

- Aisha M.: Welcome to today's webinar, A Conversation about Youth Access to PrEP. My name is Aisha Moore, and I am the project director of What Works in Youth HIV and your moderator for today. This webinar is being recorded, and you can get a copy of the slides and the recording, and other materials on our website within a week of this webinar. First I'd like to give some housekeeping messages. Attendees are in listen only mode. So if you have a technical issue or a question, please use the chat box at the lower right of your screen to chat with the host. Make sure you select host from the dropdown box. You may also send questions to WhatWorksinYouthHIV@jsi.com.
- Aisha M.: This audio is being shared via your computer speakers and headset. If you can't hear the audio, which means you can't hear me right now but you can read, make sure your computer audio is turned on. If you're still having problems, please use or call the number that you see here on screen. You have control over the size of the slides you see today. You can use the WebEx interface in the upper right hand corner to adjust your screen view. So you can go from full screen to other views. So if things are hard to see, please adjust your view.
- Aisha M.: So for those of you who are not familiar with our project, What Works in Youth HIV, it's operated by JSI Research and Training, an international public health organization, and we are funded through a cooperative agreement with the Department of Health and Human Services Office of Adolescent Health with funding from the Secretary's Minority AIDS initiative fund. To learn more about our project, please visit WWW.WhatWorksinYouthHIV.org. But to summarize what we do, is our goal is really to improve the health and well-being of America's adolescents by providing practical and innovative website content that empowers youth serving providers to meet the needs of youth at highest risk for HIV.
- Aisha M.: The strategies that we use include, supporting and promoting intervention to better integrate HIV prevention focused on youth, because there a lot about adults and we definitely need more strategies focused on youth. To promote evidence based practice in the programs, and connect with training and technical assistance opportunities like webinars that we are hosting today. Our objectives today for this webinar are to describe PrEP, meaning how it works for HIV prevention, and who can take it. Discuss common challenges related to youth and PrEP. Describe program strategies for educating youth about PrEP. Increasing their access to PrEP, and helping them adhere to PrEP if desired, and identify one strategy that you can apply in your program. There's definitely one that could be practical today.

Aisha M.: So let me go quickly over our agendas. Next we will do our speaker introduction. Then we'll have a presentation about the basics of PrEP. We want to make sure that everyone has a clear understanding of what it is and how it works. Then we'll have a conversation question that we will ask all of you to participate in the conversation, and we will have our panelists also answer the question. Then two of our panelists who work in community based organizations will talk about the strategies that they use everyday. Then we'll have our second conversation question, and we'll then take questions from our audience via the chat.

Aisha M.: So now let me introduce our speakers today. First we have Dr. Bisola Ojikutu. She's the senior advisor at JSI. She's also assistant professor of medicine at Harvard medical school and she works in the field everyday as an infectious disease physician and researcher at Massachusetts General Hospital, and the Brigham and Women's Hospital. Next we have Sabrina Cluesman. She's assistant director of clinical services for JASMYN Inc. in Jacksonville, Florida. She supports JASMYN's sexual health clinic, and they launched their PrEP access project in fall of 2016, and she will describing more of that in our presentation of strategy section. She's also a licensed clinical social worker.

Aisha M.: Next let's meet Aruna Krishnakumar. She's the director of HOTT, which is the Health Outreach to Teens program at Callen-Lorde's Community Health Center in New York City. This program provides comprehensive services to LGBT youth ages 13 to 24. She's also a licensed clinical social worker from Columbia School of Social Work, and an adjunct lecturer at Silberman School of Social Work at Hunter College in New York.

Aisha M.: So next I will turn it over to Dr. Ojikutu to give us some of the basics about PrEP because I know many of you know that PrEP is a once a day pill, but there's more to it. And Dr. Ojikutu will explain that to us now.

Dr. Ojikutu: Next slide. In order to understand why PrEP works, or its mechanism of action, we need to discuss a bit about the science behind HIV transmission. So what happens when an individual is actually exposed to HIV? So actual infection requires a series of steps. I know that that's not something that we think about necessarily, but it's really important for you to recognize an infection is not immediate. So first, of course you need exposure okay. And that's when, in the case of sexual exposure, you have sex with somebody who's HIV positive. Then to actually cause infection after an exposure, HIV needs to cross the cell layer and actually avoid being destroyed by the immune cells.

Dr. Ojikutu: If the virus overcomes these defenses, it can then spread past the site of infection to other parts of the body by entering the blood and lymphatic cells in the mucous membrane tissue. And then once HIV has spread throughout the body, the virus can establish infection in different organs and tissues. In some cases, HIV may not be able to cross the mucosal cell layer or win its battle against the immune cells in the mucosal tissue, but in many cases it actually does and establishes permanent infection. And this actually happens over a

course of days. So the question for researchers who developed PrEP was can this early pathway, before infection is permanently established, be interrupted? Next slide.

Dr. Ojikutu: So over the course of several days we can sort of look at the path or the course of infection in a little bit of a different way. We have exposure as I just said. We have infection of the immune cells, and then we have actual permanent infection. When a patient has developed permanent infection, we all know that we treat them quite successfully with antiretroviral therapy or ART. And that's three drugs at least to treat infection. Through a number of clinical trials researchers have determined that you can interrupt infection during exposure and infection of immune cells, and during this sort of window of opportunity you can take antiretroviral therapy or PrEP, and we'll talk about [inaudible 00:08:30] selection of PrEP, to actually stop permanent infection from happening. So that's really a quick 101 on why PrEP works. Next slide.

Dr. Ojikutu: I think it's important, since we all sort of work in the field, is for you to understand that antiretroviral therapy or ART is used as both treatment and in PrEP, and certainly as treatment we decrease the risk of transmission to other individuals. So and HIV positive individual who's having sex with HIV negative individual may be at very little to no risk of actually transmitting HIV if they're actually on antiretroviral therapy. That's ART as treatment. Now if that's not the case, and certainly not everyone knows their partner is ... Not everyone knows their partner's clinical history. Certainly somebody who's HIV negative can also take PrEP as we just discussed. That will decrease their risk of infection if exposed. And that decrease is upwards of 99% in clinical trials as well as sort of real world implementation studies that we've seen in the literature. Next slide.

Dr. Ojikutu: So why Truvada? You know when it first came out I think the first question was, "Well about the other drugs? Maybe one of them could work too." Well, and I'll tell you about some other studies that are going on to look for other agents that can be use in PrEP. But in general, Truvada was chosen that ... Because it's a good drug for this purpose. It's a combination of two effective HIV medications, Tenofovir and Emtricitabine, and they block HIV replication by inhibiting transcriptase, and they are taken, or Truvada as a dual ... One pill, dual drug medication is taken only once per day and that's great for convenience. It has a low rate of side effects, and I'll talk a little bit about those. And I think one of the most important things, and something that we're still looking for more information on, is that Truvada has pretty good penetration in both the genital and the rectal tissue.

Dr. Ojikutu: So I mentioned this issue about, what about other agents. So there are other agents that are under study now. We'll hear more about them. I think one of the things that people are waiting to hear more about is injectable PrEP since, of course, if you're taking this once a day, you're supposed to be taking according to clinical guidance every single day, could you give somebody a monthly injection that would make it easier for them to be adherent? So you know look

out for those results in the coming probably year or two. It takes a while for these clinical trials to really share data. Next slide.

Dr. Ojikutu: What about side effects? So there are two side effects that are incredibly important and well studied. In a series of studies of patients on Tenofovir a small decrease in bone mineral density was noted. But there hasn't been a consistent association with actual bone fracture. So that's important to know. The second is kidney toxicity. And when used as treatment for HIV infection, and certainly I see this in my practice, Tenofovir's been associated with acute and chronic kidney injury including small decreases in kidney function, and damage to the tubules which are part of the kidney that serve the filtration function of the kidney. In the efficacy studies of PrEP kidney toxicity was rare, and did not differ among participants randomly assigned to use the active drug or placebo.

Dr. Ojikutu: But, when you look at large numbers of studies with lots of people in them, it was found that basically Truvada did cause an increased risk of elevated creatine level which basically means decreased kidney function. But all these elevations were mild and they normalized after stopping PrEP. And this is, again, something that is seen in both HIV negative as well as HIV positive individuals. So because of this, for both HIV negative and HIV positive individuals who are taking Truvada, we check kidney function regularly. And for folks who come in who are interested in PrEP we check their kidney function prior to start, and we don't start if patients have evidence of significant kidney injury, and we certainly continue to check it during treatment.

Dr. Ojikutu: So I mentioned the other drugs that are undergoing clinical trial, and if you click on the last piece I just want to mention that in the real world, you know what I see on a daily basis when I'm treating patients, those on PrEP as well as positive patients, is that most of them who are taking Truvada, if they have any side effects at all, have nausea, headache, and occasionally weight loss. Okay, so nausea, headache, maybe some abdominal pain. But it's generally safe and well tolerated. Next slide.

Dr. Ojikutu: So Truvada was approved as PrEP for adults back in 2012, and now as PrEP in adolescents in 2018. And the new approval basically expands the indication for use for those adolescents who weight at least 77 pounds. And the approval was based on the adolescent trials network, or ATN 113 study, which looked at high risk adolescents between the ages of 15 and 17, and they found that the side effects of Truvada's PrEP were really comparable to those in adults. The most common were headache, abdominal pain, weight loss as I mentioned already. A few of the participants did have this decrease in bone mineral density, but it really wasn't significant. It certainly wasn't associated with fracture. And this was really the major concern. Both the bone density, both the kidney or the renal problem. And you know it was a major concern for providers that people were already prescribing PrEP to adolescents prior to this approval.

Dr. Ojikutu: The other thing I think is really important to note is that there's a lot of concern that still remains about the efficacy of PrEP being lower in high risk adolescents

not because it wouldn't work, but because adherence is generally lower in adolescents, and we see this in adolescents who are dealing with any chronic illness. I mean it's difficult to keep them adherent. Certainly I have some younger people in my practice that's very difficult to keep them retained and engaged in their care and treatment. So certainly that's an ongoing issue. So a lot of scale up work is necessary, and certainly research and hearing about what's happening in the real world is important for all of us to learn from.

Dr. Ojikutu: So I think I'll stop there and turn it over to the host.

Aisha M.: Thank you so much for that informative presentation, and I hope everyone understands a little bit better about how PrEP works, what are some of the clinical indications, and some of the other things that the providers work with their patients on. Not just their HIV but looking at bone density, kidney status as well. So now we're going to get interactive. And in just a second you will receive a link in the chat box. And so that link is to something called an idea board. And we have this question that you see on the screen, "What makes youth access to PrEP so challenging," and we want to hear from all of you.

Aisha M.: So this is a public board, and when you click on the link you will see two questions there. So we want to focus on the question that's on the left side of the board, and if you have an answer to this question, press the green plus sign, and that will bring up a little post it note and you can type in your answer right into the post it note. And you will also be able to see post it notes from other people. And if you see one that you like that someone else has written, go ahead and go to the right hand corner of that note and press the plus one or thumbs up button right there, and I'll read a few of them out on the screen.

Aisha M.: So now we're going to unmute all of our presenters so that they can answer this question based on what they have seen in their own work everyday. So let's just go ahead and follow up with Dr. Ojikutu about what makes youth access to PrEP so challenging.

Dr. Ojikutu: Well I'm really just going to stick to the clinical stuff because I know the other two presenters have expertise in regards to access in terms of insurance and navigation, and so on and so forth. From my perspective I mention what I think is the most difficult issue amongst youth. It's really adherence and engagement in care. Right now the CDC guidance is that individuals who are taking PrEP should be taking it on a daily basis. That's very challenging. I know in adults who I have on PrEP I see them start PrEP and maybe they'll stay on it for a little while. So I'll see them maybe the next three months, then maybe a sixth month after that. And then they're gone. The PrEP cascade is really steep. Is a steep fall.

Dr. Ojikutu: You start PrEP and then you basically have patients who just don't follow up. And either they're not taking it, or they're taking it sporadically which theoretically does decrease the efficacy. There have been some trials about taking PrEP around the time of sexual exposure. I think that's difficult for a lot of

patients if you don't know when you're going to have a sexual encounter necessarily, but it does work if you take it around a sexual encounter. But will adolescents do that? Or will they just stop taking it? Or will they just take one pill prior to having sex and think that that's going to help.

Dr. Ojikutu: So I'm concerned, and I'm looking forward to the research into other methods of PrEP and other drugs that can be used.

Sabrina C.: Hey everyone. This is Sabrina Cluesman down in Jacksonville, Florida JASMYN. A lot of what we see in Florida, we haven't expanded Medicaid so young people often don't have access to insurance. Especially if they aren't on their parents' insurance plan, and if their parents have rejected them or their families have rejected them at 18. So even at 18 without health insurance it makes it almost impossible to be able to afford getting quarterly labs done, and that makes a real barrier for young people. And especially if they're experiencing unstable housing or precarious employment it does make it really hard for them to maintain the daily usage.

Sabrina C.: And then the other piece, and I think some folks said this on the post it board, is that if young people say they are on their parents' insurance but they don't want their parents to know they're on PrEP, they run the risk of their parents finding out if they go ahead and use the health insurance because EOBs might be sent electronically or to the home. And then also, if their parents do find out they may ... That could lead to family rejection and withdrawal of support and withdrawal of health insurance in general.

Aisha M.: Definitely. We're seeing a lot of these comments on the board about lack of insurance, health insurance and access to care. We've got like 25 people who are saying that ... 25, 30 people are talking about that. And then other people did mention as well about not being able to talk to their parents, or wanting their parents to know that they are seeking this type of healthcare. Okay. So now we're going to move onto the section that is the presentation of strategy. And we're going to have first up, we're going to have Sabrina Cluesman of JASMYN in Jacksonville, Florida talk to us a little bit about how they are working with young people to help them gain access to PrEP and what some of the challenges are, the misconceptions, and the things that they've been able to overcome in the process.

Aisha M.: All right. Sabrina you're up next.

Sabrina C.: Hey everybody. So I'm with JASMYN, again in Jacksonville, Florida, and JASMYN is an agency that works with young people. Our mission is that we support and empower LGBTQ youth by creating safe space, providing health and wholeness services, and offering youth development opportunities while bringing people and resources together to promote equality and human rights. So it's a big mission, but what my role is here at JASMYN is to run our sexual health clinic, and all of our HIV testing services. And in 2016 we launched PrEP through our sexual health clinic. We are currently a department of health clinic and our

county has a satellite clinic here at JASMYN which they staffed with a nurse practitioner and they have to meet every week from four to eight o'clock on Thursday evening.

Sabrina C.: And so we've been running that clinic since 2007, and in 2016 we finally got the opportunity to launch PrEP for our clinic. We see a massive amount of young people even though it's only once a week for four hours. For instance last year we had 707 sign ins to our clinic for the year. And we currently have linked over 30 young people to PrEP either in our clinic or in the community. And so our project goal is specifically to reduce the number of young men who have sex with men and trans women being diagnosed with HIV by working directly with those who have the least access to PrEP.

Sabrina C.: So we specifically are working to make sure that young people who do not have insurance and don't have access are able to connect to PrEP, and we do this by continuing to develop a community plan that cultivates resources. We are working on creating education tools. We do webinars like these and trainings in the community, and we also have created a linkage process that will allow young people to access nPEP through our clinic and through partner clinics in the community, and we work to provide training to those clinic so that they're able to be LGBT inclusive and sex positive. We want to go to the next slide.

Sabrina C.: Some of our strategies include, again prioritizing those with the least access and the highest needs. So we know traditionally across the country the young people of color, young gay men of color, and trans women of color are some of the least ... Have the least amount of access to PrEP so we only have the ability to put a certain number of people on PrEP, and that's a funding constraint. And so we prioritize those spots for people who do not have access to health insurance, young people of color, gay men and trans women. And we do that because we know that the people with the least access are at the highest rate for HIV infection, and we feel that if we can provide and carve out space for them through our clinic that we'll be working to end the epidemic. We also offer PrEP education in all of our programs, services, and our social media.

Sabrina C.: So all of our staff are trained in at least basic information on PrEP and PrEP delivery, and all of our HIV testers are talking about PrEP with everyone that gets tested, and we do a PrEP eligibility screening, and we have a PrEP navigator who can meet with anyone whether or not they're in that high priority population, and connect them to PrEP in the community. Our second strategy is that we have our onsite clinic every week, and that we do daily HIV testing everyday here at JASMYN. And then we also are working to continue to develop community and medical partnerships in the [inaudible 00:25:03] As many of you may know, there is not as much access to resources. There's not as much access to PrEP.

Sabrina C.: And so we've really been ... At the local LGBT agency we've be leading that conversation with our health department and with the other clinics in our community. And we've been doing ... In the past two years we've done several

trainings in the community, and we continue to develop partnerships with other providers, and looking at creating a PrEP taskforce locally so that we can get interested providers together meeting regularly to continue to lead a conversation and explore the future sustainability models. So that's what I got. Thank you.

Aisha M.: All right. Thank you so much Sabrina for that information. And it's not Q&A time, but I wanted to ask you one question to make sure we clarify something. So one of the questions we got so far was about what is PEP. So PEP is postexposure prophylaxis, which means taking antiretroviral medicine after being potentially exposed to HIV to prevent becoming infected. And on your slide you mentioned nPEP. So can you discuss a little bit about what nPEP is?

Sabrina C.: So nPEP, the N just stands for nonoccupational. So PEP postexposure medicine has been around for a long time in the medical community for potential needle sticks. The N stands for nonoccupational for folks that are potentially exposed through other methods like sex or sharing of needles. And so what we do is make sure that young people, if they come to us and they let us know potentially if they've experienced a sexual assault, if a condom broke with a positive partner, or they've just recently had sex with somebody who they just found out was positive for instance, then we can ... If you get someone on PEP within 72 hours of potential exposure, it greatly reduces the risk that they'll become infected. And nPEP is a 28 day regimen, and often people can transfer from nPEP straight to PrEP right after that 28 days.

Aisha M.: Thank you for clarifying. Okay. We're going to move onto our next presentation. That is from Aruna Kushnakumar of Callen-Lorde in New York City, and she's going to tell us about their experience with PrEP in New York City.

Aruna K.: Good afternoon everyone. So my name is Aruna, and I'm the director of the HOTT program. The Health Outreach to Teens program at Callen-Lorde community health center. So the HOTT program is a welcoming, non-judgemental, confidential program designed to specifically meet the needs of LGBTQ youth around health and wellness. We provide services to uninsured patients as well as insured patients, and I'll talk a little bit more about what that looks like in New York because it's quite different than Jacksonville. And we are the youth clinic of Callen-Lorde community health center which is a federally qualified health clinic in Manhattan in the Bronx, and in 2019 we'll be expanding to Brooklyn.

Aruna K.: So in terms of PrEP we have actually seen quite a few young people over the past few years start PrEP, and I think one of the biggest challenges is of course adherence and retention. The challenge is less so about insurance in New York. For us in 2017, out of 2700 patients, 425 patients access PrEP. 30% of them identified as trans or gender non binary. Nine of those youth were under 18 years old, and we're seeing that number increase already. Now as Dr. Bisola pointed out, as of May 15th this year the FDA did approve Truvada for minors. Now in New York City, and New York state, in April 2017 there was expansion of

minor consent for HIV treatment access and prevention which means that in New York state, minors can not only access HIV treatment but they can also access any preventative services include PrEP and tests.

Aruna K.: So the science has just caught up with the law in New York state, and so access will change and increase significantly. For us, some of the program strategies ... Can you go to the next slide? First of all, in terms of accessing any PrEP services it looks the same for uninsured patients versus insured patients. The only difference is one step where an uninsured patient would meet with a PrEP specialist who completes all documentation for any assistance programs through the PrEP math program, or the Gilead assistance program. After that, a patient will have their initial PrEP visit where there's a risk assessment done, HIV and STI screenings, and baseline labs. This is done with a medical provider, and it's available everyday of the week in New York.

Aruna K.: The next step will be a two week visit right after the initial visit, and usually that's done by the nursing staff or a case manager just to assess barriers and adherence. After that, there's a one month follow up that's performed by the same medical provider, and one of the things we find is provider directed counseling is really key to having young people adhere to PrEP. Having that relationship with their medical provider, and seeing them frequently, especially in the first three months, really changes their own investment in the process. So PrEP education is offered to every patient and then followup is almost always done by a medical provider. After that step, there's routine three month followup visits, and that just continues as is. Next slide.

Aruna K.: So in terms of our program strategies, we have an open access walk-in PrEP clinic where young people can get a same day prescription. We also have a pharmacy on site which reduces a barrier as well. And they see a prevention counselor and a medical provider in the same day. This also separates our sexual health from primary care so that anyone can walk in and just access PrEP, and they don't have to complete a full intake and become a patient. The next strategy we have is we have a mobile health van which goes around New York City to the five boroughs and provides low threshold services such as urgent care, sexual health screenings, information on PrEP, and a range of other sexual health needs. We find that going into the community where we know young people are is the best and most effective way to get young people to be invested in their health, but also destigmatize health services.

Aruna K.: So we partner with various community organizations, and then we also go to parks and different areas where we know young people are to give them information in their communities where they feel safe. And finally, we provide creative media. We find that that's the most effective way in getting young people interested in PrEP services. So we have fun, youth friendly video series. It's a diverse cast, and young people who are patients are involved in the process of creating the videos and also being a part of the cast. One of the most important things that we found is having creative media that's reflective of our patient population, where they see themselves in our media and our campaigns

is one of the most effective ways to get them interested in the services we provide. And so that's it for me. And so we have questions. Thank you.

Aisha M.: Thank you so much Aruna for sharing your exact process of how this works, and also these three strategies. Especially the piece around creative media and thinking about addressing stigma. Okay. Well we're going to jump into our second question. And it is right on our idea board, which you guys have already answered it. So I don't even have to ask it, but I will. What misconceptions do youth have about PrEP? And some of the things that you are saying go right in line with why it's so challenging. So the fact that [inaudible 00:33:44] is expensive. But then there's other misconceptions about who PrEP is for, and one of those misconceptions that someone wrote is that it's only for gay men. That's the only people who need.

Aisha M.: And so some other young people may not properly assess their own risk for needing it because they think that because they know people only through school and community, that that makes them safe. Another misconception is that they will not need a condom. And we didn't get into this as much in this presentation, but yes we need to remind young people that PrEP is for HIV prevention, and they do need to take other steps for preventing other STDs as well as pregnancy if they are having sex that will lead to pregnancy.

Aisha M.: So now I want to jump right back to our three presenters and have them answer this question themselves. So from the work that you're doing, what misconceptions do you believe that youth may have about PrEP that we need to address as professionals?

Aruna K.: Hey. This is Aruna again. So I just wanted to address that first myth around PrEP being for gay men. When we started providing PrEP services about five years ago, we found that that was one of the biggest misconceptions among our patients. And so we did utilize our social media and creative media projects to really emphasize that it's not just for gay men, and I think that's why we saw the increase and saw that 30% now of patients identify as trans or gender non binary in terms of who we are seeing. I think one of the most effective things we've had is to have very specific information around how hormones also are not impacted by PrEP. That was one of the other misconceptions, and having information that is specifically for our trans patients around PrEP.

Aisha M.: Thank you. Sabrina, Bisola, would you like to chime in about misconceptions?

Sabrina C.: Yeah. One misconception that we've heard from our young people that I don't see on the board yet, unless I missed it, is that if I become positive, then antiretroviral treatment won't work for me if I take PrEP. So we hear that a lot. We have a really high rate of positivity in our area unfortunately. So a lot of our young people have tons of friends that are HIV positive, and they're worried to take PrEP because then they think that HIV medicine won't work for them. And so we do a lot of education around that.

- Sabrina C.: Also that PrEP is only needed for people that bottom for anal sex. We hear that a lot and there a lot of mistrust of the medical community that our young people experience, and it's kind of passed down through generation to generation. And so many of our young people have been told not to trust medical providers, and so we have to work to build relationship with those young people so that they can feel safe and feel comfortable.
- Dr. Ojikutu: So this is Bisola. I just wanted to add to that. I think that the issue about mistrust is really important. It's definitely something that I see and that we studied, and published on the issue of mistrust particularly in communities of color. But I want to go back to the issue of who PrEP is for. Yes, obviously it's not just for gay men, and certainly it's also not just for trans individuals. Certainly cisgender women who are at high risk, who had bacterial, sexually transmitted infections, who have a high number of partners. I see a number of women who are engaged in transactional sex and have a history of being consistent or no condom use.
- Dr. Ojikutu: We certainly in this country have seen a decrease in infections, new infections amongst women. Cisgender women. But there has been some changes, or shifts in the surveillance data showing us that women are certainly still at risk for HIV, and those numbers may go in the opposite direction, and unfortunately that tends to happen when we shift focus off on groups. And going back to the issue of risk and who is at risk, amongst my gay men, male patients who come in for PrEP, sometimes their first question is, "Well do I really need this? Am I really at risk?" And I think that even if a patient or client comes in and says that they are having sex with other men, sometimes they still don't necessarily believe that they are truly at risk for HIV.
- Dr. Ojikutu: I think the concern around HIV has diminished in the community in general. The other thing that goes along with this issue of mistrust is questions about side effects. So we did a national survey on HIV within the black community, except it was a probability survey. So it was a random sample of individuals across the country, and though we didn't include adolescents, there were younger people in this study. Individuals who were 18 or older. And one of the primary issues that they had was that they did believe that there were significant side effects to take Truvada, and that would stop them from using it even if they were at risk.
- Dr. Ojikutu: And understanding the real risk, and data that I've presented, and information that I've presented, is very important when talking to patients because they don't want to take something. Remember these are the patients walking in who probably are on no medication whatsoever, and now you're telling them to take a pill, and that pill does have some risk, and kind of putting that in perspective of the risk of HIV. So I do think that there are definitely issues that we have to overcome and a lot of education and coming up with culturally appropriate strategies in terms of increasing uptake of preexposure prophylaxis.

Aisha M.: All right, thank you guys so much for all of that detailed information because I do think just because there might be a solution that is available from a clinical perspective, that doesn't mean in the minds of those we serve they feel that way about it and they're ready to uptake and accept it. So we do have to think about some of those barriers before we can kind of say we have a solution to an issue.

Aisha M.: So now we're going to turn to audience questions, and we have lots of them coming in. And in the background we've been checking with our panelists about some of these questions, and so we have a few that are in the queue here. So if you would like to ask a question, please chat to the host, make sure you use the dropdown for the host. And the host will put your question in the queue to be answered, and we'll try to answer as many questions as we can in the time that we have allotted.

Aisha M.: So my first question is for Sabrina. Does JASMYN also serve young trans men who have sex with men?

Sabrina C.: Yes. We actually ... We do serve a lot of young trans men at our agency, and we don't have a high population of trans men that have sex with men, but we have some trans men that have sex with men that have come through our clinic, and we also offer PrEP to them.

Aisha M.: All right thank you. So this question is for Aruna. Aruna you mentioned patient assistance programs. So can you say a little bit about patient assistance programs for those under the age of 18? How easy or difficult is it for those youth to use those programs?

Aruna K.: Sure. So there are two different assistance programs that we work with. One is to cover the cost of the medical visits, which is through New York state, and then the other [inaudible 00:42:19] cost of the actual medication which is through Gilead assistance program. And I often emphasize that we're really fortunate in New York to have these systems in place. At the same time, it takes a lot of advocacy and we still have a lot of challenges working with those assistance programs and also insurance companies in general to make sure that their privacy clauses, and that our patients are not being billed or that bills are not getting sent home.

Aruna K.: And so we have quite a robust referral system and we have a really strong case management system that addresses a lot of the issues with insurance companies and the assistance programs, and they have connections in those organizations. And I think that's one of the things that I would really emphasize. Putting the onus on the organization to do all of that navigation, rather than on the patient because that's what scares young people, and that's what prevents them from actually accessing care because if they're afraid that their guardians are going to find out, or they're afraid that they're going to get a bill later on.

Aisha M.: Right, right right. And I actually have a follow up question from someone else on some other issue around the insurance. And so you stated that in your context, in New York, insurance is not as big of a barrier for patients regarding prep, but one of your colleagues in New York is concerned about meeting for prior approval from insurance companies and EOBs going home. So they're interested in how you work that out with insurance companies around the prior approvals and other things to make it easy for young people to access PrEP, for those who have insurance.

Aruna K.: Sure. So what we have done is we've developed relationships with each insurance company that really is specialized around PrEP access. And so our case managers get on the phone with them as soon as they know that there is a patient who's interested in PrEP, and they make sure that we understand what the EOBs are going to look like, and we're able to prepare young people. What we often do also is have bills sent to our clinic rather than to their home addresses. So that's one way we get around that. But it's challenging because every insurance company is very different, and works differently. So it's also about knowing what the EOBs are going to look like, and which insurance companies need prior authorization.

Aruna K.: So for the people in New York, if they want to reach out to me directly I can give them sort of a cheat sheet of how we run through different insurance companies.

Aisha M.: That's great Aruna. Thank you so much for offering that because a lot of this is peer to peer work that you know is not something you can find a website, how to do this. There's a lot of creativity that happens and what we think is so important in our project, what works with youth HIV is making sure that people who are working in this space can connect with one another and share strategies because we have our evidence base, but when it comes to work on the ground, learning from your peers is so important. So thank you for offering to share your cheat.

Aruna K.: Yeah.

Aisha M.: This next question is for Sabrina, and maybe Aruna you might want to chime in on this as well. But what have you found to be an effective way to break down stigma around HIV to get people to come in and get tested, and get treatment and screening, or even PrEP?

Sabrina C.: Well one of the things that we do ... This is Sabrina from JASMYN. Is we are pretty active on social media. It's one of our strategies. So we have a really fun Instagram page, and it used to be that it was a little bit more monitored by our administrative staff, and I found the leeway to let my full-time HIV testers that are also in the population that we serve have taken control of our Instagram page. And it's gotten super fun. It's very sex positive. It's very queer. And I think that that's one way that we've been able to break down stigma, and we also talk

about testing and we talk about PrEP, and we talk about HIV in all of our programs and services in our drop in center.

Sabrina C.: And so it's part of normal conversation with the young people that we serve. And you know we have ... I think we had over 1000 different young people here last year throughout programs and services. And so as we make it common in our center, it becomes more common in their conversations with their peers.

Aruna K.: Yeah. And to echo what Sabrina said, I think we don't just focus on HIV testing, or just focus on PrEP. While those are services that are really accessible, and they're walk in based, we make sure that we're talking about sexual health, we're talking about HIV, and STIs in every interaction a patient has when they walk in the door. And so it's normalized and it's destigmatized, and we found that actually about 50% of patients come in specifically for PrEP who had started PrEP. But another 50% it really takes a long time for them to trust their provider and make an informed decision around whether or not that's what they are interested in. And so I think building a relationship is so important.

Aruna K.: And then on the other side of things, I think we do a lot of outreach. We do a lot of engagement in schools, in shelters, in foster care agencies, so that people know that we are a site where you can go if that's something that you're interested in.

Aisha M.: All right. Thank you so much for that. And Aruna, I have another question for you. Are the youth friendly PrEP video series ... Is the youth friendly PrEP video series available to the public?

Aruna K.: Yes it is. You can check it out on YouTube under the Callen-Lorde subscription, or you can go straight to our website, and it's all available there. And feel free to use them. There's a whole series.

Aisha M.: Yes thank you. And we will post links to the YouTube page on the archive page for this webinar where you will also be able to find the recording and the slides. All right let's see. So Bisola, a couple questions for you that you can touch on and maybe can elaborate. Can you first talk a little bit about are there significant side effects to PrEP?

Dr. Ojikutu: Right. So that's an important question. As I mentioned that's one of the reasons why people oftentimes don't present for PrEP. They're worried about that. So I mentioned that in general, in the clinical trials that have been published, the most common side effects have been moderate. Meaning like nausea, stomach ache, head ache, and maybe a bit of weight loss over time. And that's what I also see clinically in my own practice.

Dr. Ojikutu: But there are two side effects that we are paying a lot of attention to, and there's been a lot of research focused in on them. One being loss of bone mineral density which is moderate, and has been noted in a number of studies,

and was noted in the FDA trial network study that led to the FDA approval of PrEP for adolescents, and it wasn't associated with any fracture. So it is something that we do see and do pay attention to. And the the other one is kidney dysfunction and what we do is way screen patients prior to starting PrEP and that's one of the first things we do in the workup is we look for patients who already have some elements of kidney dysfunction, and we don't prescribe PrEP to those individuals.

Dr. Ojikutu: The other thing is that we monitor patients because in the studies there has been noted a small increase in creatine which is an indicator of kidney dysfunction in patients who are on Tenofovir. And that's something that I have seen and certainly monitored for over time, and usually what happens is you stop the Tenofovir and the kidney function recovers. So the creatine goes back down. I would add, that again, that let's keep our eye for result of new trials that are out there looking for other medications. There are certainly some in the pipeline that may be very good and may be useful for PrEP in the future that don't have these adverse side effects.

Aisha M.: Thank you Bisola. And to all of the people out there in webinar land, we are going to put together a frequently asked questions input in the presenters because we're getting a ton of great questions, and I don't think we'll be able to get to them. But I'll continue with Bisola on the clinical track, and I'm going to read this question as is. I don't quite understand it because I'm a health educator and not a clinician.

Aisha M.: But the question is, "Besides checking CHEM-7 every three months, do you recommend any other labs while a patient is on Truvada, and how often do you check for HIV?"

Dr. Ojikutu: So you know I tend to follow the guidelines. You may want to deviate slightly given your patient population or whatever it is that the patient may be going through or dealing with. You want to have a followup visit every three months, and during that three month visit you get an HIV test. So HIV antibody preferably four generation testing. At that time you also want to assess for side effects. You certainly want to ask whether or not they're actually taking it. And then you also want to check for STIs because that's the other thing is that this is a great opportunity to test and treat, and be proactive about catching gonorrhea, chlamydia, syphilis, as well as acute Hep-C which are a problem in a lot of our patients.

Dr. Ojikutu: And then at three months and every six months thereafter, you do want to assess the renal function because that's the CHEM-7 that's being referred. The BUN and creatine. So interestingly, I think the CDC guidelines do say that every six months you test for bacterial STIs. I actually oftentimes check more often just because given ... You should know your patients, or your clients, and kind of screen them and see how risky their behaviors are, and then make your own judgements in terms of those tests. The other thing is that before you start you also want to document their Hepatitis B status.

Dr. Ojikutu: Okay, and now the reason why you do this is because you want to know if your patient is living with untreated active Hepatitis C because those, Tenofovir and Emtricitabine, do have some activity against Hepatitis B and what will happen if they stopped Truvada randomly, which happens all the time with people on PrEP, they may have acute exacerbation of Hepatitis B. I've seen this in both patients living with HIV and patients on ... Well not patients on PrEP to be honest with you because many people are astute enough to be testing for that. But patients living with HIV, maybe they weren't tested for Hepatitis B then they stopped whatever combination they're on that included Truvada or you know included one of the two agents that I mentioned. And then they end up with an acute exacerbation of Hepatitis B.

Dr. Ojikutu: Now that's not to say the patients living with Hepatitis C should not be on Truvada because I do have actually two patients who are living with Hepatitis B who are PrEP and they're on it because they're on another agent. Their second agent, or a third depending on how you want to look at Truvada, that's treating the Hepatitis B and then keeping it under control, and then they're also on something for PrEP.

Aisha M.: All right thank you. So as you said, it's about the relationship. Knowing what your client needs and coming up with the best regiment that works for them. So Bisola we're just going to keep with you. Just got a couple of questions more in the clinical realm, but I think most people would also appreciate this answer, especially when we're talking about use. And does PrEP have any side effects on women taking hormonal birth control, or being on any birth control method?

Dr. Ojikutu: So that's a very good question. So Truvada is not one of the drugs that we are particularly concerned about in terms of looking at hormonal birth control. Now with some antiretroviral therapy as you know, or probably know if you're asking this question, there has been found that there are interactions between the antiretroviral therapy and say OCPs, oral contraceptive medications. It decreases the efficacy. But Truvada I do not ... There's no known ... There's no impact that I am aware of in terms of OCPs. So now. And I want to emphasize though also that as one of our presenters mentioned, certainly people can be on hormones and Truvada if they're transgender.

Aisha M.: Okay. Thank you. Thank you for that clarification because I know a lot of people were curious about that one. So I'm going to take just one or two more questions, and again as I said we've got a lot of questions so we'll try to answer a lot of them afterwards and put them into a frequently asked questions [inaudible 00:56:09] and post that with the recording and the slides, and the idea board. But let's talk about parental consent for minors for a second.

Aisha M.: And especially for Aruna, and for Sabrina, do you have any success stories for getting parental consent for getting on PrEP because it's required in some states?

Sabrina C.: This is Sabrina at JASMYN, and we have currently not been able to get parental consent for anyone. And we've been working on it for the past year. And now with the FDA approval for minors we're hoping that we may be able to be more successful because maybe parents will feel safer about their young person taking PrEP, but most of our young people are detached from their families, and the ones that are connected to their families that are at high risk for HIV, their parents have a great mistrust of the medical system, and have been adamant about not letting their [inaudible 00:57:17]

Aruna K.: This is Aruna. We actually ... We have had two success stories that I can think of in the past year, and I think both of them were parents who were already really engaged in their child's health. They were both for young people who were about 17 years old, but had been patients of ours starting at about 15 [inaudible 00:57:46] So I think that's what [inaudible 00:57:50]

Aisha M.: Thank you for that Aruna. Just to talk about, you know, parents being active in the life of their young people around everything, and not just around sexual health, but also sexual health. So I'm going to give this last question to you Aruna. What affected retention rate among the youth in the HOTT program? Was it access? Insurance? Low levels of stigma? Health issues?

Aruna K.: So for us I think the biggest thing that we've seen ... The biggest thing we see is actually challenged around insurance and retention. So I think young people's relationship to risk shifts. So they might start PrEP as a direct response to the sexual activities they're engaging in, but then they stop when their relationships change. So first of all, a lot of young people, about 23% of the patients we saw who initiated PrEP had started after completing a cycle of PEP, which I think is not uncommon. And as it means that they're accessing care at a time when they perceive as high risk.

Aruna K.: So the other thing is other environmental and structural factors like housing issues, family conflict, schoolwork, immigration. All of those things impact their ability to come for follow up appointments, refilling their prescription, but also prioritizing other needs in their life. So I think one of the things that we find is we really need to reframe our understanding of prevention. Young people are generally healthy, and so it's hard to convince a young person that they're invested in taking a pill everyday for the rest of their lives, which seems unreasonable and it seems difficult for them to do, and for adults too.

Aruna K.: So I think developmentally young people are thinking about the here and now and the immediate consequences of their actions, and so you know as Dr. Bisola said, if there are different ways and methods of taking PrEP I think that would really change the way young people think about their health. But yeah, I think the biggest issue is just changing circumstances and changing their relationship to their health, and also their relationship to risk and sex.

Aisha M.: Thank so much for that. That is very important to think about. The psychology and how you perceive risk, and how that affects their behavior. So I want to

thank all of our panelists. Dr. Bisola Ojikutu, Sabrina Cluesman, and Aruna Krishnakumar for helping us today to understand PrEP a little bit better, and how that impacts access to PrEP for youth. For everyone listening to this webinar, please [inaudible 01:00:40] at WhatWorksInYouthHIV.org within a week to get slides, to get the recording. We will post some frequently asked questions, and we will post a social media link to the presenters that have them and their organizations. We saw that as a request as well.

Aisha M.: And please check your chat box right now for your evaluation link, and definitely check out our next webinar that is going to be happening in June about social media. Some of you are on this webinar because you have followed us on social media and seen our little quiz we did around PrEP. So we're going to break that down and talk to you about how to use innovative ways to increase online engagement, because we don't want you to waste your content. We want your content to soar and be as useful as possible. So please join us on June 19th from 2:00 to 3:30 PM and we're going to go really in depth on how you can use some innovative ways to increase online engagement with your social media content.

Aisha M.: Thank you.