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Perspectives and Recommendations from LGBTQ Youth of Color regarding Engagement in Biomedical HIV Prevention

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Abstract

Purpose.—Young people of color have the highest HIV incidence rates, and suffer the greatest health inequities with regard to daily oral PrEP. While the next generation of biomedical HIV prevention products is already under clinical development, little research has examined whether such products address the needs of this population or identified specific strategies for educating this population about prevention options that might result in the greatest interest in and uptake of new prevention modalities.

Methods.—We analyzed data from seven focus groups (n = 93) conducted between July 2016 and March 2017 in partnership with an LGBTQ youth-serving community-based organization in the northeastern United States. The study aimed to understand concerns, priorities and preferences around biomedical HIV prevention modalities (i.e., daily oral pill, long-acting injectable, topical microbicide) among LGBTQ youth of color.

Results.—Our findings identified four key dynamics specific to educating young people about biomedical prevention, including: a) providing information with a sufficient level of detail and complexity, b) contextualizing messaging in terms of young people's existing knowledge and beliefs, c) providing detailed information about side effects, drug- and multi-method interactions, and dosing/usage contingencies, and d) working proactively to support transgender youth and ensure that prevention products are accessible to them.

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Conclusions.—As we plan for a future of choice in biomedical HIV prevention, we should consider how novel products can address inequities in PrEP access and HIV incidence by valuing the concerns and needs of this highest priority population.

Keywords

pre-exposure prophylaxis; PrEP; HIV prevention; youth; transgender; biomedical prevention; long-acting injectable PrEP

INTRODUCTION

Young people ages 13-24 account for 21% of the approximately 38,000 new HIV diagnoses in the US. Youth of color – especially those who are gay, bisexual, and transgender – carry the largest burden of the epidemic, making up three-quarters of new infections among young people.[1] Given this data, prioritizing youth engagement in existing and emerging biomedical HIV prevention strategies is of utmost importance.

The real-world impact of daily oral PrEP in combination with universal treatment is evinced by the decreased numbers of new infections in places where PrEP has been widely implemented.[2-6] However, access to daily oral PrEP remains largely dependent on geography, race, and gender.[7-10] Only 7% of the 1.1 million individuals with indications for PrEP were prescribed PrEP in 2016,[9] and PrEP use is among the lowest for youth under 24 years of age.[11] Despite clear evidence from the experience of scale-up of HIV combination antiretroviral (ARV) therapy indicating that new interventions widen disparities, [12,13] these data indicate that policy makers, the pharmaceutical industry, and health care systems are failing to address inequities in PrEP access.

Learning from the contraceptive field,[14] HIV researchers anticipate that more choice in biomedical HIV prevention methods will translate into greater population-level coverage. However research indicates that the introduction of new technologies do not increase uptake unless attention is paid to: how they will be delivered (i.e., service delivery systems), by whom (i.e., provider and practice types), to whom (i.e., user preferences and markets) and where (i.e., social and environmental contexts).[15,16] Given existing inequities in PrEP uptake, the availability of multiple PrEP modalities could easily translate into more choices only for those who *already* access biomedical HIV prevention. In this scenario, new HIV prevention options might benefit only the existing oral PrEP market, rather than driving up the total number of people who benefit from PrEP.

The next generation of biomedical HIV prevention products (i.e., long-acting injectable formulations, vaginal rings, topical microbicides) are already under clinical development. While such clinical development is scientifically exciting, little research has been conducted in the United States to assess whether such products address the needs of populations who are not already benefiting from daily oral PrEP.

In 2017, READY, an NIH-funded research project designed to accelerate the pace with which emerging HIV prevention technologies will be disseminated to highest priority populations, conducted a series of focus groups to elicit concerns and questions about

biomedical HIV prevention salient to young people of color whose race, sexual orientation, and zip codes put them at highest risk of HIV acquisition. We focused on this population because many are not benefiting from the biomedical HIV prevention revolution that is driving down incidence rates in large urban capitals.[5, 17-19] By listening to young people articulate their questions and concerns about HIV prevention, we sought to collect data that could inform public health campaigns and patient education materials to support engagement of this population with emerging modalities in a manner that might ameliorate rather than exacerbate inequities in PrEP coverage.

METHODS

Overview

READY partnered with a community-based organization (CBO) that provides social support and programming exclusively for lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) identifying youth (ages 13-24) to implement this study. Participants were recruited for focus groups from the CBO using flyers placed in the facility. Focus groups took place in a community room at the CBO during hours in which youth attend regularly-scheduled programming. Nine focus groups were held between July 2016 and March 2017. Focus groups ranged in size from nine to seventeen young people, and were facilitated by a trained research team member who was also on staff at the CBO. Each session lasted approximately two hours, and participants received \$40, a round trip transit card, and pizza. All participants signed an informed consent before sessions began, and chose pseudonyms with which to identify themselves during the groups. All procedures were approved by the City University of New York (CUNY) Human Research Protection Program and the Institutional Review Board of Hunter College, CUNY.

The focus groups followed a structured agenda and format that was divided into three sections. First, the facilitator provided information about PrEP in its current form as a daily oral pill, and led participants in a general discussion about what they had heard about PrEP, what questions they had about PrEP, and what they thought were the pros and cons of PrEP for young people. Second, the facilitator provided a brief introduction to four novel PrEP modalities: (1) an-antiretroviral-based (ARV) long-acting agent administered via injection every 2 months; (2) a broadly neutralizing antibody (bNAb) modality administered intravenously every 2 months; (3) a topical ARV-based gel applied before and after sex, and (4) a vaginal ring that could be inserted for up to a month at a time. Third, the facilitator used a semi-structured focus group guide to facilitate discussion of the pros and cons of different strategies, how young people would go about making decisions about what strategies they would adopt, and what questions they would want answered in order to make an informed decision among different strategies.

Analysis

All focus group sessions were digitally recorded and transcribed by a member of the research team. We used inductive thematic analysis [20] to analyze focus group data. Consistent with the six steps outlined by Braun and Clarke,[21] the research team began by familiarizing ourselves with the data; we then generated initial constructs that were coded

and collated. Coding was done by three trained members of the research team, who met regularly to identify, discuss, and resolve discrepancies through consensus. Emergent codes were then organized into themes, which were reviewed and refined, and then named. In the final stage, we organized these themes into a coherent structure for analysis, focusing on providing a true account of the data and its interpretation. The final four thematic headings presented below were derived from this analytic framework, and represent findings and subthemes deemed most useful to understanding prevention education for this population.

Results

A total of 123 young people participated in the focus groups. Because of a recording error, two focus groups were corrupted and unusable. We present data from the 93 young people who participated in the other seven groups. Demographics characteristics of focus group participants are presented in Table 1. Participants ranged in age from 18-25 (M = 21.41, SD = 2.21). Participants were diverse in terms of gender identity and sexual orientation and all (100%) participants were young people of color.

We identified four key themes that can inform approaches to patient education and awareness efforts designed to engage this population in emerging HIV prevention modalities: 1) key dynamics specific to educating young people about biomedical prevention and developing messaging for this population; 2) modality-specific questions and concerns raised by the young people that would need to be addressed in patient education; 3) critical issues in communicating with young people about side effects and drug interactions; and 4) specific considerations for engaging transgender youth. In the analysis below, we explain and describe each theme, and summarize key findings and subthemes in tables of quotations.

Key Dynamics in Educating Young People about Biomedical Prevention

The primary finding that emerged centers on the level of detail and complexity of information that young people desire in considering biomedical prevention options and integrating biomedical prevention into their everyday lives (Table 2). Young people's questions about each modality were detailed and specific, and they expressed frustration with the generalities commonly used to discuss prevention with them. Two key themes emerged. The first was the extent to which young people want detailed explanation of prevention strategies and the way in which they work to prevent infection (Theme 1.1). Young people want to understand the mechanism of action for biomedical prevention in the specific context of HIV transmission (Quote 1-2). In Quote 3, the young person includes all the pre-requisites for exposure: a known HIV-positive partner, receptive sex, and exposure to ejaculate. In this context, the young person wants to understand *how* biomedical prevention is going to protect him. Much of our patient education around biomedical prevention is vague; patients are told that "PrEP can stop HIV from taking hold and spreading throughout your body,"[22,23] but the specifics of what this means is rarely addressed. In contexts in which detailed biological information is provided, the biology is often presented in a vacuum, e.g., pictures or videos of immune system cells and receptors with no connection to the larger body in which they operate or the behavior that led to the exposure in the first place.[24]

The second emergent theme was the extent to which young people understand new information presented to them in the context of their existing knowledge (Theme 1.2). Many of their questions indicated a relatively sophisticated understanding of concepts including immunology, antibodies, half-life and extended release (Quote 4). However, without more detailed information, the young people often applied this knowledge incorrectly and made incorrect assumptions about the way biomedical prevention might work (Quote 5).

The concepts of immunity and drug resistance were most commonly mentioned by young people as concerns about the medications (Quote 6). Their words reveal that young people often combine several different pieces of information they have been told about biomedical prevention. The idea that “Truvada is in every medication” may be related to messaging designed to reduce concerns about PrEP as a new medication: patients are often told that the medications in PrEP have been used with HIV-positive individuals for years, and that they are used in multiple anti-HIV combination formulations. Some young people have also clearly been told about adherence concerns associated with PrEP (Quote 7). They understand that, for HIV-positive individuals, non-adherence to medication can lead to the development of drug resistance, and understand that the main fighter of HIV infection is the person’s immune system. They conceptualize drug resistance as becoming “immune” to the benefits of a medication, and are concerned about the spill-over effects between HIV treatment and prevention.

In contrast, several of the young people had a sophisticated understanding of half-life, and applied this knowledge to explaining to their peers why missing PrEP medication for more than four days puts a person at risk for infection (Quote 8). Some of the young people have internalized not only the message that missing more than four days of PrEP medication renders PrEP ineffective, but also understands that waning effectiveness is tied to the level of medication in their body. Their words make clear that young people have the capacity to understand complex biological concepts and apply them to their use of biomedical prevention strategies.

Modality-Specific Questions and Concerns

Young people had many questions about each biomedical prevention modality (Table 3). Across all modalities, the overarching theme was young people’s desire for information about the logistics and practicalities of product use. Their interest went beyond what would be included in a product insert or basic patient education to information about contingencies, hypotheticals, and complex scenarios. For PrEP pills (Theme 2.1), these questions were largely about what to do about a missed pill and about the point at which PrEP is effective in the body (Quote 9). Other participants wanted to understand whether they should double up after missed pills, and how many days needed to elapse before they were considered to have “stopped” taking their PrEP medication as opposed to simply missing pills (Quote 10).

For long-acting injectables (Theme 2.2), young people had a lot of questions about why the shot needed to be “in the butt,” what the shot feels like, and whether or not you are sore after getting it (Quotes 11 and 12). Young people had the most questions about the logistics of microbicide gels and the vaginal ring. For the gel (Theme 2.3), young people wanted to know practicalities about its use: how thick it was, how sticky it was, how much lubricant

was in the applicator, and what happened to the gel after sex (Quotes 13-15). One participant was particularly astute about the logistics of travel with this type of biomedical prevention strategy (Quote 16). In general, the young people had strong feelings about microbicide gels in one direction or the other. Some felt that they were the best option, because people already like to use lubricant during sex and because they believed that a lube would be easy to get and keep on hand without a prescription. Others were strongly turned off by the “mess” of it, or were concerned that because it was topically applied it was not as strong as some of the other biomedical methods, so they wouldn’t feel as safe and protected.

When discussing the ring, there were a lot of questions about how the ring was placed, whether it could be felt by the ring user or by their insertive partner, and whether or not it could get lost “up there” (Theme 2.4, Quote 17). There were also questions about cleanliness, odor, and the use of the ring during menstruation (Quote 18). Transgender women and cisgender men were particularly interested in the ring (Quote 19) and interest in the ring regardless of gender seemed to stem from its combination of a long-acting agent that is still under complete user control. There seemed to be potential interest in the ring for anal sex even if it was more event-dependent (Quote 20).

Communication about Side Effects and Interactions

Across all modalities, young people were concerned about potential side effects (Table 4). Side effects were cited as the biggest “con” of any biomedical prevention strategy (Theme 3.1), and participants reported hearing about negative side effects of oral PrEP from both doctors and peers (Quotes 21-22). One theme that emerged in discussion of side effects was the belief that any type of biomedical prevention had to be very “strong” to fight the virus, and was therefore likely to be very “harsh” and interfere with other processes in their body (Quotes 23-24).

Participants were also concerned about interactions between biomedical prevention and other drugs, including prescription medication, over the counter medication, and recreational drugs (Theme 3.2, Quote 25-26) and about interactions among different biomedical prevention strategies (Theme 3.3). Across focus groups, young people were adamant about the fact that they and their friends were likely to mix prevention strategies and needed to understand how to do so safely (Quote 27-28).

Specific Considerations for Engaging Transgender Youth

All focus groups included transgender people and our young participants were extremely attuned to the specific needs of the transgender community (Table 5). There was a clear call for information to understand interactions between biomedical prevention strategies and hormones (Theme 4.1, Quotes 29-30). Throughout the focus groups, young people wanted to make sure that any medication incorporated into a prevention strategy would be able to be used in conjunction with any gender-affirming interventions.

However, transgender participants varied in the extent to which they wanted to add another pill or injection to their routine (Theme 4.2). Some young people thought it would be easy to add another medication, while others didn’t want to add to their logistical burden or to the number of drugs in their system (Quotes 31-32). One transgender participant explained that

a long-acting strategy would be attractive only if it could be integrated into their existing routine (Quote 33).

A third theme was the implication of biomedical prevention strategies for gender-affirming surgery and intervention (Theme 4.3). Young people had questions about the efficacy of the vaginal ring for a constructed vagina (Quote 34), and the use of microbicide gel as part of vaginal dilation (Quote 35). Young people also raised important questions about the feasibility of long-acting injections in the gluteus for those receiving gluteal silicone injections (Quote 36). On the one hand, this was seen as a barrier for use, but the young people immediately thought creatively about marketing long-acting gluteal injections as part of gender-affirming care (Quotes 37-38).

Discussion

Our study intentionally recruited LGBTQ+ young people of color, as they represent those who will most need access to novel HIV prevention products presented with culturally-competent messaging that engages them in care. In this context, cultural competence requires the integration and transformation of knowledge about the needs, priorities, and concerns of this population into specific programming, practices, and standards.[25] Our data suggest that young people want detailed explanations of prevention strategies and their mechanisms of action. They understand information presented to them in the context of their existing knowledge. Incomplete or vague explanations of prevention strategies can engender mistrust of a medical system that past life experiences have positioned them to expect.[26] This potential for mistrust is particularly troubling given our hope that the introduction of novel prevention methods can be positioned to redress inequities in access and uptake. Care needs to be taken in the development of educational materials that clearly and completely articulate features that our research indicates are most important to young people.

Understanding the logistics and practicalities associated with choosing different prevention methods is critically important to young people. Logistical information needs to be specifically applied to the context of everyday situations, decisions, and contingencies of young people's lives. Inserting the voices of people who have usage experience with products in the context of clinical trials into written materials for end users may be an effective method to address the logistical and practical issues that might arise from normal use.

Similar to adult users, young people are concerned about the side effects of prevention modalities. Young people seem particularly concerned about how "harsh" longer-acting formulations of medication may be, equating longer-acting with stronger side effects. While numerical representations of side effect risk are standard on labels, numeracy varies widely and complementary approaches to explaining side effects may be needed.

From the standpoint of developers of HIV prevention medications, there has been an unexamined assumption that longer intervals between injections or administrations is preferred over shorter intervals. The data from our focus groups suggests that this may not always be true and that the ways in which novel modalities can be integrated into existing

healthcare routines may be more important than the length of the interval of protection. In addition, for transgender women the ways in which an HIV prevention method can be incorporated into or support gender-affirming interventions is critical, as is data to document the presence or absence of interactions with hormones. Clinical trials of HIV prevention products have under-enrolled transgender women [27] despite extraordinarily high rates of HIV in this population and have neglected to ask questions that are responsive to their specific concerns.

An important theme that emerged from the focus groups was the extent to which education about prevention options provides an opportunity to provide broader sexuality education for young people. Their reactions to questions and the questions they raise highlight the extent to which young people need opportunities to ask questions and hear answers that cater to their informational needs. Importantly, healthcare professionals – whether they are health educators, counselors, nurses, or clinicians – need to engage with young people in understanding what they know first, so that their educational messaging can be directed to assuage existing doubts or correct misinformation before giving new information. HIV prevention counseling offers an opportunity for exactly such interactions.

Limitations

Our study collected data from a convenience sample of young gender non-conforming people in NYC recruited from a single CBO. These young people may therefore be particularly knowledgeable about HIV and the disproportionate rates of HIV among their peers, raising questions about generalizability. However, given the underrepresentation of young LGBTQ people of color in research, we contend that our findings are valuable regardless of generalizability to other groups. We did not track the specific gender identity, race/ethnicity, or sexual identity of focus group participants during the focus group conversations, so we are unable to identify differences in responses or concerns by these demographic factors. Due to IRB concerns, the sample was limited to young people over the age of eighteen. More research is urgently needed with younger people given rates of HIV among 13-18 year-olds in NYC [28, 29]. Discussions pertaining to novel PrEP modalities were hypothetical as information relating to formulations, safety, efficacy, and cost were not fully ascertained. A natural limitation for focus groups is that discussions may follow the lead of particularly strong individuals in the group, however the consistency of themes across all focus groups suggests that strong facilitation skills minimized this effect and lends credence to the findings.

Conclusion

Our findings underscore the importance of developing PrEP messaging and educational materials that recognize the unique needs and concerns of LGBTQ+ young people, and directly answer the questions and concerns about which they care most. Our findings also suggest the importance of provider-focused intervention to enhance communication about HIV prevention with young LGBTQ+ patients. As we plan for a future of choice in biomedical HIV prevention modalities, it is important to begin developing and testing new strategies *now*, in tandem with product development, to increase accessibility, impact, and health equity for highest priority populations.

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Implications and Contribution Statement

Youth of color represent a disproportionately high percentage of incident HIV cases, but a disproportionately low percentage of those engaged in biomedical HIV prevention. This study examined young people’s concerns, priorities and preferences around biomedical HIV prevention modalities in order to identify strategies for enhancing engagement and improving messaging.

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Table 1.

Demographic characteristics of focus group participants (N=93).

Variable	N (%)
Gender Identity	
Male/Man	59 (63.4)
Female/Woman	9 (9.7)
Transfemale/Transwoman	12 (12.9)
Transmale/Transman	2 (2.2)
Gender queer/Gender non-conforming	6 (6.5)
I don't use labels	5 (5.4)
Sexual Identity	
Gay	52 (55.9)
Lesbian	2 (2.2)
Heterosexual	10 (10.8)
Bisexual	11 (11.8)
Queer	2 (2.2)
Not sure/questioning	2 (2.2)
Other/refuse to classify	14 (12.9)
Ethnicity	
Hispanic/ Latinx	27 (29.0)
Race	
Black or African-American	70 (75.3)
Asian	1 (1.1)
Native Hawaiian or Other Pacific Islander	3 (3.2)
White	2(2.2)
Arab	1 (1.1)
Affirmed Latinx as race	6 (6.5)
Multiracial	8 (8.6)
Declined to answer	2 (2.2)
Education	
Less than High School Diploma	17 (18.3)
High School Diploma/GED	40 (43.0)
Some College	15 (16.1)
Associates/Vocational Degree	5 (5.4)
BA Degree	3 (3.2)
Declined to answer	13 (14.0)
Health Insurance	
Public Insurance (as individual)	42 (45.2)
Public Insurance (through parent/guardian)	15 (16.3)
Private Insurance (through parent/guardian)	9 (9.7)
Uninsured	3 (3.2)
Don't Know	10 (10.8)

Variable	N (%)
Declined to answer	14 (15.1)

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Table 2.

Key Dynamics in Educating Young People about Biomedical Prevention

Theme	Example quotes
<p>Theme 1.1 Young people want detailed explanations of prevention strategies and the way that they work to prevent infection.</p>	<p>Quote 1. "OK, what exactly does the pill do to your body, like the actual process of it stopping the virus?" (Focus Group B) Quote 2. "The IV one [monoclonal antibodies] does that enhance your white blood cells to give them the power to fight back against that specific virus or sickness, or does it also help with others as well?" (Focus Group H) Quote 3. "My question always is, so does it kill the virus? So say someone had HIV and you had unprotected sex and you were bottoming. So there was a sperm emission. And does it kill the virus? Does it keep it in your body? Like I don't get how it actually works." (Focus Group G)</p>
<p>Theme 1.2 Young people understand information presented to them in the context of their existing knowledge.</p>	<p>Quote 4. "Because the pill normally targets the white blood cell, rather than target the virus itself. We can't control the virus, but we can control the white blood cell from saying 'Okay, I'm not going to make it.'" (Focus Group B) Quote 5. "If someone gets a condition where they're taking medicine, bacteria can turn into super bacteria. Wouldn't it [PrEP] make the virus to some degree evolve?" (Focus Group G) Quote 6. No, Truvada is bad because Truvada is in every [anti-HIV] medication. And people are taking PrEP and they're not taking it properly, and they're building an immune system to PrEP. They're building an immune system to Truvada, which is in every medication. (Focus Group D) Quote 7. Participant #1: "Is it possible that if someone takes it a certain amount of time that their body will somehow get immune to it?" Participant #2: "No, that's if you skip days. Like, if you don't take it how you're supposed to take it, your body will get immune to it so it don't work after a certain while." Participant #3: "Also there are side effects to it. So when you first start taking it you gonna get side effects but after a while you're not, because you get immune." (Focus Group H) Quote 8. When you were talking about the four days -- pills have half-lives, and anyone knows what a half-life is, it's when a pill gets into your body breaks down... Let's say the pill lasts 24 hours, so after four hours the pill would break down and be like three-quarters, and then the pill will break down to a half, then it will break down to a third until it's gone, which is basically the half-life of the pill. Let's say it takes four days for you to get to unprotected. So after the first day, you used about 1/4th of the pill. On the second days, the pill in your system is basically like a half, and then it goes down to a fourth. (Focus Group B)</p>

Table 3.

Modality Specific Questions and Concerns

Modality	Example Quotes
Theme 2.1 Daily Oral	<p>Quote 9. If you miss out on taking your PrEP days, do you double up the next day? Do you take more than one pill -- would you have to extend it? Like, let's say you don't take it today, Thursday, so like if I skip today, next week Friday, is it extended? Like when I'm about to finish -- like, for the 7 days? (Focus Group H)</p> <p>Quote 10. [What if you] take it for one week, and then next week when you're on vacation then you don't take it, then like when you come back then you resume it, then that will be okay? (Focus Group D)</p>
Theme 2.2 Long-Acting Injectable	<p>Quote 11. Why it [the long-acting shot] got to be in the butt? (Focus Group B)</p> <p>Quote 12. Yeah, like wouldn't you be sore [after the long-acting shot]? (Focus Group E)</p>
Theme 2.3 Microbicide Gel	<p>Quote 13. Say you gotta go to the bathroom, like you gotta pee or whatever? Don't that have to come out? It might drip out. (Focus Group C)</p> <p>Quote 14. How long does the effect last if you are using the gel? Let's just say I'm in the zone and I want to have a three-hour session. How long does that last? (Focus Group D)</p> <p>Quote 15. You be putting mad shit in your butt! You putting the thing [applicator with microbicide] in your butt, then you put the dick in your butt, and then putting the thing back in your butt. I think that's really messy, it would go all over the place. What do you do with that shit, the extra stuff? [...] I don't think it would really work because it's like everywhere, you know? I wouldn't feel safe. (Focus Group H)</p> <p>Quote 16. No shade, they're not letting you on the plane with that lube. (Focus Group E)</p>
Theme 2.4 Vaginal Ring	<p>Quote 17. Does [the ring] have a pressure or something? Or do you feel it? (Focus Group B)</p> <p>Quote 18. Wouldn't [the ring] cause rashes and infections and stuff? And throw off your PH balance? (Focus Group F)</p> <p>Quote 19. I like the ring. I just want to know if it's safe for the anus. (Focus Group A)</p> <p>Quote 20. You know how the condom has like the ring in the little pouch-- what happens if they do that for the ring? Make it look like you can put it in your butt. Like the trash bags, we call them trash bags. (Focus Group D)</p>

Table 4.

Side Effects and Interactions

Theme	Example quotes
Theme 3.1 Modality-Specific Concerns	<p>Quote 21. Daily Oral: One con I had for PrEP was I heard that Truvada is such a potent medication that it does affect the liver heavily. So that's like a thing where I kind of don't want to be on PrEP because it is affecting your body. I understand that all medications affect your body some way somehow, but when I heard that how potent the Truvada pill was compared to other medications, that kind of...[trails off]. (Focus Group D)</p> <p>Quote 22. I wanted to know how harsh it was on the body. Speaking to people who are positive and have been taking medication for long periods of time and seeing that it's not good on their body, and so my question always is if you're using a medication that's an HIV medication, then how harsh is it? (Focus Group G)</p> <p>Quote 23. Long-acting Injectable: My biggest concern with any type of medication or shots is when you have a medication or a shot that sustains you for that long, it has to have side effects.... So my question would be, what would be the side effects with that shot? Even though it's a good thing, it's just, that's a little scary to me. Cuz it has to be strong, it has to be. (Focus Group D)</p> <p>Quote 24. Monoclonal Antibodies: With the IV, seeing as how that's not a drug and that's an antibody, would that affect the antibodies that they already have inside their body? Like, does that mess with them in a way? That's still something foreign entering the body. Would your antibodies counter-react to those new ones now? (Focus Group D)</p>
Theme 3.2 Drug Interactions	<p>Quote 25. So if you're on prep, like are there any other drugs that you're not allowed to take? [...] both drugs like legal and illegal, are there any substances you're not allowed to take or mix with PrEP? (Focus Group D)</p> <p>Quote 26. What about if you smoke weed, because I smoke weed all the time. So would that affect me? (Focus Group C)</p>
Theme 3.3 Multiple Modalities	<p>Quote 27. Back to what I asked about doubling up on things. Because people most likely use the shot, and then they still gonna use the lube anyway. (Focus Group D)</p> <p>Quote 28. So what if I'm a person that wants to try how to take all of this in every way possible, would that mess me up? (Focus Group A)</p>

Table 5.

Specific Issues for Transgender Youth

Theme	Example quotes
Theme 4.1. Hormone Interactions	<p>Quote 29. 'I went to the doctor and I told her that I wanted to get back on PrEP and she was like, 'Okay.' But I asked, 'Is there a catch because I take 'mones [hormones]? Would it affect my body differently, because of the 'mones and PrEP?' (Focus Group D).</p> <p>Quote 30. 'What if you're wanting to transition and take hormones, would prep affect it?' (Focus Group A)</p>
Theme 4.2 Adding HIV prevention to an existing regimen	<p>Quote 31. 'I'm not pill taker, so I would say [I prefer] the shot, because I take hormones through shots. (Focus Group A)</p> <p>Quote 32. 'For me, I would stick with the pill because I do hormone pills so it's just another pill for me to take.'" (Focus Group A)</p> <p>Quote 33. 'Personally, I take hormones and my hormones are every day and the shots every two weeks. So with that [long-acting injectable PrEP] being every two months, it would fuck up my whole routine. Because I'd be used to taking something every two weeks or every day, and then I gotta wait every two months to take it. (Focus Group G)</p>
Theme 4.3 Implications for gender-affirming surgery and intervention	<p>Quote 34. 'You have some transgender women who end up having a surgery and get a vagina. Would that [vaginal ring] affect them?' (Focus Group A)</p> <p>Quote 35. 'Let's say a post op trans woman got her vagina or whatever... when like they dilating and stuff, they can use the gel? Like, when you first get your pussy, you know you gotta dilate for a while to keep it open before it closes on yourself. So then you could use the gel as lube and then you can kill two birds with one stone. (Focus Group E)</p> <p>Quote 36. 'So I have a question, so she said it [long-acting injectable] couldn't work with silicone. So what if somebody has they ass done and they can't get the shot?' (Focus Group E)</p> <p>Quote 37. '[Here's an idea] When I'm getting my PrEP shot given, have my street doctor [here], and I'm getting put with my sil [silicone] right after. It's like, take your turn. You [PrEP doctor] pump the left cheek, you [street doctor] pump the right, and then alternate. (Focus Group E)</p> <p>Quote 38. Participant #1: 'Would it double – would it make my ass fatter?' [Raucous laughter]</p> <p>Facilitator: "Wait, wait, wait. I just want to take a quick short-hand poll. Raise your hand if you would take the PrEP shot if it made your ass fatter? [laughing and talking] Keep your hands up! Let the record show that eight people raised their hands, OK. (Focus Group E)</p>