10 Years Later, Where Are My Options?

Lingering questions from a black gay advocate.

July 6, 2022 By Matthew Rose

Over 10 years ago, I stood in front of a group of experts and regulators at the FDA and asked fundamental questions about the shocking increase in the number of new infections of HIV among people who look and live like me. I explained that the current system was failing us and that the available options were insufficient to address the burden sweeping through our community.

Although a deep stigma around taking daily medication to protect ourselves exists, I championed that we need to be the central advocates involved in the decisions around our care. We should be presented with all of the options available and given the ability to make informed decisions about our lives.

In those few minutes, I spoke an inconvenient truth, highlighting the way the advisory panel thought of men like me, that the options that were providing us were insufficient for our actual lived experiences. That day I said:

“As a young black man I long known that data would paint a grim picture… We proving over and over again the current model of prevention is inefficient at turning off the incidents faucet. Today I stand before you to ask for a promise that gives my community another option. I do not believe that a single drug or strategy will be what ends this epidemic but I do believe that in life you have to meet people where they are and then gives them the tools that will allow them to manage their situation”

Yet all these years later, we are confronted with the reality that as of 2019, only 9% of black Americans who could benefit from PrEP were currently taking the medication. And we consider this a high mark since the Covid pandemic makes it less likely to have increased opportunities for people to gain access to PrEP. However, opportunities for success remain. We now have evidence-based approaches to PrEP access and a distinct possibility that we could finally deliver what it takes to make programs work and give people what they need to make the choices in their lives around taking PrEP.

Four years ago, while working for NMAC, I helped shepherd a report on the effective implementation of biomedical interventions for communities of color. Looking back on that time, that report is a bedrock for actual expansion of access. We do not have to engage in radical

reimagining; Rather, we must embrace giving people what they have already asked for at the levels they asked for it for years. There is still an opportunity to fundamentally shift and build the type of infrastructure and programmatic elements required to have people of color be able to engage in interventions that can change their lives, allowing them to live a life they were promised when PrEP came online a decade ago. It is this body of evidence that should continue to form a basis for any efforts to establish a national PrEP program, such as the once recently proposed by President Biden as part of his FY 2023 budget proposal.

-Focus on the South and strengthening healthcare infrastructure

It is critical to build up southern healthcare infrastructure through various channels aggressively. Given the current political landscapes, this must be done through novel approaches changing funding streams that allow the supporting of community-based clinics and organizations that exist outside of some of the hostile political structures that continue to impede progress that supports science within the region. Additionally, we can learn from our colleagues on the global scene how to bring healthcare access to more rural parts of communities, creating an almost spoke and hub model that allows hubs to exist in central locations. But also push resources out rapidly to communities. Also, health care systems can effectively deliver PrEP through mobile services, pharmacies, and pop-up clinics. We must redesign how we approach southern medicine to meet the area's needs and political realities. There must be a system to handle and care for individuals who want to engage in PrEP services. And these efforts need sustained and stable funding from multiple sources to ensure that people can access PrEP at the points and during the times they need in their lifetime.

-Promote biomedical HIV prevention tools through community education and awareness campaigns

This has been a critical question and discussion for years of how we make the right level of community education and awareness campaign that allows individuals to know about their options and make informed choices about them. We've seen many PrEP campaigns over the years; now, we must evaluate them to determine which ones are genuinely penetrating within markets.

-Strengthen health literacy and increase health system navigation services

Many people of color do not access health care regularly and do not have a relationship with a medical provider. It is essential to promote health literacy by increasing the capacity of these individuals to navigate the health system, including assessing insurance coverage options, enrolling in coverage, identifying a primary care provider, making medical appointments, accessing services, and troubleshooting if problems arise.

-Adapt service delivery to reach people of color

To take full advantage of biomedical prevention tools, it is not enough to merely offer PrEP in traditional clinical settings. Instead, we need to adapt to meet the needs of priority populations. We need to deliver PrEP across various settings outside standard business hours while streamlining PrEP delivery in clinical practice. This means expanding prevention education and

services within primary care facilities, pharmacies, STI and family planning clinics, faith-based settings, and other places where people of color. With a strong emphasis on places and spaces that align and affirm gay, bisexual men, same-gender-loving men, and transgender women are located, such as youth centers, sports clubs, hair salons, and barbershops.

-Actively counter mistrust of providers and the health system

As evidenced during the COVID-19 crisis and persistent lower uptake of vaccines, medical mistrust remains a problem. Mistrust of the healthcare system is a barrier to effective HIV treatment and prevention. People of color may choose not to go to the doctor because they do not trust the healthcare system.

-Train more providers to be equipped to navigate across cultures and communities and provide effective HIV treatment and prevention.

As efforts are made to expand access to HIV treatment and PrEP among people of color, predominantly gay and bisexual men and transgender women, and the massive disparity between women of color and white women, we need providers who are: (1) willing and equipped to discuss sexual behavior; (2) willing to treat those with HIV and to prescribe PrEP; and (3) willing to provide respectful and appropriate care, free of stigma and judgment with a contextualized understanding of race.

At the same time, this has to be coupled with the reality that we face a world where religious exemptions and the new Supreme Court makeup drastically affect how individuals access health care. Given that in many rural states and southern jurisdictions, the only large healthcare serving system is religiously based and can often be hostile to the most vulnerable members of the current community. We must find places where affirming service providers can flourish while serving the needs of our community. This will require restructuring and demands on how we create funding streams that allow us the flexibility to support the types of providers. These providers would be individuals committed to providing the highest level of care to all community members without stigma or judgment.

These steps, further outlined in detail in the NMAC paper, provide examples of key features that have long been asked for by communities. Features represent the collective requests of communities for what they need to address the gaps and barriers inhibiting overcoming the obstacles to our promises of prevention.

There are two final areas in which the initial report does not delve deeply into what I think are essential for our discussion about the way forward for pre-exposure that believe in prevention.

We have to be able to think more broadly about who needs PrEP. One of the initial misses as a community was not giving particular attention to the overlap between the opioid epidemic and those at risk for HIV. We missed outreach efforts designed to meet the needs of people who inject drugs and the impact that PrEP could have on stemming the risk of outbreak cases within their community and improving their overall health. We must do better to involve individuals who inject drugs within the conversation, recognizing significant overlap in communities of color who would

be indicated for PrEP. We must stop separating people's behaviors as if an individual is only vulnerable to one type of risk in their life but look at a person holistically and say how can we help. How can we support you to live your best life and be informed with all the information you need to access this vital service if it makes sense in the context of your life.

The second area that we have not had a strong reflection on is the question of PrEP persistence. Giving people tools and options/flexibility on how to use them allows them to move in and out of seasons of risk and match the correct tool to their perception of risk and how that risk might change over time. Most often, we see that people can initially engage in about six months of PrEP before seeing a moderately decreased fall-off. We need tools and instruments that allow individuals to understand and contextualize what risk means to them and what options mean to them, whether they be a daily oral situation, a 211 option, or looking at more long-term injectables formulations. We have at least three different ways to deliver PrEP within this country and need to act like it for the good of individuals. Helping people narrow or cover their seasons of risk is critical in getting the kind of coverage we need to disrupt transmission in a meaningful way. All of this rests on the idea of people being informed of what their options are for their health. And those individuals can access those options and engage in the critical decisions around their care.

We must start at a place that recognizes that our promises alone do not mean anything. If we are not accountable to the communities we serve and delivering to them what we promised, we need to reflect on our role in those failures. This is a constant game of building and creating more trust that achieves the shared vision of ending the epidemic. However, this does mean that we must stop kidding ourselves and acting like our current ways of operating are working at a meaningful level. It matters that the holes in the system and challenges we continue to paper over only worsen. And if those fault lines are not dealt with, these issues always drag down our opportunities and inhibitbit real exponential gains. We have seen what happens in 10 years since the promise of prevention was made. We must admit that on PrEP, we have failed the most affected communities, further building the divide between the have and have-nots. However, it is still possible to right the ship and create a world that sees an end to the pandemic by delivering what people need to live their best lives.
