TRANSCRIPT
Online Event

“Ending the AIDS Pandemic: What Still Needs to be Done?”

DATE
Tuesday, December 7, 2021 at 3:00 p.m. ET

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Hello. I’m Jeff Sturchio, senior associate at the Global Health Policy Center here at CSIS, and I’d like to welcome you all to today’s discussion on “Ending the AIDS Pandemic: What Still Needs to be Done.”

Forty years into the HIV/AIDS pandemic, progress toward the goal of eliminating AIDS is mixed. On World AIDS Day on December 1st, UNAIDS reported that there were 37.7 million people living with HIV/AIDS of whom an estimated 27.5 million people were receiving antiretroviral treatment.

That was an impressive increase from the 7.8 million who were on treatment in 2010. New infections had declined by 31 percent between 2010 and 2020, and AIDS-related deaths declined by 47 percent during the same period.

But there are still over 1.5 million infections per year globally – that’s about 4,000 a day – and some 680,000 deaths. Prevention rates are not falling fast enough to stop the pandemic, and infections are actually rising in some countries and regions and among certain key populations.

UNAIDS also reports that six in seven new HIV infections among adolescents in sub-Saharan Africa are occurring among adolescent girls. Gay men and other men who have sex with men, sex workers, and people who use drugs face a 25 to 35 times greater risk of acquiring HIV worldwide.

In the United States, the U.S. government adopted an ambitious plan in 2019 to end the HIV epidemic with goals of reducing new HIV infections by 75 percent in 2025 and 90 percent in 2030. But new data from the CDC show, for example, that the rate of new infections among Black and Hispanic, Latino, gay, and bisexual men did not decline over the past decade.

The global targets adopted in 2016 were not reached by 2020 despite ambitious efforts to address the challenges of HIV/AIDS, nor were the U.S. goals for EHE – that is, ending the HIV epidemic – on track. Of course, the disruptions caused by COVID-19 over the past 20 months explain part of the shortfall in delivery of HIV prevention and treatment services. But what else explains why the HIV response seems to have been stalled?

As Winnie Byanyima, executive director of UNAIDS, has said, quote, “To beat a pandemic, you have to confront the inequalities that drive it, inequalities in wealth and power and status and in access to services, stigma and denial, structural racism, discrimination against adolescent girls and young women, as well as bias and barriers to access for other vulnerable and key populations, social determinants of health like poverty, housing, and education, these are all persistent sources of inequalities that have an impact on efforts to fight HIV/AIDS.”
The renewed U.S. HIV/AIDS strategy also notes that structural inequalities have resulted in racial and ethnic health disparities that are severe, far reaching, and unacceptable. The solutions to these problems will require renewed efforts beyond technical interventions, such as better prevention tools, diagnostics, and medicines. It will require efforts that place affected communities at the center of the public health response.

So in our panel discussion today we’ll explore these issues in more detail from both the U.S. and global perspectives. The discussion will focus on how inequalities are the drivers of HIV transmission and how they still affect vulnerable populations disproportionately in countries rich and poor alike.

It’s a pleasure to welcome my fellow panelists. Here on the stage with me at CSIS are Kate McManus, assistant professor of medicine, infectious diseases and international health at the University of Virginia, and Greg Millett, the vice president and director of public policy at amfAR. And joining us virtually is Wafaa El-Sadr, founder and director of ICAP at Columbia University’s Mailman School of Public Health, and she’s joining us from New York.

So welcome to all three of you and thanks for participating.

So let’s start with Greg. Greg, what’s the status of the HIV epidemic in the U.S. today? What’s driving it? What are the key sources of risk and vulnerability and, you know, and how do those make it challenging to achieve the EHE goals?

Greg Millett: Great. Well, thank you, Jeff, thank you, CSIS, for the invitation to speak today.

When you take a look at the U.S. epidemic, we know that there are 1.1 million people in the U.S. who are living with HIV with 35,000 new infections that took place in 2019 alone, and that was an 8 percent decrease from 2015.

However, an enduring hallmark of the HIV epidemic globally as well as in the U.S. is that HIV infection risk, morbidity, and mortality are not equally shared by all, and what I mean by that is to take a look here at this first slide that I have prepared. There we go.

This is a slide from Patrick Sullivan that he published in The Lancet earlier this year where they’re looking at HIV disparities in the U.S. by different risk groups, and starting from right to left, you can see that the greatest disparities are among LGBT populations, particularly men who have sex with men versus heterosexuals, followed by transgender women as well as transgender men, and then you also have disparities from people who inject drugs versus heterosexuals, and then the racial and ethnic disparities that we see in the U.S., and then that’s followed by the geographic disparity.
So we have a slew of disparities in the U.S. that are really complicating our efforts to address HIV, and these disparities, particularly racial disparities, are enduring and have been evident in the U.S. epidemic for decades.

Unfortunately, many of these disparities are also evident for other diseases such as asthma, cancer, diabetes, and other conditions, and the latest example, of course, is COVID-19. Although communities of color accounted for the lion’s share of HIV cases only 14 years into the epidemic, the disproportionate impact of COVID-19 in communities of colors was immediate.

This is a slide from May of last year where you could see that in nearly every state that’s displayed on this slide that Latino proportions of a population in a state were much smaller than COVID-19 diagnoses. This is very early on in the pandemic, and this is not just something that we’ve seen among Latinos. We’ve seen some similar issues in terms of diagnoses per 100,000 for Native Americans, where American tribal nations really comprise the greatest proportion of COVID-19 diagnoses compared to even the most affected states like New Jersey and New York.

And similarly, my colleagues and I published a paper where we looked at those counties where 13 percent or more were African American and found that they accounted for 50 percent of COVID-19 cases and 60 percent of COVID-19 deaths by April of last year. Moreover, these disparities are not isolated from one another. We have these interrelated overlapping epidemics that are taking place.

We’ve already seen a rise in opioid cases in the U.S. during the COVID-19 era, a hundred thousand COVID deaths – rather, opioid deaths that have taken place during COVID-19, and a lot of these are some of the stressors that are associated with the COVID-19 epidemic.

And there’s also a racial component as well. For instance, here in Washington, D.C., we’ve witnessed an increase in overdoses with 84 percent of those opioid overdoses taking place among Black residents. Similarly, we see greater COVID-19 diagnoses among communities of color living with HIV.

When you take a look at these data here, this is from a paper that was published in AIDS of a clinic in Massachusetts, and one thing that you can see rather clearly is that even though the clinic is 50 percent White of people living with HIV, when you take a look at COVID-19 diagnoses, COVID-19 diagnoses were primarily among Latino as well as Black residents of the clinic and more so than their share, proportion, of the clinic. So even among
people living with HIV, we’re seeing these racial differences in terms of COVID-19.

Now, disappointingly, and getting to what you were talking about, Jeff, some of these common narratives for greater COVID-19 rates were the same disproven “blame the victim” theories that we’ve seen for HIV. Just as communities of colors have greater rates of HIV despite similar or lower risk behaviors, we’re seeing the same for COVID-19 where there are greater rates of COVID-19 despite the fact that underlying health conditions are not explaining these greater rates.

So what is explaining these greater rates of HIV in communities of color? Well, the first is health care, and I know that Kate is going to go into this quite a bit, but African Americans are more likely to be tested for HIV but less likely to be diagnosed early in their infection, to have access to ART or to be virally suppressed.

HIV-negative African Americans and Latinos are also less likely to have access to preexposure prophylaxis, despite being at greater risk for HIV, and part of the problem here is that communities of color are less likely to have access to new innovations such as COVID-19 testing or vaccines, et cetera, which complicate their risk.

Traveling is another issue that we see in communities of color. We see here in Washington, D.C., that if you’re HIV positive and you travel five or more miles, that’s associated with a 70 percent drop in retention and it’s also associated with a 70 percent drop in viral suppression.

And then last, of course, is Medicaid expansion. In most states that have not expanded Medicaid, or, unfortunately, in the South, where most African Americans also live, Medicaid expansion is associated with greater HIV testing, PrEP use, sustained viral suppression, as well as a decrease in HIV diagnoses.

Now, there are many other factors that are associated with why we see communities of color at greater risk for HIV in the U.S., including lower income, greater rates of homelessness, languages, such as monolingual Spanish speakers, as well as residential segregation.

And this was a slide that colleagues and I prepared for an analysis that we published last year just looking at COVID-19 in residential segregation where there are greater rates of COVID-19 in those places of the U.S. where there are more communities of color as compared to Whites in the U.S., and you find exactly the same pattern for HIV as well.
So this is something that is enduring, it’s something that we see over and over again, and, unfortunately, a part of it is driven by policy. And when you take a look at, you know, the policymakers in the U.S., particularly in the House of Representatives, even though the U.S. is 60 percent White, the House of Representatives is 78 percent White. In the Senate, it’s 90 percent White. And to complicate matters, of course, is the fact that it’s overwhelmingly male and overwhelmingly wealthy.

This is really not representative of the U.S., and if these individuals are the ones who are creating policies, sometimes those policies are not fitting for those communities who are at risk for various diseases.

So all of this, of course, complicates our efforts to end the HIV epidemic, and this is actually part of a modeling analysis that colleagues did where they’re looking at various cities where we can end HIV, and what they, basically, find is that we’re going to have epidemic control among White Americans in each one of these cities before we have them for Black Americans or for Latino Americans, and these estimates were done before COVID-19.

And what added weight to these estimates as well was that CDC released data for the fortieth anniversary of the HIV pandemic where they found that the pandemic has grown progressively Black and Brown and far less among Whites. There were 56 percent new infections among Whites in 1981. That went down to 25 percent of infections among Whites by 2019.

So a confluence of social determinants of health as well as bad policies place certain communities at greater risk for HIV and we need to address these policies head on, and the National HIV/AIDS Strategy released by the White House is a step in that direction.

Dr. Sturchio: Great. Well, that gets us off to a good start, and I – and, actually, you’ve given a terrific lead-in to the question that I wanted to ask Kate, because you’re talking about how it’s not just social determinants of health that explain some of these disparities but also the unintended consequences of HIV policies are also having an impact on the differential access of people to care and treatment as well as prevention resources.

So Kate, as Greg has now indicated, you know, the U.S. health-care system itself with its patchwork system of uneven coverage and access to HIV prevention and treatment services is preventing – excuse me, presenting substantial barriers to access to care and treatment for key populations around the U.S. And, of course, this uneven playing field interacts with inequalities that lead to disparities in health care and health status, factors that Greg also mentioned like housing, poverty, education, structural racism, stigma, and discrimination.
So let me just ask you to share with us some insights or perspectives from your own experience as a physician at a Ryan White Care Clinic at the University of Virginia. You know, how do these issues present themselves among the patients who you treat and what are the ways that you and your colleagues are trying to address to level the playing field, to help make access to care and treatment more equitable for people who, you know, whatever – wherever they live, wherever they work, whatever ethnicity and race they are, you know, they’re all just people living with HIV and they should have equal access to – equitable access to care and treatment?

Kathleen McManus:

Yeah. Well, thank you for that great opening and that really insightful question. So I think practicing in a Ryan White Clinic I feel very fortunate to be able to practice in that sort of setting where it’s really a comprehensive medical home for patients. We really can address the whole person, I really think. I wish more people could actually get health care in that kind of a setting.

But often, when people come to clinic, I’m actually the least important person that they see. So we can figure out their HIV medication. You know, thanks to all the wonderful advancements in science there are great options for HIV treatment. But it’s really the logistics of getting them that treatment and then their social determinants of health that take up the bulk of the visit.

So I’m fortunate to work with a lot of wonderful colleagues there. So we have psychologists, psychiatrists, community health workers, case managers, peer coaches, substance use counselors, and we really work as a team to address all these sorts of issues. And I would say a lot of the issues that come up are housing, unemployment, food insecurity, incarceration, racism, structural and interpersonal, discrimination, mental health issues, substance use, and many of these issues have been exacerbated by COVID-19, especially the unemployment and food insecurity.

So very early on when COVID-19 hit a lot of our patients lost jobs or had hours reduced. People were very nervous to go to the food store because we didn’t know much about COVID-19. We actually worked with a nutritionist at the clinic to actually figure out what should – what kind of food should we get for patients and got two weeks of food in boxes and had community health workers actually go and deliver it to patients.

We also saw huge increases in need for help with paying for housing and paying for utilities, and, fortunately, we were able to rise to the occasion and meet those needs, based on clinic funds and then donations to the clinic as well.

But, really, just on an everyday basis, people come in and they’re struggling with all these basic necessities, and if you don’t know where your housing is
going to be or you don’t know where your next meal is coming from, you’re trying to take care of children, you know, taking your HIV medication might not be your top priority. And so we really work with people to make sure that we try to meet some of those needs so that they can then focus on their health and think about taking that HIV medication every single day.

In terms of the patchwork nature of our system, it was really working in the HIV clinic as a resident that kind of inspired me to study this sort of thing. I was sitting there in clinic knowing that we have all these amazing advancements and great HIV treatment, but I could not actually get the medication to the patient or the patient couldn’t actually get the medication. And I was thinking, you know, what is this, you know, and also at the population level, why haven’t we seen a larger decrease in the number of new HIV infections.

We have PrEP, which can prevent HIV. We have wonderful HIV treatments. We know about U=U, or undetectable=untransmittable. And so I really felt frustrated and blocked by these structural and policy barriers that I couldn’t deliver the type of health care that I wanted because of these issues. And what I was feeling was this difference or this gap between the clinical trials and, you know, what we see in the real world when we're actually sitting there face to face with someone who needs this medication.

So it’s really inspired the type of work that we’ve done and the research that we've done and I’ll give you a few examples of the real-world work that we’ve looked at. So AIDS drug assistance programs are the programs, or AIDS apps, where people with low incomes who have HIV and are underinsured or uninsured can get medications for HIV and some other medications free from the state.

So it’s really important. They’ll have consistent and free access to these medications. We have found that even when people are able to get these medications, Black Americans who have HIV have lower rates of viral suppression than White Americans who have HIV who both rely on these AIDS drug assistance programs. So there’s still work to be done in terms of making sure that we’re able to get equitable outcomes for people based on this program.

But these programs did do some really innovative work when the ACA came out and they offered patients the option of you can either continue to get your medications or you can actually – we’ll buy you an ACA insurance plan. And we studied this in one state and in three states, and we were able to find that actually people who were offered the ACA insurance plan and took that actually had higher rates of viral suppression.
We think that’s related to probably having better access to non-HIV care as well as having either real or perceived better access to HIV medications. We also were able to find that that actually cost the state less money. So it cost the state about $6,000 per patient per year to buy that health insurance plan when it was costing the state $10,000 to buy just the medication per patient per year.

But knowing the numbers in viral suppression are not everything. We also spoke to patients to try to understand what was their perspective, what was their experience, and people almost universally liked their private health insurance plans and the transition went OK for them. But there were a lot of concerns about privacy and strong feelings, both positive and negative, about having to use a mail order pharmacy. So some things that were good, but some things that probably needed work.

And then our state recently expanded Medicaid and we were able to study that in our clinic. This is a caveat because it’s a small study. It was just our clinic.

And while we found higher rates of viral suppression than historically have been found with Medicaid, for our patient population we actually saw a decrease in the rate of viral suppression for people who shifted to Medicaid. And, again, wanting to understand what was the patient experience, what did people think about this, patients were pretty satisfied with this transition to Medicaid and with the coverage that they were able to get.

But they did tell us that even with a lot of support from clinic with this transition it was really hard, and I think that that’s really important to just stop and acknowledge that these transitions and these logistics are really hard for our patients. They’re also really hard for the clinic and takes a huge toll on both parties.

And in terms of what may have caused this dip in viral suppression from the patients that seemed to think that they – they seemed to say that they had trouble getting medications when they either had a gap between their previous coverage and Medicaid or when they actually had an overlap between their previous coverage and Medicaid, and both insurance plans were pointing to each other. So, again, we hope to study this in a larger patient population. But that’s just one example of what we’ve seen in our clinic with the transition.

And then looking at access to HIV preexposure prophylaxis, we looked at that for people with ACA insurance plans. So we studied 17,000 plans and tried to understand, you know, what was the prior authorization requirement for PrEP. This was back when there was only one formulation of PrEP and so there was really only one option. And we found that,
unfortunately, these ACA insurance plans that were in the South were actually 16 times as likely to require prior authorization compared to plans in the Northeast.

And when we tried to understand was it something about these insurance plans we could not find any explanation and people said maybe it’s small regional plans versus national plans. But, actually, we found that national plans were more likely to do this.

So a company that has plans in all four regions was choosing to do something different in the South, which is concerning because, you know, the South represents about 38 percent of the U.S. population but 50 percent of the new diagnoses each year, and also more African Americans live in the South so they are going to face this barrier at a higher rate. So it’s the structural racism there in that policy.

And then in terms of solutions, you know, I think – we like to think that we – in the U.S. we have the best health care, but, really, we pay the most and we don’t have the best outcomes and that holds up for HIV care. Compared to our high income peers, we have the lowest rate of viral suppression, and when we look at these peers there are lots of differences but one that we cannot ignore is universal health care.

You know, we really don’t make it easy for people to get what they need. We have this patchwork quilt. At the Ryan White Clinic, we can, you know, provide wonderful HIV care but we cannot provide HIV prevention and we cannot provide care that is not related to HIV.

So, you know, with universal health care everybody would have access to HIV prevention and people with HIV would have better access to non-HIV care. That’s really the direction that we need to be going, and the National HIV/AIDS Strategy does start to talk about some structural issues and some policy issues and we really need to be moving things in that direction.

Dr. Sturchio: Well, thanks, Kate. And I’m just shocked by your finding that insurance companies were – I hope it’s not consciously but that they were putting prior authorization rules in place that actually worked against the whole point of having PrEP in the first place, which is to make sure that people who are at risk have access to this harm-reduction strategy.

So I’m sure we can come back to that, because what I’m interested in are your comments about universal health coverage and the gaps in care that you and Greg have been talking about also help us to see how it’s important to have an integrated approach that takes into account the complicated lives that people live and that, you know, the kind of care and treatment delivery
resources they have should be congruent with and support the kind of life they live, not put more barriers in their way of getting care and treatment.

So let’s switch now to the global context and come back to this same question and I’d like to turn to Wafaa. And, you know, let me just make a couple of points. To reiterate some of the points I mentioned earlier, only about two-thirds of those living with HIV globally are now virally suppressed, which means there’s a gap of about 5 million to achieve the UNAIDS 395’s goal, and every day there are some 4,000 new HIV infections globally. Three out of five of those are in sub-Saharan Africa. Roughly, half of those new infections are in women, three in 10 are in young people from 15 to 24, and, roughly, two-thirds of those new infections are in young girls.

If we look at key populations – men who have sex with men, sex workers, injecting drug users, transgender women and their sexual partners – they account for two-thirds of new infections worldwide.

Wafaa, you published a really interesting article in PLOS Medicine a few years ago entitled, “Reaching Global HIV/AIDS Goals: What Got Us Here Won’t Get Us There,” which focused on the need for differentiated HIV prevention and treatment delivery services.

Could you tell us more about that perspective and why it’s so important? And you’ve also tested these ideas about differentiated services with key populations and their communities in Tanzania. So maybe you could share with us some of the learnings from that program as well.

Wafaa El-Sadr: Thank you very much, Jeff, and thank you for the opportunity to be with my colleagues today.

Yeah, I think what – it’s interesting that the gaps that we are noting in terms of access to treatment or access to prevention are not distributed evenly across the population, as you indicated by the data that you cited, Jeff, and this means that there are specific subgroups in communities around the world that are struggling and have struggled with getting access to the services they need, whether this be testing or prevention services or treatment services, and supporting them to stay on prevention, to stay on treatment, for the long term.

And in thinking about it, I think what became very clear is that in order to now be able to reach these subsets of our populations that are facing the impediments, the challenges, that both Greg and Kate mentioned is that we needed to think differently, and we needed to think outside the box and we needed to evolve our services, to reshape them, to tailor them to the needs of specific populations, to their needs as well as to their preferences.
So while, traditionally, services were kind of designed, obviously, hopefully, with engagement of the affected populations themselves, but nonetheless, they were defined across the board. And what we've learned is that's not working for everyone. You need to differentiate the service.

You need to shape it for the people that you want to reach and you need to involve them from day one – the recipients of the care – involve them from day one and asking the question of, you know, what are your needs? What are your preferences? How do you want these services? Where do you want them to be delivered? How do you want them to be delivered and by whom? And I think that's the concept – that's really the key concept behind differentiated service delivery and its goals.

And I think over the past several years, we, at ICAP, and with others have been attempting to take some of the initial models and pilots that have been successful and take them to scale because, ultimately, you need to take these models to scale if you want to achieve the desired impact at a population level from a public health perspective.

And I think through the CQUIN network, which is funded by Gates and supported by ICAP which includes now 21 ministries of health, countries in sub-Saharan Africa, we established or helped establish a community – a learning network, a community across these different countries where there’s sharing of ideas, sharing of models, a very intensive self-examination of where countries are at in terms of reaching the gaps, the populations that they need to reach, and then working together collaboratively on trying to identify better ways to move forward and then to scale them up. And I think, thus far, there's been enormous success with these different models and the scale-up.

I do think there are opportunities here for – I always say there's – we need to bridge both the local and the global, right, and there are enormous opportunities for learning for the United States and for meeting the challenges that both Greg and Kate mentioned, which is that we need to reshape our services, reshape our programs, bring the recipients of care to the table and ask them to help us shape the kinds of programs for their needs, and I think that has been shown to be the way forward.

Globally, we've seen success. You mentioned the one paper that was published based on the work of our team with the ministry of health in Tanzania, for example, where, again, by shaping these – the programs differently, by going out in the community and doing the services out there in the community, we've been able to and the country has been able to achieve remarkable progress in terms of meeting the needs of some of the most vulnerable of their population.
Now, you know, shifting to maybe another aspect of this whole issue is that – and going back to, actually, something that Kate mentioned is – obviously, I’m a researcher as well as a public health person but I do think that we need to also examine some of the fruits of our research.

Enormous advances have been achieved in responding to HIV. Amazing medications now available for treatment. One pill a day, very well tolerated. One pill a day. And we have at our fingertips tools for prevention, harm reduction. We have PrEP. We have also voluntary medical male circumcision. We also have as well the potential not just for daily oral PrEP but, hopefully, soon in the future we’ll have the potential for injectable PrEP – long-acting injectable PrEP.

But, nonetheless, we have to always resist the temptation of thinking that these are magic moments. There is no magic bullet. If we are to – we have to take these amazing discoveries and then be able to wrap around them the kinds of supportive services and interventions that specific populations need. Otherwise, it’s not going to get us to where we want to get to.

None of these magic bullets that are amazing through our – that we found through our research – will never get us where we want to want to get to if we don’t think very carefully about wrapping around them the supportive services, whether it be adherence support, whether it be outreach, whether it be food supplements, or many, many, many other types of interventions that are necessary to be able to gain the – really, garner the fruits of our remarkable scientific discoveries.

Dr. Sturchio: Well, Wafaa, thanks so much. In just a few minutes, you’ve done a really terrific job at succinctly summarizing a huge body of work that you and your colleagues and many others have pioneered in improving service delivery for people living with HIV and AIDS in the global context.

And, you know, just to summarize, you talked about how important it is to have – invite people living with HIV to be part of the process of designing those services from day one to make sure that they meet their needs and preferences, that we want to make sure that those services are differentiated so that they meet the needs of specific populations. And then as you were saying, it’s not just prevention and treatment services but, you know, whether it’s access to food, to adherence counseling, to a variety of other services that can help people make sure that they’re able to live healthy and longer lives with HIV.

And, finally, you made this point about how important it is to have learning networks so that, you know, what worked in Tanzania can be applied in other countries and other settings and adapted in ways that will help make it just as helpful there.
So what I wanted to ask next of Greg and Kate before I turn to our audience here in the room – and we do have a microphone and you’ll have a chance to ask questions or make comments in a few minutes – but, you know, I just summarized some of the things that Wafaa mentioned that she’s been working on in the global context.

How is that – you know, if we want to learn from what’s been happening elsewhere, how do those kinds of insights apply to what needs to be done in the U.S.? And, you know, this is really just a way of digging further into some of the issues that both of you raised earlier.

Dr. McManus: I’m happy to go first. So the EHE plans did have to have a fair amount of community involvement and had community advisory boards, and I know in our Ryan White Clinic we rely very heavily on our community advisory board, and it’s really important because something that works in Charlottesville, Virginia, is going to be different than what works in New York City or San Francisco. And so there are kind of certain things that our community has asked for that we’re able to do and we take those requests – their preferences, really – you know, as our marching orders because we want to serve our community.

So some of the things – you know, our community wants to have HIV-only specific times for clinics, so they don’t want to be sitting in the waiting room with other people from the community. So that’s something that we do for them. But I’ve heard from people in other areas that that’s totally different than what their community wants.

So it’s really interesting and important to get the community’s input and make sure that you’re following that because, you know, we’re serving the community and want to help them achieve good health, well-being, and that’s, you know, an important way to be.

Dr. Sturchio: At your clinic, Kate, and in the work that you’ve been doing in Medicaid populations and looking at how policies have an impact on them, is the kind of specific tailored or differentiated service that Wafaa was talking about something that’s a characteristic of the settings you’ve been working in?

Dr. McManus: I think it’s something we want to strive for. I think that example of when people had the private insurance plans and they all had to use the mailed pharmacies, and probably half the people loved it and half the people hated it, there was an opportunity to probably do a better job if we had given people more of a choice about that. You know, the people who loved it loved the convenience and the people who hated it had some very bad experiences with it.
So I think that we do need to be offering more differentiated care, more differentiated options, because it’s not one size fits all.

Dr. Sturchio: Greg?

Mr. Millett: You know, I think that there’s a lot of parallels that we see between the domestic and the global epidemics. I mean, it’s good that we have strategies for both and, by and large, a lot of the things that we have in each one of the strategies are fairly similar.

But we also face similar challenges, too, and Wafaa talked about what some of these challenges are, you know, for either PrEP or for ART. The hard part for all of us is keeping people in care, of keeping people, you know, taking some of these drugs and exactly what Kate and what Wafaa outlined, you know, making sure that people are integrally involved in their care makes you understand why people cycle in and out of care, either for PrEP or for ART.

I think the other thing that’s similar, too, between global as well as domestic is, you know, some of the policies that keep people living with HIV or are at risk from HIV from accessing services. I mean, domestically, we have issues in terms of criminalization where in some states, you know, you can be prosecuted if you’re HIV positive for just spitting on somebody, even though you cannot transmit HIV through spitting on someone. And those policies – I saw this while I was at CDC in Georgia. I had friends who knew that they were positive, but they hadn’t tested for HIV and refused to get tested to know for sure because of the criminalization policies in Georgia.

We see criminalization policies as well for key populations, you know, all across the world for sex workers as well as for people who inject drugs and for men who have sex with men, and some great work that our colleagues at Hopkins have been doing showing that those policies are associated with people not getting tested for HIV across the world as well as not getting access to services that they need.

So we have to do a better job of really trying to tackle many of these issues, not only just getting people with HIV involved in their care and trying to understand where, you know, some of these places are where we’re seeing these hiccups, but to also make sure that the policies are in place are facilitating care for either prevention or for HIV care, both domestically and globally.

Dr. Sturchio: Those are important points.

Wafaa, let me just come back to you. Are there – is there a forum or is there an existing learning network where the kind of work that you and your
colleagues have been doing globally where you can actually share those insights with people like Greg and Kate, who focus on the U.S. pandemic? You know, presumably, some of that kind of information exchange occurs at IAS meetings and, you know, global AIDS conferences.

But I just wonder, for instance, in universal health coverage there’s the Joint Learning Network, which is managed by MSH here in Washington, and they are explicitly – you know, they have the explicit mandate to foster that kind of cross country learning on the application of universal health coverage. I just wonder if, you know, there are similar fora for that kind of information exchange.

Dr. El-Sadr: Yes, there are a several, actually, and I think for the CQUIN Network – and CQUIN stands, by the way, for Coverage, Quality and Impact Network. And there are – there’s a very excellent website where we post a lot of the available experiences as well as share a lot of different tools as well.

The network has established some communities of practice, which are groups of individuals from various countries that are interested in one specific aspect of differentiated service delivery, for example, for key populations or some are focused on the whole issue of advancing quality care for individuals with advanced HIV disease or for maternal-child health care as it relates to HIV.

So there are these communities of practice that are very vibrant and enable the sharing of information as well as, of course, there are opportunities for seminars and satellites and so on. There are a variety of conferences, and, people, please feel free to reach out to me as well.

I think one of the – if I have a minute just to comment on the lessons global to local, and I agree with Greg is that there’s so much we can learn from the global response to local response, and vice versa. I always have enjoyed very much working and continue to work in New York City, obviously, as well as globally because I feel their connection is so important.

And one of the things that I feel sometimes inhibits the kinds of innovations that I’ve seen elsewhere from taking root in our own country is, honestly, our fractured health system and also the multi-layered hierarchy within our health system, as well as the very much – they’re kind of a – almost we are wedded to working within buildings, whether it be hospitals or clinics.

And what I’ve seen elsewhere is that it’s so much easier to innovate and to move forward when you have a simpler health system, not as – you know, that’s more streamlined and also that’s not as fractured as we have in the United States, as well as also at the same time where there’s, you know, much more of an openness.
The walls of a clinic, the walls of a hospital, are not as constraining as, I think, they are often in the United States, where there’s a much bigger focus on the community, the connection to the community, the engagement of community health workers, moving out to where the people are at rather than expecting them to come to us.

And I think if we don’t do that, I think we’re going to be, largely, dealing with the tip of the iceberg, the people who find this. But what we need to do is to think differently and to really think of how do we get out of these walls and be able to actually go to people who haven’t connected to us yet and engage them in the process of gaining – of health education as well as navigating them directly to services that maybe that they need to access.

So I think we need to try to really work very hard to try to break the barriers and simplify much more of structures and then as well to go beyond the walls of our health institutions.

Dr. Sturchio: Well, I think that’s really a very important perspective, Wafaa. Thanks for that.

I wanted to turn to our audience to see if they have any comments or questions to add. Maybe Chris Collins might like to start. Not to put you on the spot. (Laughter.)

Q: That was not putting me on the spot. No. This is a wonderful panel, and thank you, Jeff, and everybody.

You’re the A team and, you know, it’s so interesting what you’re talking about. I mean, you’re finding on Medicaid the transition. I mean, it’s interesting because I haven’t read this study but I’m wondering is a lesson, perhaps, from that that the comprehensiveness of Ryan White care services great when you get the Medicaid coverage, but you’re leaving that comprehensiveness of Ryan White, and if that’s maybe one thing you’re seeing what’s the implication for where we need to go in health in this country, right, that – because we are all, of course, storming the barricades for Medicaid coverage, which of course you want. But what does it say about what Medicaid needs to be like? What’s the Medicaid we want to invent that will work for poor people?

And then I also just – yeah, the theme of disparities unites the global and domestic responses. What have you seen? We need to listen to people about the kind of care they want. What does it mean for advocacy, going forward, in terms of how we need to tackle disparities at home and around the world? What’s the advocacy agenda?
So I guess those are two questions I have.

Dr. Sturchio: Thanks, Chris.

Dr. McManus: Yeah, it’s a great question about the Medicaid. So I think in Virginia we’re kind of a unique state in that the patients that we were studying had – mostly had private health insurance plans from the AIDS drug assistance program. So they were transitioning from private health insurance with Ryan White support to Medicaid with Ryan White support.

We do think that – we’re hopeful that the decrease in viral suppression was kind of just a result of the transition and kind of the complication of, you know, the year changes and you have to figure out how to get your medication on this new plan and all of those other sorts of things.

Also, I do think we have to think more about Medicaid because we talk about it as though it’s one thing but there are lots of different Medicaid plans in every state. So in Virginia, we have one fee for service. Then we have six commercial plans. You’re on the fee for service for 60 days before you then are transitioned to a fee for service.

That’s so complicated, and, you know, I didn’t even know that that was the process and so how are my patients supposed to know? OK. They get it figured out for the fee for service and then all of a sudden 60 days later has to figure it out again for a commercial plan. So it is very complicated, and I think we talk about Medicaid as though it’s one thing but we really need to delve in and make it a more streamlined process, make it easier for patients, and figure out exactly what is the right kind of Medicaid that works for people living with HIV.

Mr. Millett: And I think for advocacy that – you know, I see, again, a lot of similarities between the U.S. as well as globally, and there are three places where I see us moving forward with advocacy.

The first is access to new technology and new medications. So, for instance, long-acting agents are, certainly, going to be a game changer for keeping people on ART or keeping people on PrEP. We have the issue both domestically as well as globally.

We need to work now with policymakers and others to make sure that we have access to long-acting PrEP at prices that are available for both people domestically as well as globally. We’ve already seen the hiccups with COVID-19 and vaccines where both domestically there are populations who need it the most. Some of them are populations living with HIV don’t have access to COVID vaccines, and we’re seeing the same thing globally as well with some
terrific work that Kaiser Family Foundation has been doing in terms of access to global – to COVID vaccines in lower income countries.

I think the second thing for advocates to consider where we see some similarities as well is the degree to which there are these, you know, interlocking epidemics that are all associated with one another, that we can’t necessarily work in a silo of just HIV because HIV is being impacted, at least domestically, by the opioid epidemic. It’s being impacted by the STD epidemic, et cetera, and we’ve, certainly, seen the numbers associated with that.

Globally, you know, WHO released data yesterday showing how the malaria epidemic has worsened by leaps and bounds in 2020 because of COVID-19, and we know that people living with HIV are at risk for death because of malaria in the global pandemic. So there must be a lot more cross work among advocates in recognizing some of these similarities between these interlocking epidemics.

And I think the last thing that we need to think about as well is the degree to which whether or not there’s going to be any crossover from some of the vaccine hesitancy as well as the trust – the dip in trust in science that we see domestically. Are we going to be seeing that globally as well and do we need to get ahead of that? We’re, certainly, seeing that, of course, in Austria. We’re seeing that in France. We’re seeing that in many European countries.

But I just read a paper where they saw vaccine hesitancy among a population, and when they were asked if they’d like to have access to a vaccine in Zambia. I have friends in South Africa who are talking about, you know, rises in vaccine hesitancy there.

So those are things that we have to get ahead of and we need to start thinking concretely. You know, is there going to be any spillover effect from some of this distrust or mistrust in science to some of the work that we’re doing around HIV and scientific advances? And if so, then how do we counteract that and how do we use our advocacy networks to deal with that?

Dr. Sturchio: Yeah, that’s a critical question. I think, you know, my immediate reaction to that, Greg, is that, you know, for people who have been on chronic HIV medication, in some cases now for decades, they’re less likely to be affected by the kinds of issues that are leading some folks to be hesitant to use a new COVID vaccine because they trust their providers. They, you know – I mean, I’m generalizing, obviously – but, you know, but I think it would be interesting to just try to tease out all of these different aspects to understand what it is about the kind of constructive relationship that many people who have chronic conditions have with the providers they work with regularly, like, you know, Kate and her patients, for instance. And that may help – what
we learn from that may help in dealing with the other issues that we’re seeing in hesitancy with respect to COVID vaccines.

Mr. Millett: Well, where I see it and where I’m most worried is, actually, for people who are HIV negative. So, for instance, for PrEP, you see in many studies in the global space, both in Europe as well as in several African countries, that the reasons why people are not taking PrEP is because they believe that, you know, it might do something untoward to their bodies. They believe that, you know, it’s not something that, really, they need because they’re not at high risk.

So we need to get ahead of some of those narratives beforehand and, particularly, when we get to other, you know, new therapies that are available, particularly for prevention for people who are negative, to really try and dispel some of these things before they take hold.

Dr. Sturchio: That’s important.

Wafaa, I know you have to leave us a little bit early. I wondered if you’d like to just make some final comments, share some thoughts with us before you have to go.

Dr. El-Sadr: Yes. I think, just to build on my colleagues and the conversation just now, is I do think there are lots of lessons learned from HIV that we have garnered over many decades and I think those could be very, very helpful, moving forward, as we tackle COVID as well as also other health threats. And so – and I think one of them is I think we forget sometimes that it wasn’t easy to get to where we’re at today.

I mean, I recall very much early on in the early 2000s when we were first starting this I got to actually try to work on bringing life-saving antiretroviral therapy to many – several countries in sub-Saharan Africa and, you know, again, it was quite difficult. There was hesitancy. There was concern about the medications, about the side effects, about, you know, whether they would actually result in deleterious – more deleterious effects than benefits. And it took a lot of work and concerted work to be able to – actually, to overcome some of these concerns.

How was that done? It was done using the usual traditional building blocks of how do you engage individuals in communities. It was hard work at finding the key spokespeople, the trusted community members, the leaders, to engage with them first and then through them to reach their communities and inspire them to think differently about HIV and getting tested for HIV and HIV treatment. And this emanated from this huge movement of recruiting peer educators, people living with HIV who volunteered to help others living with HIV.
And similarly with prevention. Circumcision champions is one example. PrEP champions, others that we have also worked with and trained. And this idea that you kind of have to go back to – you have to start out with where people are at and then work diligently and consistently with them so you can get them to move along the – a trajectory towards, hopefully, wanting to be engaged in the service and wanting to stay on the various services.

This doesn’t happen overnight. It takes time. It takes resources. It takes enormous efforts to be able to get from here to there, and we can’t wait. We have to do the work now because I think we’re facing it with the COVID vaccines and we’re likely to face it with, potentially, other health threats as well.

Dr. Sturchio: I think, you know, you’ve made such a basic and profound point about the need to work with people where they are. It can’t be repeated too often because I think that’s often the basis of successful prevention and treatment programs and designing the right kind of care and treatment delivery services.

So thanks for that and, Wafaa, thanks again for joining us. You know, we really appreciate your tuning in from New York.

Now we have time for one other comment or question from the floor, if anybody would like to – Charles, please. Charles Holmes?

Q: Thanks so much, Jeff, and, thanks, Greg and Katie. This has been great. Wafaa, thank you. I caught her just as she was going off screen.

This is, really, a question that could cut across the global and the local, and I think it’s about kind of the way we think about the functions of HIV prevention, the functions of preventing any pandemic. And, you know, we’ve been plateaued globally and locally. How long have we been saying there have been about 40,000 new infections every year in this country despite the fact that we spend whatever percent of our GDP on health care?

I’m interested in this moment in terms of how we can coalesce around some of those functions relating to prevention. We know it involves targeting. We know prevention is best done when demand is raised routinely. We have to have quality delivery, which means, in many cases, differentiated delivery that’s meeting people’s preferences and needs, as well as addressing higher level structural and social issues that we need for sustained use.

So that goes for just about anything, whether you’re trying to get people to come back for their COVID booster or whether someone’s on the border and thinking about whether or not to come back for their next PrEP refill.
And so interested in any thoughts you may have about ways in which we can get smarter about maybe coming together around some of those functions. Maybe there are common sets of data that our disease-fighting programs can be using either here domestically or globally. Thanks.

Dr. Sturchio: Thanks, Charles. Over to Kate and Greg.

Dr. McManus: Yeah. So I think there are a lot of barriers to HIV prevention. I think – speaking as a clinician, I think that probably we need more clinicians who want to prescribe PrEP. I think infectious disease doctors have done a really good job saying how complicated infectious – antiretroviral therapy is. And so we've kind of made it that these are special medications. They're very complicated. They're hard to prescribe. So now when we're trying to say, oh, well, we want primary care doctors to do PrEP, they're saying, but this is antiretroviral therapy. It's very complicated. Now you're pushing it back towards us.

So I think there's this push and pull in medicine of who owns this. You know, a lot of infectious disease clinicians are saying it should be done in primary care because that's where people are, and a lot of primary care doctors are not comfortable doing it and they're pushing it back to infectious diseases.

So I think we're seeing some of that. But we're seeing innovative models where some states are allowing pharmacists to prescribe, and I think that's great and we need to be doing more of that – you know, meeting people where they are, making it no wrong door. I think probably infectious disease doctors and primary care doctors and pharmacists should be able to get people this medication.

I think people are also very bad at perceiving their own risk. There was some work presented at IDWeek where people's perceived risk was much lower than what their actual risk was. So we need to be working on education about what is – you know, what is risk for HIV and how can people better understand their own personal risk.

And then in terms of policy, we need to make it easier. So those prior authorizations that I talked about, you know, there is some regulation of prior authorizations of ACA plans but each state looks within their state. So if a whole state has it locked down with prior authorizations, that state – you know, they're not going to find that. And so there needs to be more regional looking at prior authorizations and things that might lock down medications, and then also looking at it at the national level and trying to level the playing field so that everybody has equal access.
Mr. Millett: And, you know, what I would say is that we’ve never been good at even just funding prevention in the U.S. and that’s a major issue. And, I mean – and, of course, you know, full transparency, I’m a former CDC scientist – but we do need to fund CDC at a level that’s adequate to do actual prevention for most of these diseases.

Even when we are talking about ending the HIV/AIDS epidemic, we’re not even funding that effort at the scale where we need to be funding it. The Trump administration – outgoing Trump administration wanted to fund the second year for EHE for about 400 million (dollars). We’re only funding it at about – for 700 million (dollars). We’re only funding it now for 400 million (dollars). So we have this yawning gap that’s there in terms of funding for prevention. We’re not willing to fund for prevention in the U.S.

And I think the other issue as well is funding public health infrastructure. Our public health infrastructure has been crumbling for quite some time and COVID has really made that clear, and the fact that we’ve lost in excess of 25,000 public health workers in the last decade really screams at the fact that we need to make sure that we fund public health in a manner with which we can be more resilient when the next pandemic hits and then more resilient as well to getting us towards the end of the HIV pandemic.

So, at least for me, a lot of it is about funding and our country, unfortunately, has never been great about funding prevention.

Dr. Sturchio: Well, it’s – you know, you raise an important and interesting question there, Greg, that, you know, when it comes to pandemics we seem to always be fighting the last war. But that’s a whole other conversation we’ll have another day.

But I wonder in the last few minutes, Kate and Greg, if you just had a final comment or two you wanted to leave us with. So we’ll start with Kate.

Dr. McManus: Yeah. So I think we’ve made some great strides with the Ending the HIV Epidemic Initiative and it’s exciting to see this new National HIV/AIDS Strategy now calling out some of these structural issues, some of these policy issues, and I think we’ll have to watch to see what the federal implementation plan looks like in early 2022 because I think that will really show us, you know, how seriously are these policy issues going to be tackled. And so I think we can all look forward to seeing that document.

Dr. Sturchio: Greg?

Mr. Millett: Yeah. And I’d say that, you know, I’m definitely more of an optimist in nature in terms of ending the HIV/AIDS epidemic. One thing where we haven’t necessarily been the same as in the global community is having the political
rancor taken out of domestic HIV. In the global community, you see both sides of the aisle work together to address HIV.

Where I am optimistic, though, is that even from the prior administration as well as other people on the Hill, is that we’re seeing more of that working together across the aisle for even the domestic epidemic, and a lot of that started with the opioid epidemic and now has bled into ending the HIV/AIDS epidemic as well, and I’m hopeful that that’s going to be the key for us ending HIV both domestically as well as globally.

Dr. Sturchio: Well, and I share that hope, Greg, because, you know, so much of the progress we’ve made in the last 40 years has been through bipartisan approaches to these issues and, you know, let’s hope for an outbreak of bipartisanship again as we continue to grapple with these challenges of ending the HIV pandemic.

So all that’s left for me to do is to ask you to join me in thanking our panelists, Kate McManus, Greg Millett, and Wafaa El-Sadr for a really interesting and stimulating discussion. So thank you all. (Applause.)