure prophylaxis (PrEP). By building upon each individual success and relying on a strong administrative infrastructure, the state was able to roll out innovative programs quickly to achieve the greatest impact. Ending the epidemic in New York State is within reach, thanks to aggressive and systematic public health initiatives that have made it possible to drive down rates of new infections. The State's Ending the Epidemic (ETE) initiative was launched with visionary leadership and extensive stakeholder leadership and participation.

New York State was on track to end the epidemic by the end of 2020, with outcomes measuring ETE progress available by December 2021¹. However, the State and providers on the frontline have spent the majority of 2020 and early 2021 responding to an unprecedented pandemic and will continue to do so for the foreseeable future. Providers adapted to the new landscape and found innovative ways to deliver services and support clients. Still, the public health emergency has delayed the achievement of ETE goals. Since the start of the COVID-19 pandemic, there have been increases in HIV cases in certain parts of the state, significant reductions in HIV testing and reporting of diagnoses, and decreases in the number of persons accessing PrEP. As a result, New York State is revising the ETE timeline and pledges to reach ETE goals and end the epidemic by the end of 2024, with outcomes measuring ETE progress available by December 2025.

¹ Most outcome data are lagged one year. Thus, 2020 data are not available until December of 2021.

The Ending the Epidemic Plan, or The Blueprint, has guided and will continue to guide all ETE efforts. This report describes how New York State will build on the Blueprint to take the ETE initiative beyond 2020. This report serves as an addendum to The Blueprint, sharing key themes and outcomes informed by feedback received from stakeholders throughout 2020. This report also provides a summary of New York State's ETE planning process, the essential partnerships that support the ETE initiative, statewide ETE metrics, progress to date, and community-identified emerging priorities.

Plan to End the Epidemic

In June 2014, New York State announced a three-point plan to end the AIDS epidemic in NYS. This plan provided a roadmap to significantly reduce HIV infections to a historic low by the end of 2020, with the goal of achieving the first ever decrease in HIV prevalence. The plan also aimed to improve the health of all HIV positive New Yorkers and was the first jurisdictional effort of its kind in the U.S. The three points highlighted in the plan are:

- 1) Identify persons with HIV who remain undiagnosed and get them linked to care;
- 2) Link and retain persons diagnosed with HIV in health care to maximize viral suppression;
and
- 3) Increase access to Pre-Exposure Prophylaxis (PrEP) for persons who are HIV negative.

ETE Blueprint

New York State's plan also called for the creation of an ETE Task Force (Task Force), charged with advising the NYS Department of Health (NYSDOH) on strategies to achieve the goals outlined in the three point plan. Sixty-four members, including representatives of community, government, academia, and advocacy, were appointed to the Task Force in October of 2014. The Task Force reviewed nearly 300 recommendations submitted online and during regional listening forums held throughout NYS. The feedback was synthesized into 37 distinct recommendations. In April 2015, the [Ending the Epidemic \(ETE\) Blueprint](#) developed by the Task Force was publicly released.

Since then, the NYSDOH has repurposed existing funding and leveraged over \$20 million of ETE-specific funding to help meet the goals set forth in the ETE Blueprint. The NYSDOH has worked collaboratively with communities statewide over the past six years to develop and implement strategies to increase HIV testing, address stigma and health equity, expand access to Post-Exposure Prophylaxis (PEP) and Pre-Exposure Prophylaxis (PrEP), ensure rapid initiation of antiretroviral therapy, facilitate access to syringe exchange, and much more. New York's commitment to end the epidemic has been unwavering in its intent to care for and improve the lives of all New Yorkers vulnerable to HIV as well as those living with HIV/AIDS.

As the NYSDOH seeks to maintain current efforts while looking beyond 2020, community involvement remains a top priority. To build upon the effectiveness of the 2015 ETE Blueprint recommendations, the AIDS Institute facilitated 23 statewide community virtual listening sessions and an online survey during 2020. The listening sessions were designed to elicit feedback and provided opportunities for stakeholder discussions to identify outstanding needs and increased areas of focus for ETE efforts beyond 2020.

Partnerships

A foundation of the AIDS Institute's strategy – and one of its primary strengths – is a commitment to work with and obtain input from stakeholders. In fact, extraordinary partnerships – with consumers, service providers, community leaders, advocacy groups, research entities, and federal, state, and local government agencies – made ending the epidemic possible in New York State. Partnerships have been relied on to inform the design and implementation of ETE policies and programs. The shared goals of the ETE initiative energized and transformed these partnerships. A longstanding hallmark of the AIDS Institute's strategy is the ongoing dialogue with consumers and providers. This dialog has occurred through in-person forums, surveys, and, for the first time in 2020, virtually.

Partnerships and collaboration with other government agencies is also essential to plan and achieve ETE goals. The AIDS Institute works closely with the New York City Department of Health and Mental Hygiene (NYCDOHMH) to prioritize, plan, and implement HIV prevention and care efforts

statewide. This ongoing collaboration aims to increase efficiency in programming and funding allocation, maximize information sharing, coordinate planning, ensure community programs are aligned, and facilitate innovative strategies to address the HIV epidemic statewide.

The [New York City ETE Plan](#) reflects and builds upon the New York State Blueprint for Ending the Epidemic. The New York City ETE Plan employs an innovative HIV status-neutral approach to reduce the number of new HIV infections to non-epidemic levels; improve the health and well-being of people with HIV (PWH) and people vulnerable to HIV; and eliminate HIV-related health inequities.

ETE Advisory Group Implementation Strategies

The exceptional partnerships that have supported the ETE initiative include collaborations with 15 population-based and issue-specific advisory groups that were established to recommend implementation strategies in support of ETE Blueprint.

Population and Issue-Specific Advisory Groups

As noted in the ETE Blueprint, there are many structural and social factors that place communities at risk for HIV, hepatitis C, and STIs. Structural factors include community, cultural, economic, legal, organizational, physical, and policy aspects of the environment that impede or facilitate efforts to avoid disease transmission. Social factors include the economic and social determinants that influence the health of both people and communities, which include conditions for early childhood development, education, employment, income and job security, food security, health services, access to services, housing, social exclusion, and stigma. To help address this compendium of interrelated structural factors, fifteen population and issue-based Advisory Groups were convened to develop tailored strategies for communities disproportionately impacted by HIV and AIDS.

The goal of the advisory groups was to develop specific implementation strategies in support of the ETE Blueprint, optimize its impact on identified communities in New York State, and ensure that their health care and treatment needs would be prioritized and met. The advisory group members were geographically diverse and representative of age, gender, lived experience and racial diversity.

Members of each group met for six to eight months to develop reports recommending implementation strategies, which were shared with the NYS AIDS Advisory Council Ending the Epidemic Subcommittee and full NYS AIDS Advisory Council membership for consideration of adoption. The reports were presented to AIDS Institute management staff to assess how the strategies could be incorporated into AIDS Institute initiatives, programs, and strategic planning efforts.

The ETE Advisory Groups that developed implementation strategies include:

- [Native American](#)
- [Asian and Pacific Islander](#)
- [Transgender and Gender Non-Conforming Individuals](#)
- [Older Adults](#)
- [Women](#)
- [Expanding Employment Opportunities](#)
- [Black Men who Have Sex with Men](#)
- [Latino Gay and Bisexual Men](#)
- [Young Adults](#)
- [Sexually Transmitted Disease](#)
- [Data](#)
- [Pharmacy Planning and Partnerships](#)
- [Drug User Health](#)
- [Non-English Speaking, Migrant, Seasonal Farm Workers and New Immigrants](#)
- [Sentinel Events Injection Drug Use](#)

More than 750 implementation strategies were received across the 15 advisory groups. AIDS Institute staff recently completed an internal review of progress made on this expansive set of recommendations. As of January 1, 2021, more than 350 of these recommendations had been completed or were in progress.

Monitoring Progress

To identify and monitor key implementation efforts that address the 30 recommendations and seven "Getting to Zero" recommendations included in the ETE Blueprint and the implementation strategies recommended by the advisory groups, the AIDS Institute developed the Ending the Epidemic (ETE) Activity Report that details current progress. Evaluation of the overall ETE initiative is aligned with milestones and key ETE metrics that are tracked to monitor progress. The New York State's Ending the Epidemic ([ETE Dashboard](#)), a public facing website, was launched to broadly disseminate information on the progress of New York's groundbreaking initiative to end the HIV epidemic.

[Establishment of ETE Metrics](#)

New York State's ETE initiative outlines the need for expanded, enhanced, and transparent use of data to track and report progress. In keeping with the community-focused spirit of ETE, and in order to involve a broader range of stakeholders in measuring progress toward ETE in NYS, an ETE Metrics Committee comprised of NYS and NYC health department staff, researchers, service providers, consumers, and advocates came together to develop 16 core, population-level metrics for ETE with ambitious targets for each metric through the end of 2020. The annual target values were based on analysis of currently available data and stakeholder input. Where comparable [National HIV/AIDS Strategy \(NHAS\) 2020](#) metrics existed, the ETE Metrics Committee chose more ambitious targets, with progress prominently displayed on the public-facing online dashboard (www.etedashboardny.org).

The ETE Task Force process was transparent and promoted public access through all stages of the work. The implementation and monitoring phases also reflect public input and support. Key performance indicators were established to track the epidemic. Information learned from these indicators resulted in activities to identify gaps and best practices to promote models of service delivery.

NYS ETE 2020 Metrics

NEW HIV INFECTIONS (INCIDENCE)	Reduce the number of estimated new HIV infections to 825
HIV STATUS AWARE	Increase the percentage of people living with HIV who know their serostatus to at least 98%
NEW HIV DIAGNOSES	Reduce the number of new HIV diagnoses by 55% to 1,515
NEWLY DIAGNOSES – PERSONS WHO INJECT DRUGS	Reduce the percentage of persons newly diagnosed with HIV who indicate a history of injection drug use to 2.8%
CONCURRENT AIDS DIAGNOSIS	Reduce the proportion of persons with a diagnosis of AIDS within 30 days of HIV diagnosis to 15%
LINKAGE TO CARE	Increase the percentage of newly diagnosed persons linked to HIV medical care within 30 days of diagnosis to at least 90%
RECEIVING HIV MEDICAL CARE	Increase the percentage of persons living with diagnosed HIV (PLWDH) who receive HIV medical care to 90%
VIRAL SUPPRESSION – NEWLY DIAGNOSED	Increase the percentage of newly diagnosed with HIV who reach viral load suppression within 3 months of diagnosis to 75%
VIRAL SUPPRESSION – PLWDH	Increase the percentage of persons living with diagnosed HIV with suppressed viral load to 85%
VIRAL SUPPRESSION - RECEIVING HIV MEDICAL CARE	Increase the percentage of PLWDH who receive care with suppressed viral load to 95%
SUSTAINED VIRAL LOAD SUPPRESSION TIME TO AIDS DIAGNOSIS	Increase the percentage of PLWDH with sustained viral suppression to 75%
TIME TO AIDS DIAGNOSIS	Reduce the proportion of persons newly diagnosed with HIV who progress to AIDS in 2 years by 50% to 5.1%
HIV RELATED DEATHS	Reduce the percentage of deaths among PLWDH directly related to HIV to 20%
STIGMA	Decrease stigma experienced among PLWDH with diagnosed HIV by at least 65%
PrEP UTILIZATION	Increase the number of individuals filling prescriptions for PrEP to 65,000
PrEP UTILIZATION - MEDICAID	Increase the number of Medicaid recipients filling prescriptions for PrEP to 30,000

Progress to Date

In 2019, estimated HIV incidence fell below HIV mortality for the first time, resulting in the first ever decrease in HIV prevalence in NYS, thus achieving a major ETE goal. Additional data confirm that the ETE initiative has made tremendous progress. At its peak in the mid-1990s, New York diagnosed nearly 15,000 new AIDS cases per year. New HIV diagnoses declined for a fifth consecutive year in 2019, reaching an all-time low of 2,377 – a four percent drop from 2018 and a 31 percent drop since 2014, the year the plan to end the epidemic in New York State was announced. New diagnoses among gay, bisexual, and other men who have sex with men decreased 10 percent from 2018, the fifth straight annual decrease after little change in over a decade. Estimated new HIV infections (HIV incidence) declined for a sixth consecutive year, reaching an all-time low of 1,700. HIV incidence has decreased 38 percent since the ETE initiative began in 2014, compared to a 24 percent decrease in the five years before ETE. Eighty-nine percent of persons living with diagnosed HIV in care were virally suppressed in 2019. The number of persons accessing PrEP in New York State continues to increase significantly. Prescription data show nearly 40,000 New Yorkers took PrEP in 2019 - an increase of almost 25% from 2018.

While we have achieved critical milestones, the focus for ETE beyond 2020 will be to continue to address disparities to ensure these gains are realized equitably by all populations. Beyond 2020 efforts will include increased emphasis on health equity. No matter what progress is made overall, ending the epidemic cannot be achieved if some people are left behind. Ensuring *all* populations are achieving the goals set forth in the New York State plan to end the epidemic will be essential beyond 2020.

ETE 2020 and Beyond Listening Sessions

In the Summer of 2019, the New York State Department of Health AIDS Institute initiated a plan to implement community forums to garner feedback to inform New York State's Ending the Epidemic (ETE) efforts beyond 2020. The community engagement process began with the collection of feedback from existing advisory bodies including the AIDS Advisory Council (AAC), the AAC ETE Subcommittee and the HIV Advisory Body (HAB). The AIDS Institute collaborated with the ETE

Regional Group Co-Chairs and subject matter experts to host in-person community feedback sessions in various regions of New York State.

Community stakeholders made it clear that future planning for ETE in New York State must remain a priority amid the pandemic response efforts. The public health safety challenges presented by COVID-19 and New York State's On PAUSE order greatly restricting in-person gatherings in March 2020 required all ETE 2020 and Beyond community engagement efforts to be held virtually.

The AIDS Institute convened 13 regional community listening sessions, eight theme-based listening sessions and two medical provider listening sessions from May through September 2020. An opportunity for other state agencies to provide input was also held virtually in October 2020. Each listening session included a trauma-informed care introduction and exercises to acknowledge current realities pertaining to COVID-19, loss, structural racism, and other difficult present-day experiences. The listening sessions were regionally based and representative of counties throughout New York State. The theme-based listening sessions focused on the following topics: Sexual Health, Trauma-Informed Care, Health Equity, Long-Term Survivors and Aging, Faith Communities, and LGBTQ Health. Each session was attended by an average of 55 participants representing different communities impacted by HIV/AIDS in New York State.

The feedback gathered from the 23 community listening forums was utilized to develop a *2020 and Beyond ETE Survey* that was used to collect quantitative data to complement the qualitative data collected from the listening sessions. Key themes from the regional listening sessions, theme-based listening sessions, provider listening sessions and quantitative survey are summarized below.

Key Themes: Regional Virtual Listening Sessions

The Summer 2020 virtual listening sessions were conducted in partnership with the Regional Ending the Epidemic Steering committee co-chairs and members. The 13 sessions provided an overview of regional HIV data and an opportunity to share ideas on the delivery of HIV/HCV/STI care and

treatment services by community members, providers, and clinicians. Sessions were held in Upper Manhattan, Lower Manhattan, Bronx, Brooklyn, Queens, Capital District, Buffalo, Rochester, , Syracuse, Mid-Lower Hudson Valley, Nassau, Suffolk and Staten Island.

The pandemic and the social justice movement had a tremendous impact on communities across the state, and this was readily apparent from input received across all 13 listening sessions. Major themes shared by the participants were:

- Ensure access to adherence, treatment, and prevention services
- Increase efforts to engage specific populations in health care services
- Increase community engagement/outreach and partnerships/collaborations
- Address mental health and substance use by utilizing a Trauma Informed Care (TIC) approach
- Increase technology resources and telehealth services
- Develop strategies to address resource deficiencies and barriers to care

Themes Identified by NYS Regions

Identified Theme	NYC						ROS					
	Upper Manhattan	Lower Manhattan	Queens	Staten Island	Brooklyn	Bronx	Nassau-Suffolk	Hudson Valley	Northeast	Central	Finger Lakes	Western
Additional community outreach and engagement	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Adolescent testing, prevention, and care services			✓	✓	✓			✓				
COVID-19 impact	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Data sharing platforms		✓		✓					✓			
Expanded PrEP/PEP/nPEP access	✓				✓		✓			✓	✓	
Focus on young MSM of color										✓		
Food security	✓				✓	✓	✓	✓	✓		✓	✓
Housing	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
Inclusive conversations					✓						✓	✓
Income/Employment security	✓			✓	✓	✓	✓	✓	✓		✓	
LGBTQ prevention and care, with a focus on transgender individuals			✓		✓	✓	✓			✓		
Linguistically, culturally appropriate materials and services			✓			✓				✓		✓
Mental health services	✓			✓	✓		✓	✓	✓	✓	✓	✓
Opioid use, HCV, STI, and HIV links	✓		✓				✓	✓	✓	✓	✓	✓
Provider training, education, and cultural sensitivity		✓	✓	✓		✓	✓	✓	✓	✓		✓
Routine testing outreach and access					✓					✓		
Rural access to testing, prevention, and care services										✓		
Services for individuals over 50	✓		✓			✓					✓	
Sexual health education	✓						✓			✓		✓
Substance abuse treatment						✓	✓	✓	✓	✓	✓	
Syringe exchange											✓	
Technology-related access and education (including Telemedicine and Telehealth, Zoom, Social media)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Transportation		✓					✓	✓		✓	✓	✓
Trauma-informed care approach (TIC)	✓	✓		✓				✓			✓	

*Nassau and Suffolk Counties are combined.

- **Ensure access to adherence, treatment, and prevention services**

Participants identified additional efforts needed to assist and support client return to routine health care, treatment, and medication adherence. The need to educate providers and clients on health care-related topics in relation to specific populations (e.g., LGBTQ individuals, persons with disabilities, persons with multiple medical conditions, long-term survivors, youth) was also noted, as were additional resources that will expand ETE outreach and harm reduction strategies. The sessions also highlighted the need to assess the continuation of some of the changes in prevention and treatment efforts that occurred due to the COVID-19 pandemic. Participants suggested supporting the delivery of prescriptions by mail to facilitate adherence for hard-to-reach populations.

- **Engage specific populations in health care services**

Session participants identified inadequate access to the resources necessary to address the unique health care needs of priority populations as an important issue to address beyond 2020. ETE Beyond 2020 programs must include methods and strategies to assess the health care needs of LGBTQ and Hispanic/Latinx communities, incarcerated individuals and those preparing for re-entry, and persons with disabilities and multiple health conditions including mental health and substance use.

Health literacy and health education for younger individuals was also identified as a need. School representatives should be invited to participate in regional ETE programming meetings to gain education resources for youth and younger adults. Furthermore, session participants noted a need to address gaps in health care resources and services for long-term survivors and older adults.

- **Community engagement/outreach and collaborations**

Creating additional community engagement efforts that promote ongoing participation in care is essential. This includes increasing opportunities to collaborate with stakeholders to ensure New York State reaches the goals of the ETE initiative. Suggested approaches include identifying new ways to work with faith-based communities and partnering with staff from all areas within the AIDS Institute portfolio to ensure additional engagement strategies are included and all community needs are addressed. Recommended strategies include collaboration with organizations focusing on mental health and substance use to promote the availability of services during and after the COVID-19 pandemic and the creation of additional testing centers located in non-traditional health care settings statewide. Lastly, ETE efforts should include improving data reporting practices and community access to reliable/updated data.

- **Address mental health and substance use by using a Trauma-Informed Care approach**

A consistent need identified across all listening sessions by community members, providers, and clinicians was the need for increased access to mental health, health education, and harm reduction services to offset barriers to care. The need for additional efforts to assess trends in substance use pre- and post-COVID-19 was also identified as a priority. Session participants also stressed the need for efforts to assess how mental health services were able to treat anxiety, depression, isolation, and stress caused by the COVID-19 pandemic.

Identified strategies should incorporate a Trauma-Informed Care approach, including harm reduction strategies for individuals with mental health conditions or who use drugs. Additionally, more mental health providers are needed, as are additional mental health and substance use educational materials in each region of NYS.

- **Technology resources and telehealth services**

The advantages and disadvantages of telehealth services were widely discussed across all listening sessions. Among the barriers to be addressed are a lack of access to technology and knowledge related to managing technological tools among priority populations and limited access to internet/wi-fi. Participants noted that telehealth services should be continued statewide post COVID-19. However, it will be essential to address the barriers to these services experienced by priority populations. Educational materials for online navigation are needed, as is training for agency staff to help individuals seeking online care services. Lastly, the use of home visits should be reassessed as an essential service to support retention in care.

- **Resources and barriers to care**

Participants shared that disparities exist in accessing resources and care across New York State. Specifically, there is a lack of education, resources and services focusing on younger individuals and long-term survivors. Further disparities exist due to lack of transportation and lack of age- and gender-based services located within clients' areas of residence.

ETE efforts need to include the development of educational materials and campaigns for community engagement and promotion of health care services. Efforts are needed to develop new strategies to address stigma in health care settings and assess discriminating and non-inclusive practices that diminish provider-client relationships. Mandatory and routine trainings for providers that encourage non-stigmatizing environments and prevention of discriminatory practices should be developed, with a focus on incorporating cultural competency practices and an increase of providers/staff members representative of the communities being served.

Key Themes: Theme-based Listening Sessions

Eight theme-based listening sessions were hosted to address areas of the AIDS Institute portfolio (LGBT Health, STIs, Drug User Health, and HCV) as well as strategic priorities (Health Equity, Trauma-Informed Care, Faith-Based Communities, and Long-term HIV Survivors). Community stakeholders, advocates and providers statewide were given the opportunity to comment and share recommendations to ensure New York State accomplishes the goals of the ETE Initiative.

Key themes that resonated throughout all sessions include:

- Addressing health inequities and social determinants of health
- Training for providers
- Improving engagement with priority populations, e.g., youth, incarcerated individuals, people of trans experience
- Assessing and addressing the impact of the COVID-19 pandemic
- Improving communication and expanding outreach
- Identifying additional funding opportunities, especially for small, grassroots agencies

- **Health Inequities and Social Determinants of Health**

One key recommendation, the need for increased focus on health inequities and social determinants of health, was a dominant theme discussed during all listening sessions. Session participants also identified home and food insecurity, lack of transportation, language, and lack of access to technology and education as main barriers to health care. The need to address stigma and discrimination in health care services was deemed essential to improve prevention and treatment adherence for HIV, hepatitis C and STIs. The need to examine data by race and ethnicity, and the need to better understand the intersectionality of demographic factors, were identified as important to address disparities and inequities across all communities statewide.

- **Training for providers**

The importance of providing increased training for clinical and non-clinical staff serving priority populations was discussed in all theme-based sessions. Participants believed that training would encourage a positive provider-client relationship, resulting in more individuals seeking out and adhering to care and treatment. Training topics should include substance use treatment options; a trauma-informed care approach; prevention and treatment options for HIV, HCV and STIs; and strategies to address stigma, homophobia, transphobia and racism. Also, participants stated that training on methods to create judgment-free, safe spaces should be provided at all health care and treatment organizations and clinics.

- **Improved engagement with priority populations**

Community engagement was mentioned as a vital strategy to reduce HIV, HCV, and STIs among vulnerable populations such as young people, incarcerated individuals, and people with unstable housing. During the faith-based community session, participants discussed how engaging different faith communities could benefit specific health care issues. Increased engagement with homeless populations was discussed in many sessions as necessary for improving overall prevention and care efforts, including treatment adherence. Engagement with youth was mentioned as important for syringe exchange programs specifically, as was the development of educational materials, sexual health education at schools and universities, and providing services at pediatric offices. Additional strategies to address needs of both incarcerated and community re-entry individuals was slated a top priority for ETE efforts beyond 2020.

- **Impact of the COVID-19 pandemic**

The COVID-19 pandemic has had a major impact on the HIV community, including clinical and non-clinical providers. Every listening session included discussions on the impact of COVID-19 on

service delivery and the need to develop new outreach strategies to address treatment adherence and relapse during the pandemic. Participants provided insight on how telehealth has been transformative in maintaining community engagement and service provision during the NYS On PAUSE order. However, concerns were also expressed regarding the barriers to telehealth such as inability to access technology, limited telehealth insurance coverage, privacy issues, and obtaining prescriptions. Participants also stated that COVID-19 shed more light on health disparities among Black, Indigenous, and People of Color (BIPOC) communities in NYS.

The New York State Department of Health conducted a population-level comparison of COVID-19 outcomes between persons living with diagnosed HIV and persons living without diagnosed HIV between March 1, 2020 and June 15, 2020. Results demonstrated that persons living with diagnosed HIV were more likely to be diagnosed with, hospitalized for, and experience an in-hospital death from COVID-19. Following statistical adjustment, COVID-19 hospitalization remained significantly elevated and accounted for the higher rate of elevated mortality.

- **Improved communication and expanded outreach**

Recommendations to acknowledge and adapt to the current reality of social distancing and isolation caused by COVID-19 were evidenced by the expressed need for improved communication and expanded outreach. These needs were discussed at length in relation to health equity, hepatitis C, faith-based communities, LGBT issues, and sexual health. There was consensus throughout the theme-based sessions that additional social media and virtual platforms are needed to promote clinical and non-clinical services. The value of collaborating with community members to create virtual and physical forums to share success stories and challenges was also discussed. The need for educational programs and campaigns that promote sex positivity tailored to different communities, such as faith-based, youth, people who use drugs and LGBTQ individuals, should be considered.

- **Additional funding opportunities, especially for small, grassroots agencies**

Funding opportunities for grassroots community-based organizations was viewed as a crucial element for ETE efforts among all populations in New York State. Participants in all groups mentioned lack of funding as a barrier to providing services to New York State's most vulnerable populations, including incarcerated individuals, individuals of transgender experience, individuals experiencing homelessness, and many more. Recommendations for how the AIDS Institute may increase opportunities for non-traditional community organizations to receive funding included developing or sharing guidance for providing incentives, increasing partnerships with organizations that address social determinants of health, such as nutrition and housing, and fostering relationships with community leaders, activists and local businesses. Another important recommendation was to fund programs that establish gender/sexual orientation-specific safe spaces that foster open discussion and interaction among providers and consumers.

Statewide Survey

To gain additional feedback on how ETE efforts can ensure New York State accomplishes the goals of the ETE initiative, AIDS Institute staff administered a survey for community representatives, providers, and clinicians statewide. The survey was developed utilizing feedback provided during the ETE 2020 and Beyond virtual listening sessions held during the summer of 2020.

Themes were considered for this survey based on the frequency with which they were mentioned throughout the listening sessions. A weighted ranking system was utilized for regional and topic-specific sections to obtain additional feedback on preferences related to strategies, ideas, and potential challenges to be considered for this ETE Beyond 2020 Report. The main objective of utilizing a ranking system is to identify top preferences and priorities as seen by the community, providers, and clinicians statewide.

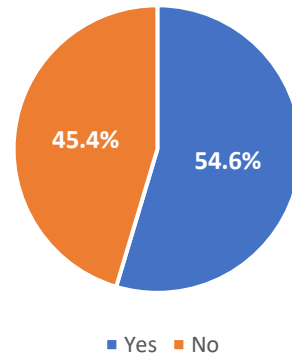
The survey was distributed through Survey Monkey from December 2020 until January 2021. Survey participants were identified through AIDS Institute databases of existing and past contractors, advocacy and advisory bodies, and regional partners. A total of 888 invitations were

sent to the sample population, and a total of 323 responses were collected, yielding a response rate of 36%. Ninety-eight percent of respondents completed the survey in English, while 2% completed the survey in Spanish. Forty-two percent of the surveys were collected from individuals residing in New York City counties, while 56% were from persons residing in rest of state (2% did not provide their county of residence).

Survey findings indicate 55% of respondents attended one or more ETE 2020 and Beyond Virtual Listening Session(s) hosted during the summer of 2020. Nearly all attendees rated the sessions as good or excellent and found them to be somewhat or very informative.

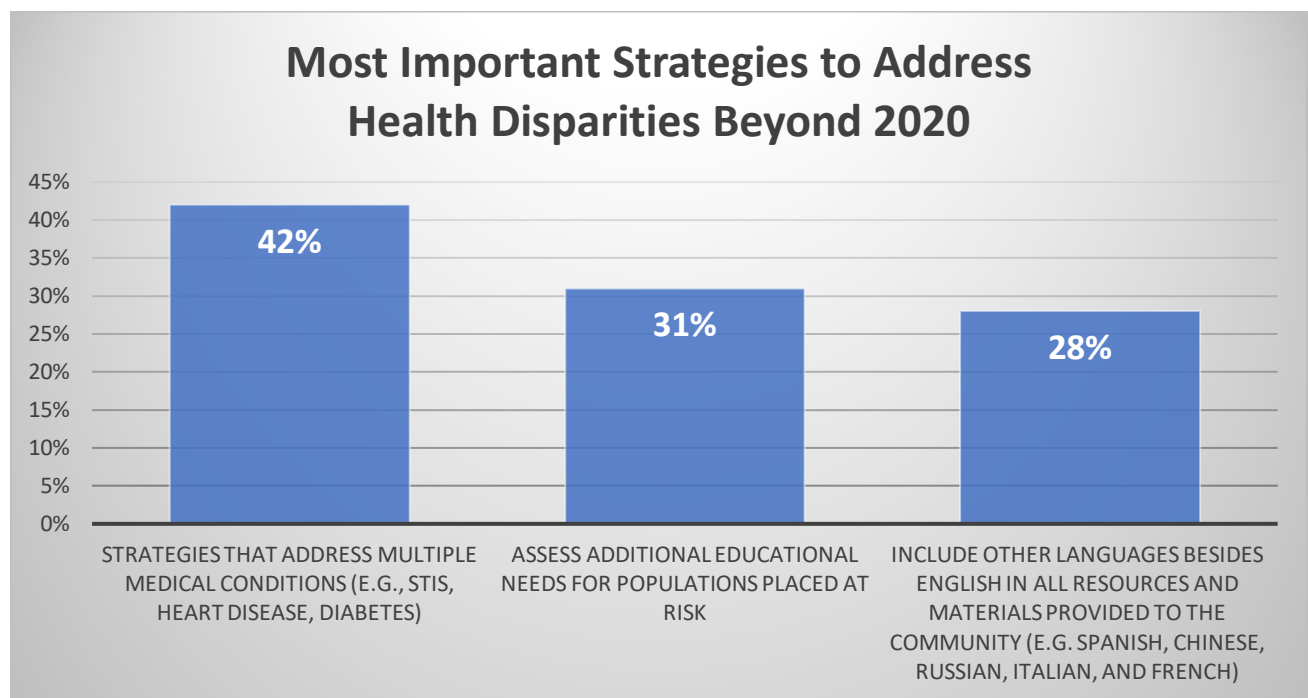
Virtual Listening Sessions Attendance

**survey respondent attended 1 or more listening sessions*



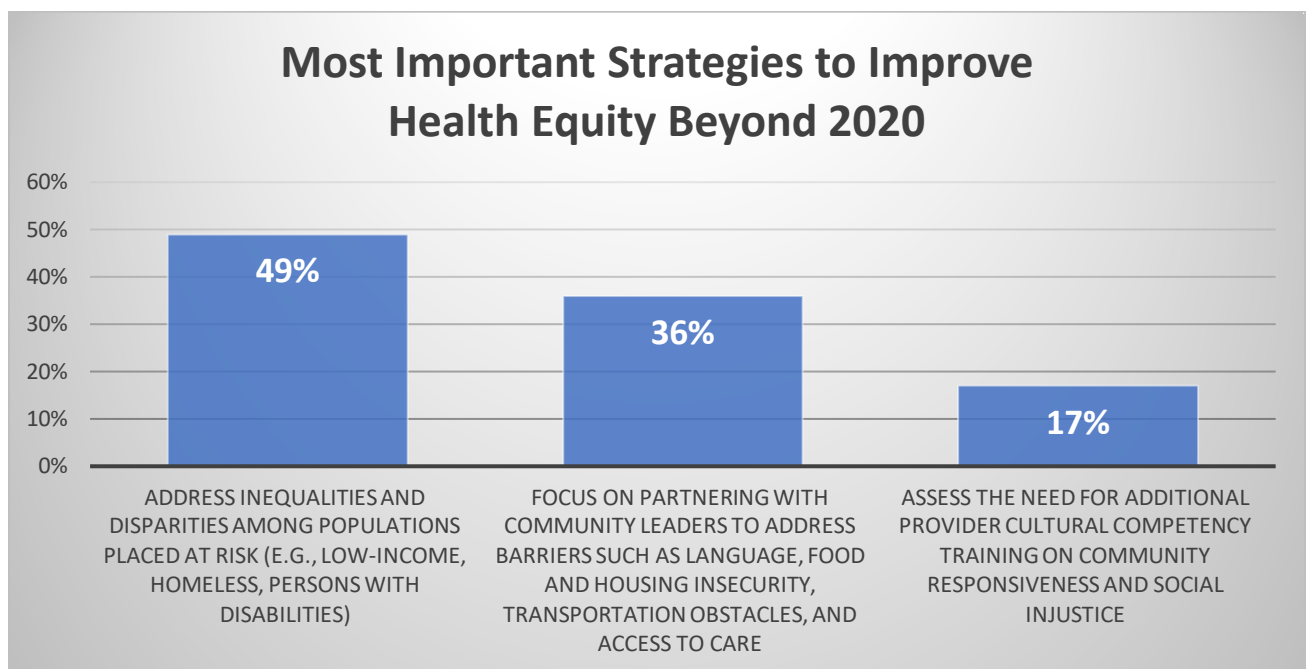
ETE Beyond 2020: Health Disparities

Survey respondents were asked to rank strategies to address health disparities in order from highest to lowest preference. Seventy-eight percent of all survey respondents (n=252) provided feedback on strategies to address health disparities beyond 2020. The results indicate that almost 42% of respondents ranked “*Additional strategies that address multiple medical conditions*” as the highest priority, while almost 31% reported that “*Assessing additional educational needs for populations placed at risk*” was the top priority. Finally, 28% of respondents indicated that “*Including other languages besides English in all resources and materials provided to the community*” was the most important disparity to be addressed.



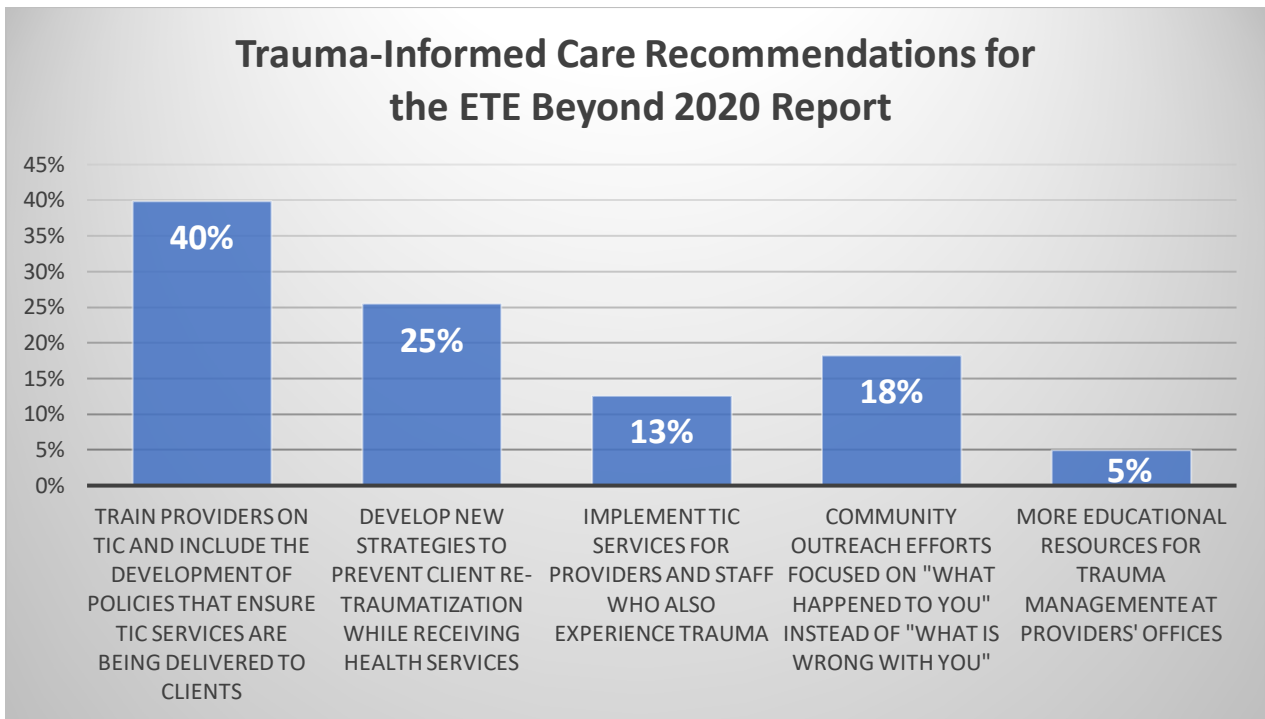
ETE Beyond 2020: Health Equity

One-half of survey respondents (50%) provided feedback on health equity (n=161). Nearly one-half of participants (48%) ranked “*Addressing inequalities and disparities among populations placed at risk*” as the most important consideration to be addressed beyond 2020. Over a third of respondents (36%) ranked “*Focus on partnering with community leaders to address barriers such as language, food and housing insecurity, transportation obstacles, and access to care*” as the most important health equity consideration. Just one in six survey respondents (17%) considered “*Assessing the need for additional provider cultural competency training on community responsiveness and social injustice*” as the most important strategy to improve health equity beyond 2020.



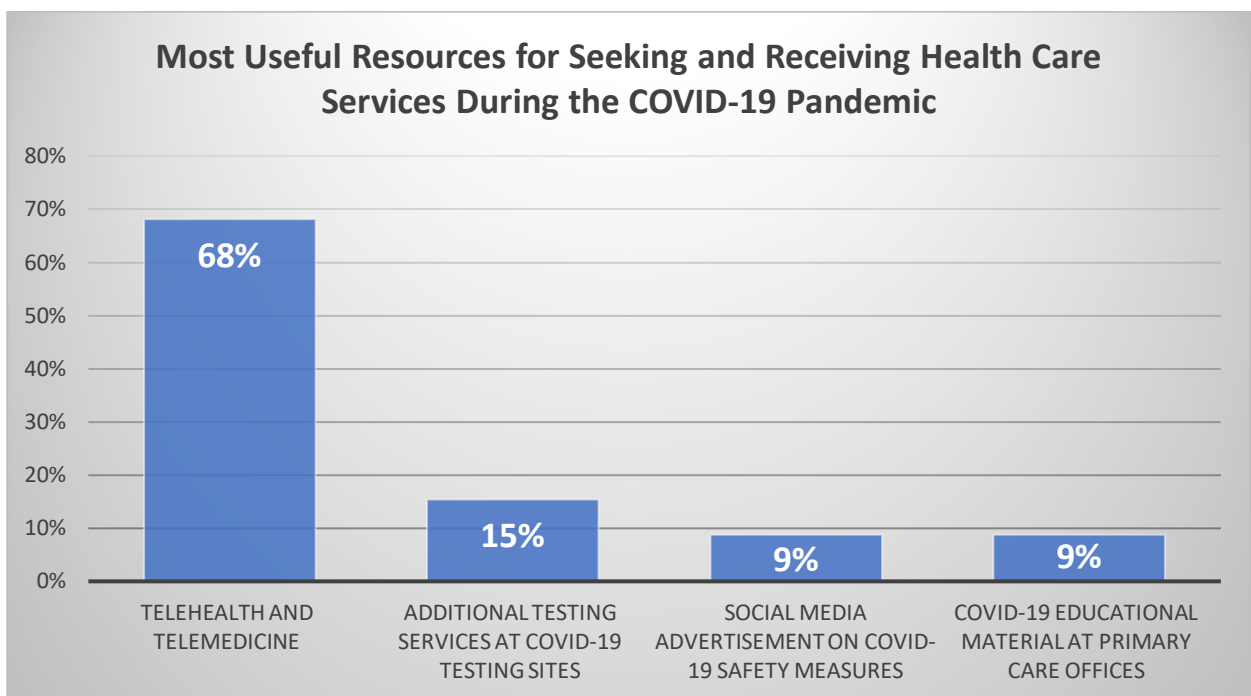
ETE Beyond 2020: Trauma-Informed Care

One-third of survey respondents (33%) shared feedback on Trauma Informed Care (TIC) (n=108). “Train providers on TIC and include policies that ensure TIC services are being provided to clients” was ranked as the best way to incorporate elements of TIC by nearly 40% of respondents. About one-quarter of survey participants (26%) ranked “Develop new strategies to prevent client re-traumatization while receiving health services” as the best method. Fewer respondents thought that “More community outreach efforts focused on ‘What happened to you’ instead of ‘What is wrong with you’” (18), “Include TIC services for providers and staff who also experience trauma” (13%), and “Include more educational resources for trauma management at providers’ offices” (5%) were the best ideas for incorporating a TIC approach into service delivery beyond 2020.



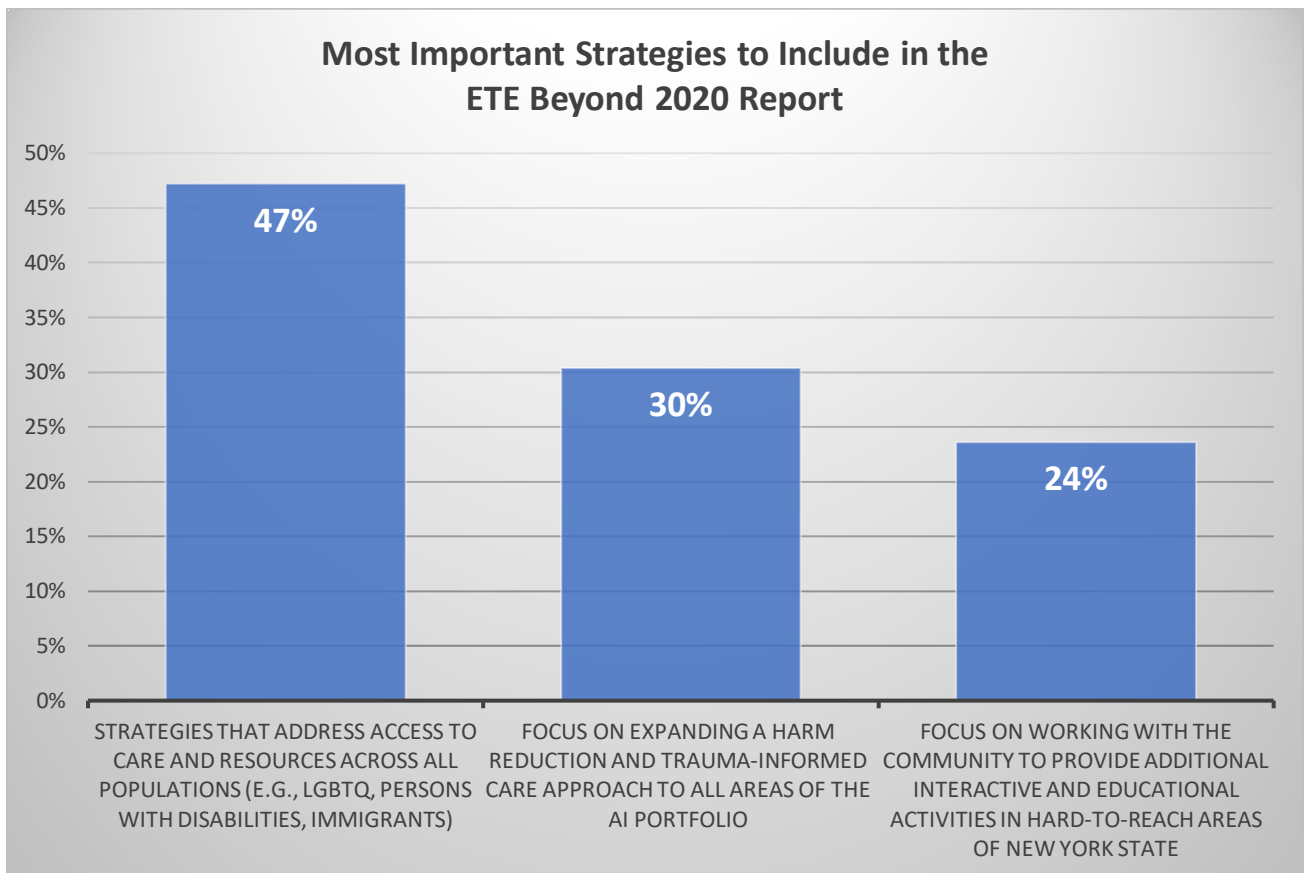
ETE Beyond 2020: COVID-19 Impact

The challenges around providing outreach during the pandemic was mentioned as a critical concern during nearly every listening session. Approximately 42% (n=135) of survey respondents ranked the usefulness of various resources for seeking and receiving health care services during the pandemic. Results indicated that the most useful resource, ranked highest by nearly seven in ten participants (68%), was the use of “*Telehealth and telemedicine.*” Fifteen percent of respondents thought that the availability of “*Additional testing services at COVID-19 testing sites*” was the most useful resource, followed by “*Social media advertisement on COVID-19 safety measures*” (9%) and “*Educational materials at primary care offices*” (9%).



ETE Beyond 2020: Considerations for the Future

Approximately 79% (n=255) of respondents ranked the most important topics or strategies to be adopted beyond 2020. Nearly one-half (47%) chose “*Strategies that address access to care and resources across all populations*” as most important. “*Focus on expanding a harm reduction and trauma-informed care approach to all areas of the AI portfolio*” was ranked highest by 30% of survey participants. Finally, nearly one in four respondents (24%) chose “*Focus on working with the community to provide additional interactive and educational activities in hard-to-reach areas of New York State*” as the most important consideration beyond 2020.



AIDS Institute “Call to Action” Letters

For the past several years, the [AIDS Institute Call to Action letters](#) written and shared publicly by AIDS Institute Director, Johanne Morne, have emphasized key priority areas to move NYS toward achieving ETE goals. The letters charged all grant-funded programs, clinical programs, health care providers, stakeholders, and community partners to implement strategies that prioritize key areas. Providers and stakeholders were encouraged to use data, program evaluation and quality improvement methods to assess and monitor the progress made within each key priority area.

The guidance offered in the letters took on even greater significance in 2020 due to the pandemic and social justice movement. Common themes resonating from the listening sessions include stigma, trauma-informed care (TIC), health equity, and social determinants of health. The priorities identified in the Call to Action letters are consistent with many of the themes that emerged from the ETE 2020 and Beyond listening sessions.

The need to address stigma and promote non-stigmatizing environments was a theme that emerged in the listening sessions. While all the Call to Action letters emphasize the importance of addressing stigma, the 2018 and 2019 letters focus specifically on addressing stigma. The letters call for combatting HIV stigma in every venue with every tool so that people will not be afraid to have an HIV test, engage in HIV care, or take advantage of PrEP. HIV clinical sites have engaged in efforts to combat stigma as part of the NYS Quality of Care Program. The AIDS Institute initiated a training, “From Stigma to Affirmation,” to help providers identify concrete steps that can be taken to address stigma. The U=U campaign is a tool to address HIV stigma. The AIDS Institute supported a statewide multi-level campaign on billboards, in subway cars, health care sites, pharmacies, social media platforms/dating sites, and TV spots with the goal of moving the needle on stigma. In addition, stigma can be reduced by diversifying the cultural and ethnic climate within organizations by hiring staff who reflect the communities they serve.

Trauma-informed care was identified as a priority in the listening sessions. The [2020 Call to Action letter](#) encouraged all AIDS Institute-funded programs to address and implement a trauma-informed

care approach (TIC) in all health care and treatment services. The listening sessions also incorporated TIC to help participants impacted by COVID-19 and the ongoing racial injustices. TIC challenges individuals to revise their systems of care to promote choice, collaboration, empowerment, safety, and trust. The use of TIC recognizes the historical impact of trauma on communities of color and emphasizes the importance of peer support. The year 2020 brought to our communities heightened levels of distress and trauma. For several years, the AIDS Institute has supported two TIC capacity-building Initiatives: one specifically for community health centers, syringe exchange programs, and health homes offered through Cicatelli Associates and the other through the University at Buffalo's Institute for Trauma and Trauma-Informed Care. The AIDS Institute also supports individual provider training on TIC. It is important that every funded agency and every stakeholder take steps to learn about, and implement, TIC.

As noted in the listening sessions, the need to address inequities and social determinants of health, such as income instability and lack of culturally appropriate education and employment, remain a persistent need. The 2020 Call to Action letter acknowledges the importance of health equity, and that all ETE Beyond 2020 work must prioritize health equity to level the playing field and promote equal access for all. A large percentage of people living with HIV in New York are aware of their status, meaning those who have access, and feel safe enough to do so, have come forward for an HIV test. With statewide viral suppression rates at 89% among those in care, it is clear those in supportive living situations who access care are able to benefit from HIV treatment. Those who access evidence-based education are taking advantage of PrEP. The challenge now is to take meaningful, targeted steps to bridge mistrust, create safety, and modify approaches to education and service delivery to reach our most vulnerable residents. Some populations have lived experiences that make them vulnerable to STIs, HIV, and hepatitis C. These experiences include poverty, lack of access to health care, and geographic disadvantage. Experiences also include institutional racism, stigma, and trauma. Trauma can have lasting adverse effects on an individual's mental, physical, social, emotional, or spiritual well-being. Historical trauma plays an important role in determining physical and behavioral health outcomes. Proven, effective biomedical interventions, health promotion messaging, and awareness campaigns that resonate with specific communities must be carefully tailored to the needs and experiences of each group. All populations must be prioritized in ETE Beyond 2020 activities so that no one is left behind. Priorities include:

- Promoting health equity and addressing health disparities and stigma.
- Partnering and collaborating with key stakeholders -- for example, policy makers; government, provider, and community partners; consumers; and research entities -- to address social determinants of health, such as poverty, education, employment, and access to insurance coverage.
- Promoting services that are responsive to the lived experiences, trauma, and stigma that disproportionately affect communities of color, indigenous populations, LGBTQ communities, and transgender and gender non-conforming individuals.
- Assisting service providers in implementing trauma-informed practices and policies.
- Promoting promising practices that address health disparities.

Consistent with themes in the Call to Action letters, the listening sessions underscored the necessity for consistent and mandatory training opportunities for providers. Training can help providers implement trauma-informed care approaches, address stigma and promote a safe environment, and furnish all services using a health equity framework. Training can help build staff skills to use affirming language during client interactions. Training can reinforce the importance of accepting and using clients preferred names and pronouns and being open to hear and acknowledge client feedback.

The AIDS Institute Director will continue to share periodic communications to address emerging needs and priorities of our communities as we move into ETE efforts beyond 2020.

Emerging Priorities

[COVID-19](#)

COVID-19 remains an emerging issue for NYS residents. New Yorkers are currently experiencing, or at risk for, one or more of the following COVID-19-related impacts: mental health issues; job loss; lack of technology proficiency and capability (i.e., telehealth); poor medication adherence; lack

of access to equitable care services’ practicing prevention strategies (i.e., social distancing); increased isolation; lack of routine HIV, hepatitis C and STI testing; misinformation, mask-wearing politicism; fear of ineffective treatments; and mistrust of the vaccine.

[ETE Beyond 2020 Metrics](#)

The AIDS Institute understands the importance of incorporating real-time performance-based measurement and timely communication to key stakeholders into its ETE efforts. These elements have been cornerstones of New York State’s ETE initiative and have helped to ensure accountability and transparency, keep stakeholders energized, fill knowledge gaps, and ensure locally appropriate programming. Tracking [ETE metrics](#) will be a focal point of ETE beyond 2020. Important work toward that end has already begun. The ETE Metrics Committee was re-convened in September and December of 2020 to review progress toward 2020 ETE targets, assess the impact of the COVID-19 pandemic on existing metrics, and discuss recommendations regarding ETE metrics beyond 2020. The Committee considered information gathered from the ETE 2020 and Beyond listening sessions, along with initial fiscal and programmatic COVID-19 impact data to formulate a path forward. Recommended enhancements to existing metrics were discussed, as was the creation of new metrics responsive to stakeholder input, including metrics related to social determinants of health. The Committee will continue its work and finalize ETE Beyond 2020 metrics during the first half of 2021.

[National Ending the HIV Epidemic Plan for America](#)

In February 2019, the U.S. Department of Health and Human Services (HHS) announced Ending the HIV Epidemic: A Plan for America (EHE: A Plan for America) which aims to reduce new HIV infections by 75% in five years (by 2025), and by 90% in 10 years (by 2030). EHE: A Plan for America focuses on four pillars: 1) Diagnose, 2) Treat, 3) Prevent, and 4) Respond. The NYSDOH and NYCDOHMH will continue to work collaboratively to ensure that the NYS ETE Blueprint and NYC ETE and EHE Plans are aligned. The NYC EHE Plan sets forth current NYC ETE goals and key activities organized by the four EHE pillars. In October 2019, the NYCDOHMH received funding to initiate a community planning process to collect feedback and recommendations to guide

the development of NYC's EHE jurisdictional plan, which builds on, extends, and updates the earlier NYS ETE Blueprint and NYC ETE Plan. Members of the AIDS Institute advisory bodies of AAC and the HIV Advisory Body participated in the feedback process to provide recommendations in 2020.

The NYC ETE Plan includes five key strategies:

- **Strategy 1:** Increase the number of people who know their HIV status by diagnosing HIV as early as possible, promoting routine testing within health care facilities, and scaling up testing options in non-clinical settings.
- **Strategy 2:** Prevent new HIV acquisition by increasing access to effective prevention interventions, including pre-exposure prophylaxis (PrEP), emergency post-exposure prophylaxis (emergency PEP), condoms, harm reduction, and supportive services.
- **Strategy 3:** Improve viral suppression and other health outcomes for PWH by optimizing medication adherence and access to care, improving coordination of clinical and supportive services, and increasing access to immediate antiretroviral treatment (iART).
- **Strategy 4:** Enhance methods to identify and intervene in HIV transmission networks to better support individuals and communities at increased risk of exposure.
- **Strategy 5:** In all NYC ETE strategies, utilize an intersectional, strengths-based, anti-stigma, and community-driven approach to mitigate racism, sexism, homophobia, transphobia, and other systems of oppression that create and exacerbate HIV-related health inequities.

Conclusion

Online surveys and virtual listening sessions are proactive and effective ways of educating and assessing needs of the community, providers, and clinicians statewide and should continue beyond 2020. Key themes from the ETE 2020 and Beyond community listening forums and the NYC EHE plan align with implementation strategies from the 14 community advisory groups, including:

- Acknowledge that increased and improved efforts for community engagement/outreach through strengthening of partnerships and collaborations with other state agencies and community-based organizations is crucial in Ending the Epidemic for all populations.

Specific populations include individuals impacted by homelessness, youth and young adults, LGBTQ individuals, people who inject drugs, long term survivors and older adults.

- Address lack of resources and barriers to care, with a focus on client difficulties in engaging in health care services due to the social determinants of health, for communities at increased risk of HIV acquisition.
- Increase mandatory and routine provider trainings on cultural competency, implicit bias, LGBTQ sensitivity, eliminating stigma in health care environments, trauma-informed care, and health equity.
- Sustainable funding for community-based organizations that reach individuals placed at risk for and living with HIV as well as organizations addressing social determinants of health (e.g., housing, transportation, mental health, substance use, etc.)
- Increased need to integrate trauma-informed care approaches in programming in AIDS Institute programming and initiatives.
- Actively develop internal and external policies, practices and partnerships with other state agencies, organizations, and entities to advance health equity and dismantle all forms of oppression, including racism and homophobia, that contribute to HIV related-health inequities.

The AIDS Institute continues to value and utilize the contributions of the implementation strategy advisory groups in programming and policy making. Themes that arose in the ETE 2020 and Beyond listening sessions are consistent with the recommendations made by the advisory groups and will inform ETE Beyond 2020 programming.

The listening sessions and survey clearly show the continued relevance of the ETE Blueprint and initiative. Stakeholders want to continue to focus on ETE post 2020. The effort is NOT over. 2020 simply marks an important milestone on a long timeline dedicated to improving the health of New Yorkers served by the AIDS Institute's expansive and growing service portfolio.

Acknowledgments

The AIDS Institute sincerely thanks the participants of the ETE 2020 and Beyond listening sessions, all those who responded to the statewide survey, and the advisory bodies who provided and continue to provide recommendations on ending the epidemic. The ETE initiative in NYS came to be due to community leadership, and community input continues to be the foundation of the initiative. The AIDS Institute thanks numerous partners -- consumers, service providers, community leaders, advocacy groups, research entities, the NYC DOHMH and other local, state, and federal government agencies – for the extraordinary collaborations that make ending the epidemic possible in New York State.