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# CEI ECHO: ETE UPDATE

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**[video transcript]**

00:08

Good afternoon. As mentioned, I'm Wendy Patterson from the New York State Department of Health. I am the Director of the Data Analysis Reporting Unit in the Bureau of HIV and AIDS Epi. And today we're going to talk about New York State's 2019 surveillance data, as well as some highlights from the past year. So as it relates to ETE, Ending the Epidemic in New York state, we're often asked if we're moving in the right direction. And as of right now, we can say we are. As a result of collective work with partners across New York State, and the many strides and improvements we have made, we are definitely going in the right direction. Currently, there are about 108,000 people living with diagnosed HIV in New York State. And we continue to achieve historic reductions in estimated new infections and diagnoses across all demographic groups. We're moving in the right direction regarding linkage to care and viral suppression, and there are increased numbers of people immediately beginning treatment right after their HIV diagnosis and maintaining a suppressed viral load.

01:13

Wendy, are you moving some slides forward? We just seeing one big slide.

01:17

Nope, not yet. As we continue to increase the number of people across New York state have been provided PrEP as well. And as we are achieving these many victories, we also have to be aware that there are disparities related to race and ethnicity and gender that must be addressed. We must address the social determinants such as poverty, housing, substance use, mental health and access to services. I will start by saying that I have no disclosures that I would like to declare.

01:56

And I will briefly go over the learning objectives for today's presentation. This presentation will cover trends on the HIV epidemic in New York State. This will include trends among people newly diagnosed with HIV and AIDS, those living with diagnosed HIV and/or AIDS, and deaths among people who have been diagnosed with HIV. We will then move on to a selection of the ETE metrics, and cover the progress on those selected metrics. And finally, we'll wrap up with understanding the definition of what it means to bend the curve and how New York State has bent the HIV epidemic curve.

02:39

First of all, we would always like to acknowledge that although we use the word data, and many of our definitions are presented as standard definitions, that these represent real people. These are our friends, colleagues, family members, and people that we hold dear to us. And we must never forget that behind each data point and generalized term that we use, that these are real people. The standardized definitions that we use are guided by national surveillance programs. So this allows for comparison of data across multiple jurisdictions in the United States. We understand and would like to convey that some of these terms are not the categories and labels

that people use to represent themselves, but this does allow for states and jurisdictions to compare data evenly across themselves. So we do use these terms, and then these are the terms that we use when we present data publicly. So this slide shows the history of the HIV epidemic in New York State. It encompasses almost all of our metrics in different measures that we have in the HIV surveillance data system. So we have counts of the number of people living with diagnosed HIV and AIDS, people who are newly diagnosed with HIV or AIDS, and then also deaths among those with HIV/AIDS as well. Named reporting did not start in New York State for HIV until June of 2000. So in the earlier years of the graph, you will notice that only persons diagnosed and living with AIDS are recorded. And then in 2000, we were able to collect data that made the distinction between the stages of AIDS and HIV, and we were able to report them separately starting in 2000. In the earlier years of the epidemic, the data show that deaths and the number of people diagnosed and living with HIV are increasing. ETE started in 2014, and you can see that the trends have been decreasing since then. Persons newly diagnosed with AIDS in 2019 reached the lowest point ever with 1098 people newly diagnosed with AIDS. Also people newly diagnosed with HIV reached an all time low in 2019, with 2377 people newly diagnosed. This is a decrease of 62% from when reporting started in 2000.

05:09

This slide speaks to the progress that New York State has made over the years from when reporting began in 2000, and from when ETE started in 2014. So the first ETE metric that I will talk about is new diagnoses. So this measures the number of people newly diagnosed with HIV per year. New HIV diagnoses declined for the fifth consecutive year, reaching an all time low in 2019. The goal was to reduce the number of new diagnoses from 2013 to 2020 by 55%, with a goal of 1515 in 2020. There's been a 4% decrease from 2018 to 2019, and the 31% decrease from 2014, when ETE began, to 2019. And if I haven't mentioned, 2019 is the latest data we have, we are still finalizing and processing 2020 data. So when we talk about the current data year, or the current data available, that would be up to 2019 data. New York State also continues to eliminate mother to child transmission of HIV. And in 2019, only one case was reported. This marks the sixth time in New York State's history that they've achieved the CDC's definition of eliminating mother to child transmission, and for the first time in the New York State that we have met the goal for five consecutive years, which would actually be every year since ETE began in 2014.

06:50

The next couple of slides we will look at some of the demographic groups among people newly diagnosed with HIV. In New York State, the number of people newly diagnosed with HIV has been decreasing among both males and females. Although the smaller number of people newly diagnosed have a birth sex of female, there has been a greater decrease over the years. The decrease from 2010 to 2019 has been 38% among males, but it has been a decrease of 51% among females from 2010 to 2019. We've also noticed decreases among all the age groups, except for 13 to 19 year olds. In 2018 to 2019, there was a 3% increase of people newly diagnosed with HIV among the 13 to 19 year old age group. And there's been decreases among all race/ethnicity groups as well from 2018 to 2019, except for non-Hispanic whites. In New York State from 2018 to 2019, there's been a 3% increase among people newly diagnosed with HIV in the non-Hispanic white race ethnicity group.

08:04

This slide reflects the number of persons with trans experience diagnosed with HIV from 2010 to 2019. Transgender women account for 86% of the new diagnoses among all persons of trans experience. And 90% of persons reported sexual risk as the transmission risk group. We include sexual risk as sex with a male and/or a female. And 73% of persons who were aged 13 to 34 at the time of their HIV diagnosis, among trans experience, were newly diagnosed with HIV. Here again, in the transgender community, we are seeing the same disproportionate impact among Hispanics, they are making up 42% of new diagnoses among the transgender experience persons, and then also non-Hispanic Blacks represent 39%. So those two race groups are still seeing the same disparities we see among all people newly diagnosed with HIV.

09:22

The slide shows the HIV diagnosis rates, which is represented by the blue line, as well as the number of diagnoses by race/ethnicity for 2019. So we'd like to look at rates as well as counts, to get a better representation of the disparities that we are seeing between the race/ethnicity groups. So the bars show the number of new diagnoses and non-Hispanic Black and Hispanic persons represent the greatest number of people newly diagnosed with HIV, followed by non-Hispanic white, multiracial, Asian Pacific Islander, and Native Americans. However now if we look at the rates, which would be the blue lines and the blue triangles, this is another way of looking at the reported data. For example, for every 100,000 non-Hispanic Black persons living in New York State, about 33 individuals were newly diagnosed with HIV. This is the highest rate among all the race/ethnicity groups in the state. And Hispanic persons had the second highest rate at about 21 Hispanic persons newly diagnosed for every 100,000 Hispanic persons living in New York State. The rates were similar among the Asian Pacific Islander, non-Hispanic whites, and Native American persons, at about three to four persons newly diagnosed per 100,000 persons in each race group.

10:56

So moving on from new diagnoses, we're going to look at another ETE metric, this one is time to AIDS. Time to AIDS is a measure of people who are newly diagnosed with HIV who progressed to stage three HIV, which is AIDS, within two years of their diagnosis. Because this measure requires a two year lag, the data is reported two years behind. So the latest data we have is 2017 data. This is people who are newly diagnosed in 2017, and then were followed for '18 and '19. So by the end of 2019, has anybody progressed to stage three, AIDS, by that point? The goal as described in the Blueprint states that by 2020, we'd like to reduce the rate of which persons diagnosed with HIV progressed to AIDS by 50%, which would be to 5.1%. We continue to make tremendous progress in this metric, starting at 10.4% in 2012, and decreasing to 5.0% in 2017. This means that of all the people newly diagnosed in 2017, by the end of 2019 5% have progressed to AIDS. The key to making further gains in this metric is to ensure that systems are in place to identify and diagnose new HIV infections as they happen, and not after a person has unknowingly been living with HIV for many years, and not gaining the benefits of antiretroviral treatments.

12:33

The next ETE metric is linkage to care after diagnosis. And this measure is about ensuring people who are newly diagnosed with HIV are receiving timely care. This is measured by evidence of care within 30 days of HIV diagnosis. Since these metrics are based off data from the HIV surveillance system, we only have lab data, we don't have information about physician visits. So we use lab tests as a proxy for care here. So if there's a CD4, a viral load, or a genotype lab test, then that is our proxy for in care. At the start at ETE, there has been an increase every year in the percent of people linked to care. In 2019, we saw a 1% increase in the percent of people newly diagnosed with evidence of care from 82% to 83%. And this metric has increased 14 percentage points from when ETE started back in 2013.

13:33

Another measure for ETE metrics is viral suppression among people who are receiving care. So this is again of the group of people who had any care, so they have to have one of the three lab tests, a viral load, a CD4, or genotype test. And then looking at the last test of the year, was that viral load test suppressed? Which are defining suppression as a less than 200 copies per mL at the last test of the year. Keep in mind, the last test of the year could be different for each person, somebody's last test could be March, somebody else's last test of the year could be November. So whatever the last test of the year for that person is the result that we use in 2019. Gains acknowledged over the previous years have been maintained. So it started at 81% in 2013, and has been steadily remaining at 89% in 2018 and 2019. Among viral suppression rates, disparities still exist among race/ethnicity groups. Non-Hispanic white and Asian Pacific Islanders reported the highest viral suppression rates at 95%, followed by Hispanic and multiracial groups. And they had achieved an 89% of viral suppression rate. Non-Hispanic Blacks were reporting a viral suppression rate of 86%. We have Native Americans reporting a 100% viral suppression rate, however, this is based on a small number of people. So the rates are unstable when there's such a small number of people that were calculating this on.

15:15

HIV deaths measure for the ETE metrics is a measure of HIV related deaths. So it's among people who are diagnosed with HIV, but then it's the cause of death that is actually related to HIV. And due to the advancements in HIV treatments, people have been living longer and the causes of death have been mimicking those of the general population. So what started at 36% in 2013 of deaths related to HIV, has decreased to 26% in 2018. This data metric also has a lag, it takes a while to obtain biostatistics data and cause of death, and then to get that matched into our systems. So this HIV related death metric does have a one year lag. So the latest data available is 2018. Percent of deaths has decreased from 35% to 26%, and that's nearly a 10 percentage point decrease over the years that ETE has been around in New York state.

16:30

So concurrent diagnoses is a measure too for the ETE metrics. And this is when a person is newly diagnosed with HIV and then progresses to AIDS within 30 days. So this is similar to the time to AIDS measure, except that is two years, this one is only 30 days. And when that happens, that could indicate that a person that has been living with HIV for a long time, it's believed that these individuals may have acquired HIV 8 to 10 years prior to their diagnosis. So there's been a 37% reduction in the number of concurrent diagnoses from 2013 to 2019. That is

the number, in the hundreds, 736, 674, the top part of the graph. The percentages represent the percent of all people newly diagnosed with HIV, what percent are concurrently diagnosed. So while that number is remaining stable, even though the number of cases is decreasing, that is all in relation to the number of HIV diagnoses which has been decreasing each year. So even though the number of new diagnosis is decreasing, and thereby the number of concurrent cases is decreasing, the percentages still remain in around the 20% area. New York State has actually been doing some activities to assist to learn more about individuals who are concurrently diagnosed, we have been matching the data. So when a person is concurrently diagnosed in some of our existing databases, we match them to other databases we have access to, to see if there's areas of missed opportunities or where treatment could have been initiated. And we also have been conducting interviews with people who are concurrently diagnosed to see what some barriers are and some limitations to care.

18:20

Similar to the concurrent metrics, we have a percent of persons who are newly diagnosed who have a history of IDU, injection drug use. The way we calculate history on the surveillance system is this is something that somebody has participated prior to their HIV diagnosis, so it's not necessarily a current behavior. It's something that has been partaken in in the past. And the numbers are different between New York City and rest of the state. One of the things we noted is that the race/ethnicity characteristics are different. In New York City, the majority of people indicating a history of ICU was Hispanics. Were in the rest of state, so that's New York State outside of New York City, non-Hispanic whites represented the largest group of people with a history of injection drug use. It is also been decreasing, especially among males, from 2018 to 2019. And about 50% of individuals newly diagnosed were under the age of 40. So those are some groups that we have been focusing on for this measure.

19:31

PrEP utilization is again another measure that has been increasing in New York State. Targets were first started in 2018, but you can see we have been recording data since 2014. And the overall PrEP uptake has increased each year to nearly 40,000 New Yorkers filling at least one PrEP prescription in 2019. The way to measure PrEP utilization for this metric is it's measured by the number of individuals who fill at least one prescription for Truvada during the calendar year. And in a recent publication by CDC, New York State was the second highest jurisdiction, so we were following California for the number of persons who have been prescribed PrEP. And we are the highest with the PrEP coverage across the nation. So New York state has the highest PrEP coverage rate of all the other jurisdictions in the United States.

20:32

Incidence is a metric that is a focus of the ETE initiative as well. And this slide has quite a few lines on it, it's describing all the different methodologies that have been used since ETE started. So when ETE started in 2013, the initial STARS methodology was used to calculate incidence. So incidence is a calculated number, it's the estimated number of people who acquire HIV each year, it's not the number of people who are newly diagnosed. So this is based on methodology from the CDC, and it's calculated. But just like everything else, it is updated each year. The methodology is new and improved. So each year, we have a different methodology. So what

started in 2013, the targets that were set have changed and updates have been made. So starting now with 2019 updates, the goal has changed from 750 to 825. Based on the new estimations that have come out, this is about a 10% higher target than what the original STARS methodology had used. But as you can see, from all the different methodologies that have come out to measure incidence, they all have one thing in common. They're all showing the overall downward trend in estimated new infections in New York State.

21:56

And the last metric that we're going to talk about today is bending the curve. So bending the curve is defined as a point where the number of HIV infections intersects with the number of deaths among people with diagnosed HIV. As noted on the previous slide, incidence has decreased out 38% since ETE began in 2014. In 2019, we are cautiously applauding the milestone of bending the curve in New York State, achieving the first ever decrease in prevalence. We began ETE in 2014, with a target of decreasing incidence by 75%, from 3000 to 750. As noted on this slide, in 2019 we have achieved this goal where the two lines of HIV incidence and the number of deaths have crossed. We are acknowledging and watching that the data is going to look very different in 2020, due to COVID we're gonna probably be seeing more deaths and more deaths among COVID. So this is definitely a measure that we're gonna keep an eye on in the coming years.

23:13

So through this presentation, I have quickly covered the trends in New York state, some of the selected ETE metrics, and introduced what bending the curve means to New York State. Haven't been watching the chat. So are there any questions?

[End]