

HIV Quality of Care Consumer Advisory Committee Meeting

55 Exchange Place, New York, NY
September 12, 2019 | 9:00AM – 12:30PM

AGENDA ITEM/TOPIC	DISCUSSION/ACTION ITEMS
Introductions and Announcements <i>Dana Diamond and Leanna Thornton, CAC Co-Chairs</i>	<ul style="list-style-type: none"> - Dana Diamond, CAC co-chair, welcomed the attendees. - The HIV Quality of Care website is live. Meeting summaries and minutes will now be posted there instead of the HIV Guidelines website. - The next CAC meeting will be held on Wednesday, December 11th and will be a full day meeting. <ul style="list-style-type: none"> o To accommodate travel plans, the meeting will last from approximately 9-3pm and presentations will not be scheduled after 2:30pm. - The QAC meeting will be held on the following Thursday, Dec. 12, via WebEx.
QAC Update <i>Dr. Christine Kerr, QAC Co-Chair</i>	<ul style="list-style-type: none"> - Dr. Kelly Ramsey, QAC co-chair, recapped the June QAC meeting. <ul style="list-style-type: none"> o Dr. Doug Fish and Dr. Lindsay Cogan gave an update on value-based payments and STI measures in NYS for 2019. o Institute of Family Health and SUNY Upstate presented their 2018 cascades. o The attendees discussed the joint QAC/CAC subcommittees of tobacco, stigma, Hepatitis C and STIs, including their purpose and background.
YACAC Update <i>Adrian Centeno, YACAC Chair</i>	<ul style="list-style-type: none"> - Leanna Thornton, CAC co-chair, presented YACAC updates on behalf of Adrian Centeno, YACAC chair. - The Youth Statewide Forum will be held in March 2020. <ul style="list-style-type: none"> o The forum is intended for youth ages 16-24 to come together and have their voices be heard. o Attendees will learn about YACAC and how they can advocate for their peers. o Location and dates are not yet confirmed. o Transportation will likely be provided. - YACAC and CAC members can serve as youth mentors, teaching youth how to advocate for their own health care and participate in quality improvement. <ul style="list-style-type: none"> o Courtney Ahmed will serve as a consumer advocate. o Contact Ms. Ahmed, Ms. Thornton or Dan Tietz if interested in serving as a mentor. - Recruitment strategy: <ul style="list-style-type: none"> o HIV-positive young adults will be recruited through current YACAC members' networks and existing provider networks. o Mr. Tietz and Adrian Centeno will announce the Youth Forum at the Adolescent Quality Learning Network meeting on September 25th. o Flyers are available for distribution. Everyone is encouraged to share the flyer on their social media. <ul style="list-style-type: none"> ▪ Email Ms. Ahmed at Courtney.Ahmed@health.ny.gov to request the PDF version. o Interested attendees are encouraged to invite their peers.

	<ul style="list-style-type: none"> - Jahlove Serrano reminded the group that YACAC is not a support group, but a working body for advocacy.
<p>United States Conference on AIDS (USCA) Report <i>Lailani Muniz, YACAC</i></p>	<ul style="list-style-type: none"> - Lailani Muniz shared her experience attending the United States Conference on AIDS (USCA) from September 5-8 in Washington, DC. <ul style="list-style-type: none"> o Ms. Muniz gained valuable information and resources from networking. She was invited to serve on the USCA planning committee for next year's conference. - Highlights from plenary sessions and workshops: <ul style="list-style-type: none"> o "America's Affordable Housing Crisis" walked participants through the journey of renting to homeownership. o "Being Positively Fearless About Mental Health" included almost all perspectives except trans perspective. <ul style="list-style-type: none"> ▪ Next year, trans perspective will be included. o "HIV Cure Research and Role of Community" was very data intensive. <ul style="list-style-type: none"> ▪ Ms. Muniz will compile data from HIV Cure Research and Role of Community plenary session to be disseminated to CAC members. o "CBO Leaders Responses to Shifting Government HIV Prevention Mandates" gave attendees the opportunity to participate in a grant reviewing exercise. <ul style="list-style-type: none"> ▪ Ms. Muniz noted it was valuable to have 3 women of trans experience who sit on review boards give advice. - Information about attending the USCA and sponsorship is on NMAC's website (http://www.nmac.org/). <ul style="list-style-type: none"> o CAC members may be eligible for funding from the AIDS Institute.
<p>Empowering Older Adults Living with HIV to Manage Their Health <i>Dr. Eugenia Siegler, Weill Cornell Medicine</i></p>	<ul style="list-style-type: none"> - Dr. Eugenia Siegler from Weill Cornell Medicine presented on aging and HIV. - Dr. Siegler acknowledged the distinction between aging and feeling old, noting that providers may not think of them as different constructs. - Aging with HIV cannot be generalized because it occurs at different rates and affects people differently. Health/medicine is a small fraction of all the factors influencing aging. - Long term survivors are not the same as older PLWH either. Aging with HIV differs from acquiring HIV later in life. - Worldwide, about half of people with HIV are over 50. In NYS, 60% of PLWH are 50+. 15-20% of new HIV cases are in 50+ age group. A third of older adults already have AIDS by the time they are diagnosed. These percentages will continue to increase. - We have to overcome biases toward age and physician ignorance. "Age is not a condom." - In general, aging leads to diminished reserve of energy and muscle mass and increases the risk of frailty (state of vulnerability, not disability). - Science cannot say exactly what HIV does to the aging process. However, people with HIV appear to have many of the characteristics associated with aging at an earlier age than their non-HIV infected counterparts. - The older you are, the more a delay in ART will harm your health. Being frail makes you more vulnerable to HIV and multiple medical problems that ensue. - Data from University of California - San Francisco (UCSF) Silver Project: <ul style="list-style-type: none"> o Median # of medications taken = 11. 34% were lonely and 27% were depressed. 41% had fallen in past year. Adherence to meds is better, but this has made people less concerned about the aging. - Long-term care needs must be met including psychiatric, existential, practical, biomedical, social, and psychosocial, and physical.

	<ul style="list-style-type: none"> - The US workforce isn't supplying enough geriatricians and full-time HIV care clinicians to meet demand. - What can you do? <ul style="list-style-type: none"> o Stop smoking, eat nutritional foods, exercise, get emotional support, and see your geriatrician once in a while. Become familiar with the aging services network in your county. - Questions to ask your provider: <ul style="list-style-type: none"> o How do you determine who needs an aging assessment? o Who will do the aging assessment? o How will you translate assessment into action? o How will you foster physical fitness and nutrition? o How will you meet psychosocial and long-term care needs? o What community-based services are appropriate for me? o How will you coordinate care? - Comments: <ul style="list-style-type: none"> o Doctors must pay attention to comorbidities and improve care coordination. o We need a new indicator for aging. o When doctors grow old with their patients, they don't have the distance to see what is happening. We have to build in a screening mechanism. o A COBRA study showed that PLWH are on average 15-17 years older than expected. o We must figure out a way to recruit more doctors to geriatrics. o Can we have funding to put a geriatrician in the HIV clinics a couple of days a week? Having an HIV/AIDS specialist, primary care doctor, and geriatrician in the same place is important. o No one is looking at PrEP for seniors. The age barrier for sexual health and STI testing must come down.
<p>PrEP Awareness Week <i>Rob Curry, AIDS Institute</i></p>	<ul style="list-style-type: none"> - Rob Curry presented on PrEP Aware, a public education campaign with activities across NYS to be held Oct. 20-26. - The AIDS Institute and Better World Advertising partnered to develop campaign materials in multiple languages that are available for use by all AIDS Institute stakeholders. - Resources and materials: <ul style="list-style-type: none"> o AIDS Institute Director Letter o Checklist of PrEP Awareness Activities o Regional Kick-off meetings conducted by AIDS Institute funded Regional Prevention and Support Programs between Oct. 20-26 o Social media materials for priority populations using PrEP Aware theme: www.health.ny.gov/diseases/aids/general/prep/social_media_toolkit.htm o Pharmacy materials o T-shirts & Ask Me About PrEP Buttons o Email signature o All resources and materials are located on www.prepforsex.org website. - Comments:

	<ul style="list-style-type: none"> ○ Sam Dien offered to make a video for the deaf community explaining PrEP services. ○ The AIDS Institute hosted 3 successful statewide forums last year: PrEP for Adolescents, PrEP for Transgender Women, PrEP for Women. Full meeting reports are at www.hivguidelines.org/prep-for-prevention/prep-implementation/. ○ Minors can now access PrEP without parental/guardian consent. ○ Michelle Lopez is doing face-to-face with seniors to inform them about PrEP. ○ John Wikiera suggested doing tv interviews. ○ Cindy Aponte asked if a sign language interpreter will be provided for her if she presents on PrEP Aware at various trainings. Mr. Curry will follow up with her request. ○ Dawn Trotter stressed that deterrence factors should not be involved in the PrEP Aware campaign to avoid deterring people from using PrEP. ○ Ms. Muniz noted that there is a lot of ignorance outside of the medical setting and pharmacies such as Duane Reade need to be involved. The AIDS Institute is doing their best to work with participating pharmacies. ○ Mr. Serrano commented that PrEP awareness should not just be spread by medical institutions but should infiltrate daily life. He would also like to see a “U=U week.” ○ Escott Solomon announced that the hospital he works with has a PrEP department. Members who are interested in partnering can contact him.
<p>Introducing the QAC/CAC Subcommittees <i>Dan Tietz and Courtney Ahmed, AIDS Institute</i></p>	<ul style="list-style-type: none"> - Courtney Ahmed, AIDS Institute, presented an overview of the four revived QAC-CAC subcommittees and their preliminary goals. - Stigma <ul style="list-style-type: none"> ○ Focusing on sharing best practices from experts, seeking youth and consumer input, and including additional populations like those aging with HIV, immigrants, and black and Latina women. ○ New CAC co-chair is Roland Marrero. - Tobacco <ul style="list-style-type: none"> ○ Focusing on marijuana and tobacco, understanding why people smoke and perceived benefits, utilizing surveys and/or focus groups, challenging e-cigarette use and vaping in light of CDC investigation, and developing patient-centered response tailored to individual’s smoking rates. ○ Must spread the message that vaping is not a viable alternative to quitting. ○ One new member, Brandan Campbell. - HIV/HCV <ul style="list-style-type: none"> ○ Focusing on eliminating HCV co-infection and mono-infection, working with agencies to develop cascades for HCV, improving transition from incarceration to community, and increasing funding for linkage and retention. ○ How do we address stigma associated with reinfection? ○ Two new members, Brandan Campbell and Sam Dien. - STIs

	<ul style="list-style-type: none"> ○ Focusing on evaluating use of HPV vaccine in HIV care facilities, extragenital testing requirements, and promoting understanding of sexual health and safer sex techniques in light of U=U. ○ One new member, Sam Dien.
<p>‘Culture of Honor’: Stigma Reduction at Joseph P. Addabbo <i>Carla Lewis-Peter, Joseph P. Addabbo Family Health Center</i></p>	<ul style="list-style-type: none"> - Canceled.
<p>Working Lunch and Closing Remarks <i>Dana Diamond and Leanna Thornton, CAC Co- Chairs</i></p>	<ul style="list-style-type: none"> - Mr. Serrano did a panel at the USCA conference on mental health and HIV and reiterated its importance for those aging with HIV. - Ms. Muniz performed an original poem. - Mr. Solomon announced that NYC Health + Hospitals is hosting a Stigma Summit next Friday at Lincoln Hospital. He will email flyers to chairs and secretaries. - Ms. Diamond stated there are plenty of “HIV Stops with Me” spokesmodels in NYS available to present and educate. CAC members can set up events at their affiliated organizations, invite spokesmodels, and bring PrEP Aware materials. - For those in southern tier of NYS, a peer certification training is in November.