

Are Rights-Based Services Important? An Adolescent PrEP Demonstration Project in Brazil

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Abstract

In this study, we systematically examined the importance of human rights standards and principles for rights-based pre-exposure prophylaxis (PrEP) provision for marginalized adolescents. Nested within a demonstration study of PrEP provision to adolescent men who have sex with men, *travestis*, and transgender women, we carried out interviews in São Paulo, Brazil with 25 adolescents, eight health providers, and six workers involved in community-based demand creation. Analysis focused on participants' narratives about aspects of human rights within service delivery, including the availability, accessibility, acceptability, and quality of services; informed decision-making; nondiscrimination; and privacy and confidentiality. Clients and service providers highlighted the importance of availing a range of services beyond PrEP and described how community outreach and social media helped promote accessibility. Acceptability centered around clients feeling heard and respected. Health workers appreciated having time to build trusting relationships with clients to ensure quality of care and support informed decision-making. Nondiscrimination was valued by all, including using clients' chosen pronouns. Privacy and confidentiality were primary concerns for clients who were not "out" about their sexuality or PrEP use; to mitigate this, health workers sought to accommodate clients' preferred channels of communication. Rights-based PrEP services can help promote engagement and retention in PrEP services, particularly for marginalized populations.

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Introduction

Brazil's HIV response, initially spearheaded by grassroots organizations, and centered around the inclusion of sexual minorities, is considered one of the most successful among low- and middle-income countries. Its past success highlights the importance of guaranteeing universal access to marginalized populations and ensuring the provision of rights-based HIV services for all.

The World Health Organization recommends oral and injectable pre-exposure prophylaxis (PrEP), as well as vaginal rings for cisgender women, as part of combination prevention approaches for people at substantial risk of HIV infection.¹ In Brazil, daily oral PrEP has been available to adults through government-run health services since 2017; event-driven PrEP started to become available in 2022.² Since then, 88,625 adults have started PrEP, of whom 64,474 were still taking it in March 2023.³

Rates of HIV among adolescents continue to increase, highlighting their need for access to the widest possible complement of HIV prevention interventions.⁴ However, most PrEP intervention studies have been implemented in high-income countries and among adults; very few in any part of the world have included the 15- to 19-year-old population. A recent review of adolescent PrEP in the United States highlighted continued low uptake, while a demonstration study in Kenya and South Africa found high demand for and moderate uptake of PrEP among adolescent girls and young women.⁵ Key to ensuring adolescents' engagement, openness, and adherence is providing youth-friendly differentiated services and PrEP modalities based on upholding adolescents' human rights.

Attention to human rights in PrEP delivery

Consideration of human rights in health service delivery usually comprises attention to the right to health and its key standards of availability, accessibility, acceptability, and quality of services; active and fully informed participation; nondiscrimination; informed decision-making; privacy and confidentiality; and accountability.⁶ Table 1 outlines the ways in which these human rights standards and principles form the basis of our analysis.

The Convention on the Rights of the Child further elaborates rights specific to children (people under the age of 18) in the context of seeking and receiving health care.⁷ The Committee on the Rights of the Child has highlighted the importance of ensuring that children, parents, and health workers have adequate rights-based guidance on consent, assent, and confidentiality.⁸ However, relatively little literature exists on adolescents' evolving capacity, informed decision-making, and privacy and confidentiality in the context of PrEP, in part because of difficulties researchers (including ourselves) have experienced in securing ethical approvals for PrEP studies with adolescents where parental consent is waived.⁹

The degree to which, and ways in which, these human rights standards and principles are implemented in health service delivery can shape populations' experiences of accessing (or choosing not to access) health services, including PrEP services for adolescents who do not conform to cis-heteronormativity and who may be disadvantaged and discriminated against for this reason.

Access to HIV-related services in Brazil

In Brazil, there is a constitutional right to health, and the Health Care Law (Law 8080/90) organizes the Unified Health System (*Sistema Único de Saúde*, or SUS) and guarantees universal preventive and curative health care coverage.¹⁰ Health is seen as citizens' right and a duty of the state. Community participation in health is also guaranteed in the Constitution.

Despite Brazil's legal guarantee of "universal access" to PrEP through the SUS, there remain several socioeconomic-related barriers for adolescents. Past experiences of homophobia and transphobia at health services can discourage individuals from visiting PrEP sites. Some studies have found that individuals who are more open about their sexuality experience less access to PrEP, most likely due to increased experience of homophobia.¹¹ Nevertheless, individuals who are less open about their sexuality may also be more hesitant to ask their physicians for PrEP for fear of disclosing their sexual orientation.¹² Despite services being free, the

associated costs of reaching services can prevent access to PrEP, as adolescents are more likely to experience financial insecurity.¹³

Barriers to acceptability include misconceptions regarding the possible side effects, efficacy, and drug interactions of PrEP with gender-affirming hormones.¹⁴ Conversely, high patient knowledge regarding PrEP can facilitate acceptability.¹⁵

Brazil’s Child and Adolescent Rights Act allows for people aged 12 years and over to access health services without the consent or presence of their parents, and this notion is reinforced through Ministry of Health guidelines on adolescent health services.¹⁶ Since 2022, PrEP has been legally avail-

able to individuals above the age of 15 in Brazil.¹⁷

The Brazilian Code of Medical Ethics, with select exceptions, proscribes the disclosure of minor patients’ medical information, including to the patients’ parents or legal guardians.¹⁸ The ability to give informed and voluntary consent without guardian permission and guaranteed confidentiality are necessary to increase participation in PrEP programs.¹⁹

Some lessons can be gleaned regarding rights-based PrEP service delivery from current literature, but no study to date has systematically examined the full complement of standards and principles understood to underlie rights-based service delivery.

TABLE 1. Standards and principles central to a rights-based approach to health service delivery

Standard or principle	Relevance to a rights-based approach to health service delivery*
Participation	Every person is entitled to active, free, and meaningful participation in, contribution to, and enjoyment of civil, economic, social, cultural, and political development. Ensuring the inclusion and full participation of key stakeholders and affected communities at every stage of health programming is an essential component of a rights-based approach to health.
Equality and nondiscrimination	Health services and programs should respect, protect, and fulfill the rights to equality and to nondiscrimination for all people. This may require specific efforts to reach populations who may be marginalized or disadvantaged.
Informed decision-making	The principle of autonomy, expressed through free, prior, full, and informed decision-making, is a central theme in medical ethics and is embodied in human rights law. In order to facilitate informed decision-making, comprehensive information, counseling, and support should be made accessible for all people without discrimination, including young people, persons living with disabilities, Indigenous peoples, ethnic minorities, people living with HIV, and transgender and intersex people.
Availability	Availability requires making available in sufficient quantity functioning health care facilities, goods, services. Although varying by context, these should address the underlying determinants of health, including safe and potable drinking water; adequate sanitation facilities, hospitals, and clinics; trained medical personnel; and essential drugs.
Accessibility	Accessibility encompasses four distinct components, all of which require special attention to the most vulnerable and affected populations: Nondiscrimination: Health facilities, goods, and services must be accessible to all. Physical accessibility: Health facilities, goods, and services must be physically accessible to all. Affordability: Health facilities, goods, and services must be affordable for all, yielding accessibility of needed services, whether privately or publicly provided. Access to information: Includes the right to seek, receive, and impart information and ideas concerning health issues but does not impair the right to have personal health data treated with confidentiality.
Acceptability	Acceptability requires that all health facilities, goods, and services be respectful of medical ethics and culturally appropriate, sensitive to sex and life-cycle requirements, and designed to respect confidentiality and improve the health status of those concerned.
Quality	Quality requires goods and services to be scientifically and medically appropriate and of good quality. This means having skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.
Accountability	Governments are accountable to their populations and to the international community for their actions that have an impact on health and development. Accountability mechanisms exist at local, national, regional, and international levels to monitor compliance and support governments in fulfilling their human rights obligations.

* S. Gruskin, L. Ferguson, S. Kumar, et al., “A Novel Methodology for Strengthening Human Rights Based Monitoring in Public Health: Family Planning Indicators as an Illustrative Example,” *PLOS ONE* 12/12 (2017); S. Gruskin, D. Bogecho, and L. Ferguson, “‘Rights-Based Approaches’ to Health Policies and Programs: Articulations, Ambiguities, and Assessment,” *Journal of Public Health Policy* 31 (2010).

The PrEP 1519 study

In 2017, Brazil adopted HIV PrEP as part of a combination prevention strategy for the most at-risk populations. However, at that time, Brazil did not have specific guidelines for PrEP use among adolescents under 18.²⁰ Along with a broader team of colleagues, we carried out PrEP 1519 as a demonstration study to assess the effectiveness of oral daily PrEP and demand creation strategies to engage adolescent men who have sex with men, *travestis*, and transgender women in PrEP services and link them to other HIV- and sexual health-related services in three cities in Brazil.²¹ Effectiveness results have been presented elsewhere.²²

This paper presents findings of a sub-study, nested within PrEP 1519, that examined the ways in which study participants in São Paulo spoke about different aspects of human rights within service delivery and how that mattered to them.

In the bigger PrEP 1519 study, we sought to help inform the Ministry of Health on how best adolescent PrEP might be delivered within the SUS, taking account of challenging questions such as evolving capacity, consent, and confidentiality.²³ In this sub-study, our aim was to help inform how these PrEP services can be designed and delivered in a rights-based manner. With our focus on providing HIV information, goods, and services to marginalized men who have sex with men and transgender women, it might be described as a rights-based intervention.

A combination of online and face-to-face peer-led demand creation strategies and direct referrals from health services and nongovernmental organizations was used to enroll adolescents from diverse socioeconomic backgrounds in PrEP services. In São Paulo, between January 2019 and March 2021, 458 adolescent men who have sex with men and transgender women were recruited to the study, 354 of whom chose to initiate PrEP immediately and 104 of whom chose not to initiate PrEP immediately but to have access to combination prevention services, including post-exposure prophylaxis and HIV self-testing. Peer navigators who were health professionals or young LGBTQ+ people accompanied participants throughout the study

to support adherence to PrEP and retention in care. WhatsApp was used as the primary form of communication with clients, with other social media outlets, including an artificial intelligence chatbot also used. The COVID-19 pandemic required some activities to be carried out remotely.

Methodology

Study site

PrEP 1519 services in São Paulo were organized in a counseling and testing center (CTC) managed by the Municipal Health Department and located in an area of high HIV incidence. Prior to the study, the well-established CTC already provided testing for HIV and sexually transmitted infections (STIs) to a large clientele, primarily men who have sex with men. It was staffed with a multidisciplinary team, which the study augmented, including by the addition of a doctor to manage HIV and STI treatments and the initiation of PrEP. The CTC is open every weekday until 7 p.m.; walk-ins are welcome for new clients.

Participants

Between June 2019 and February 2021, we carried out 25 interviews with adolescents enrolled in PrEP1519, eight with health providers who worked at the CTC, and six with workers involved in community-based demand creation strategies.

The qualitative investigation purposively sampled adolescent participants from within PrEP 1519 according to social markers, experiences of care, and access to the PrEP services. We aimed to interview clients who (1) self-identified as cisgender men, transgender women, *travestis*, or gender fluid; (2) represented the age range of adolescent participants (15–19 years); (3) reported diverse sociodemographic characteristics; (4) had different experiences related to adherence to PrEP; (5) used additional preventive methods; and (6) enrolled in the study through different demand creation strategies. Health providers helped identify potential participants. Subsequently, peer navigators and health providers facilitated the invitation to participate in this sub-study.

All health providers from the PrEP clinic and workers involved with the community-based strategies were invited to participate. We then established contact to arrange the best private place and type of interview (in person or remote). Due to COVID-19-related restrictions, from March 2020 onward the interviews were conducted remotely.

Data collection and analysis

The interviews with adolescents covered a wide range of topics, including perceptions of the demand creation strategies, access to PrEP services, and interactions with providers. Interviews with health providers explored perceptions of the impact of PrEP use for adolescents, barriers and facilitators to accessing services, and perceptions of the strengths and weaknesses of the services.

Interviews were carried out in Portuguese by trained Brazilian researchers. They were audio recorded and transcribed verbatim. Data were imported into and analyzed in NVivo in Portuguese by bilingual researchers. They were thematically coded using a coding scheme based on key human rights standards and principles widely recognized as the foundation of human rights-based health service delivery. We created matrixes to help identify patterns in the data, particularly between health workers and service users.

Results

This section provides an overview of participant characteristics and then organizes our findings by the human rights standards and principles that form the basis of the conceptual framework outlined above.

Participant characteristics

Tables 2 and 3 offer an overview of participants' characteristics, using their own self-descriptors.

Adolescent participants, who were all recruited into the PrEP1519 study when they were between the ages of 15 and 19, were aged between 17 and 20 years old at the time of these interviews. Seventeen self-identified as men, six as transgender, one as *travesti*, and one as gender fluid. Fourteen

self-identified as homosexual, four as heterosexual, three as pansexual, two as bisexual, one as bisexual and asexual, and one as a lesbian. Fifteen participants referred to their skin color or race as Black or Brown, nine as White, and one as Indigenous.

Four health providers self-identified as men, three as women, and one as nonbinary; they were aged between 25 and 52 years old. Six self-identified as homosexual or gay, and two as heterosexual. Three self-identified as White and three as Black. Three participants were doctors, three were psychologists, one was a medical technologist, and one was a nursing technician.

Workers involved with community-based strategies self-identified as cisgender gay men and were aged between 21 and 37. Two self-identified as Black, two as White, and one Yellow. (Classification of race and skin color was self-reported and based on the categories "White," "Black," "Brown," "Yellow," and "Indigenous," which are used by the Demographic Census of the Brazilian Institute of Geography and Statistics).

Availability

Very little emerged through the interviews in relation to the availability of PrEP services, as the demonstration study centered on the provision of PrEP for 15- to 19-year-olds. There were no reported challenges with the availability of medications, supplies, or health workers.

Health workers and clients alike noted the value of having multiple services available in a single location so that visits to the health facility were not solely about PrEP and could help meet a broader range of young people's needs, such as STI treatment, psychological support, referral and navigation to other services (including gender-affirming care), and diagnostic services for HIV, STIs, and hepatitis:

She helped me with other issues too, like my psychological issues. I have a kidney problem and she ordered tests for me, you know? [She showed] a general concern for my health, not just PrEP alone. I liked that the best. (Jonathan, Brown man who has sex with men)

TABLE 2. Adolescent participants' characteristics

	Number of adolescents
Gender identity	
Cisgender man	17
Transgender	1
Transgender woman	5
<i>Travesti</i>	1
Gender fluid	1
Age	
17	4
18	6
19	7
20	8
Race	
Black	7
White	9
Brown	8
Indigenous	1
Education	
Incomplete basic education	1
In high school	5
Incomplete high school	1
Complete high school	8
In university	10
Sexual orientation	
Homosexual	14
Lesbian	1
Pansexual	3
Bisexual	2
Bisexual and asexual	1
Heterosexual	4
Entry point to the project	
Spontaneous demand for CTC	14
Peer-led demand creation strategies:	11
• Community outreach	5
• Hookup app (Grindr)	2
• Social media (Amanda Selfie)	1
• Referrals from nongovernmental organization (Casa 1)	3

Accessibility

Interview participants noted the challenges associated with the accessibility of services in a city as large as São Paulo. The CTC is near a metro station, which somewhat facilitates access; however, for clients who live far away, transportation time and money can be a barrier. To overcome this, the project covered transport costs for some adolescents, which participants noted as a facilitator of access. In some cases, peer navigators met clients and accompanied them on the trip to the health facility or inside the CTC from the front desk through to the appointment with the PrEP prescriber. Peer navigation can help, particularly if clients are coming from distant neighborhoods, if they are visiting health services and the center of the city for the first

time, or if they are concerned about experiencing violence on public transportation. Highlighting the efforts made to help make care accessible, a counselor noted:

There's the real world and then there's PrEP 1519, which is us taking people by the hand. (Dante, Black gay counselor)

For some participants who work or study full time or live far away, it was a challenge to access services during regular working hours. The availability of walk-in appointments was useful for some adolescents who felt that they needed to address health concerns immediately. For health workers, their experience with social media highlighted the im-

TABLE 3. Health professionals' characteristics

	Number of CTC health professionals	Number of outreach staff
Gender identity		
Cisgender man	4	6
Cisgender woman	3	
Nonbinary	1	
Age		
21–25	1	4
26–30	3	1
31+	4	1
Race		
Black	3	2
White	3	2
Brown	1	
Other	1	2
Sexual orientation		
Homosexual	3	
Gay	3	6
Heterosexual	2	
Occupation		
Doctor	3	
Nurse/nurse technician	1	1
Psychologist	3	1
Medical technologist	1	
Undergraduate student		3
Health promotion agent		1

portance of extending the clinic's opening hours, since clients frequently responded to messages during evenings and weekends.

The ability to communicate with study staff through social media was highly valued by most study participants. Designed to facilitate rapid communication, WhatsApp was the primary avenue for communication between health workers and clients for recruitment, linkage to care, and retention. Interview participants described the frequent use of WhatsApp for project communication—and clients also acknowledged “Amanda Selfie,” the transgender chatbot with which they could interact—as useful. The use of social media made information readily accessible to clients and helped them understand when they needed to attend the facility and when their concerns could be allayed virtually.

Participants, particularly the adolescent men who have sex with men, reported that the project's demand creation—recruiting participants at venues where the target populations spend time, as well as through apps such as Grindr—made the idea of PrEP more accessible because it could be immediately explained to them in a space in which they were comfortable.

Acceptability

Clients appreciated the demand creation strategies, including social media and community outreach. One client described apps as “a young universe,” noting that this is why it is a comfortable space for them. A project psychologist, who is Black and openly gay and recruited study participants from known gay hangout spaces, spoke about how this helped him build rapport with other gay men, making them feel comfortable with the idea of PrEP and going to the health facility. When asked what makes a good counselor, he responded:

You have to be ready to listen, right? Listen to what that person has to say without any judgment because they already experience enough judgment, right? Whether it's because of their sexual orientation or gender identity. I think it's great for a health professional to really be able to listen. (Dante, Black gay counselor)

The importance of listening, as well as of clients seeing themselves represented in the health workers in the study clinics, was also articulated. Clients noted that the informality of not using titles such as “Doctor” helped them feel comfortable, and one health worker reported playing pop music to help clients relax. Clients also provided positive testimony of being well-received, listened to, respected, and given good care. They felt comfortable “unloading” on staff, being honest, and, at times, crying. Staff, from the receptionists to phlebotomists and nurses, were praised highly. Clients noted that health workers make a real effort to connect with clients, not just provide the medical service:

I felt like they're really committed to connecting with the people who go there ... And talking to the doctor, she was really kind and well-disposed. She explained and went over everything about PrEP and [post-exposure prophylaxis] and about protection and STIs, etc. She was really kind ... She spoke in a way that I could really understand. And I loved this. I thought she was a sweetheart. (Camélia, Brown trans woman)

A project psychologist spoke of the importance of the staff reflecting some of the characteristics of the clients:

They say “I love it. You're all gay there.” And there are also trans people wandering around. So, it's no longer a health service where there are only health workers who sometimes are gay, but they don't talk about sexual orientation, but somewhere where professionals who are empowered, right? Professionals who can say “Look, I'm gay and that's just a part of me.” So [clients] end up feeling really comfortable, you know? To talk about their practices because in some way or other, “You're going to understand me.” (Dante, Black gay counselor)

Participants described staff listening without judging, having honest conversations with them, and working with them to find the best solutions for their situation.

Quality

Clients reported positive experiences within the health facilities, including how they were received,

supported, and given information. Many participants were effusive in their praise for PrEP services and staff:

Top marks for all of them. They're wonderful, attentive, polite... perfect. (Jade, White transgender woman)

I think it's the best service that I've ever had in my life. All the doctors in Brazil should be like [this doctor]. (Jonathan, Brown man who has sex with men)

One participant (Renato, a Black man who has sex with men) described how when he told the doctor that he had not been adhering to his medication, instead of making him feel guilty she sought to understand why adherence was hard and congratulated him for being at his appointment.

Health workers noted the importance of a “pro-client” space, recognizing their responsibility for creating an atmosphere and relationship of trust. They reported that active listening, empathy, and team motivation were key attributes of this space.

All project staff seem well-attuned to the need to ensure that information is communicated in ways that are appropriate for young people. This might include using slang specific to the different client populations, making sketches, or simply covering material multiple times:

The approach is always formal, polite, and inclusive, you know? And sometimes it's even informal ... to see if the person relaxes and feels comfortable ... And I think it helps a lot. (Benjamin, Black man who has sex with men)

An important theme across health workers' narratives was the value of building relationships of trust over time. Many noted that it can take young people time to open up, particularly about their sexuality or about life challenges such as experiences of violence. This means that continuity of care, including offering the same providers repeatedly, is important for gaining a fuller understanding of young people's lives.

One peer navigator highlighted concerns

around many health workers' ability to provide this type of care:

Everyone knows that not all health professionals are equally available to their clients, not all have the same listening skills, and, mainly, when people talk about PrEP they talk about sexuality, sexual orientation, and gender identity so the health professional has to be trained to know that transgender is not about sexual orientation, and being gay doesn't define someone. (Dante, Black gay counselor)

Some health workers noted their workload as another challenge, which can limit the time they have to spend with each client, negatively affecting the quality of care.

Two examples of internal quality control were (1) weekly meetings to discuss complex cases and any seroconversions to identify shortcomings in service provision and (2) monthly meetings between the health professionals and experts specializing in youth, gender identity, and human rights.

Participation

Even as community members participated in the design of demand creation activities, clients did not participate in the design of the study or service delivery model. Questions were not asked about community participation in HIV service delivery more generally, even though this is a core tenet of the Brazilian health system.

Informed decision-making

Health workers reported that clients often arrive at the health facility with little knowledge of PrEP, misconceptions often picked up online (such as not being able to take PrEP alongside alcohol), and associations of PrEP with promiscuity rather than risky sexual behaviors. They noted that young people have questions about sexual practices and risk, but many are embarrassed to ask health workers about these issues.

Health workers and peer navigators noted the importance of both the content of information provided and its accessibility—that is, using simple, clear language. It was important to them that there be a range of prevention options available

that clients can choose from based on their needs and preferences. A counselor described his role as facilitating clients' informed decision-making:

The best method of prevention is the one that the client chooses for themselves ... "I'm here to allow you to choose, right? I'll give you information. We'll think it through together." (Dante, Black gay counselor)

Another health worker, when asked how he deals with behaviors such as stopping condom use when on PrEP, answered:

Without any moralizing, without imposing anything. My job is to provide correct information. (Enzo, White gay health worker)

Health workers acknowledged that even when they would not choose the client's approach (e.g., PrEP on demand), they recognize everyone's right to make their own choices, so they provide full information, thus building clients' capacity to make autonomous, well-informed decisions in their own best interests. They also tailor messages to each client's reality:

I think that what I like about supporting linkage to care is that you can't mass produce it—you know, copy-paste the message? That doesn't work with linking. You have to really hear these people starting with their lived experiences, and you sometimes give advice that might seem universal, but you have to adapt it to the life of that person. (Dante, Black gay counselor)

Health workers noted difficulty with the dissemination of information, particularly to younger clients. Clients suggested that social media, such as Instagram and TikTok, be used more for sharing information about PrEP, explaining that some of the study staff share good sources of reliable HIV information on social media. Participants who, for a variety of reasons, stopped using PrEP, cited access to information as an important reason for staying in the study even when no longer on PrEP.

Health workers also spoke about the additional responsibility they felt when dealing with clients under the legal age of majority (18 years).

They described assessing adolescents' capacity by "what they say, how they behave, the questions they ask" (Antonela, White cisgender doctor). Health workers discussed how best to assess adolescents' capacity during their regular meetings so as to ensure that they followed the law and protected the person's best interests.

There were some reports of clients using PrEP on their own schedule rather than following clinical advice. Health workers described the need to ensure that clients understand why PrEP is important to them: they have to want to take it if they are going to adhere to the medication.

Nondiscrimination

Health workers explained that many clients experience discrimination within their own families, making it even more important that they be accepted as they are within the health facility. Health worker attitudes were seen as critical to the success of these services, particularly for clients outside mainstream society such as people who use drugs or people experiencing homelessness.

Some health workers acknowledged struggling with neutral pronouns or using the right pronoun for trans adolescents, even as they all said they were trying and were aware of the importance. A client highlighted feelings of alienation when correct names and pronouns are not used:

I simply didn't want to go to a dermatology appointment because the laboratory had put my birth name on the document ... And this is a tough situation that I know a lot of trans people go through. (Jade, White transgender woman)

One participant (Jackson, a Black pansexual man) described a difficult situation outside the study where he was discouraged from taking PrEP because of his young age, with the health worker suggesting that he use condoms instead.

Privacy and confidentiality

Many clients reportedly disclose their PrEP use very selectively for fear of people not understanding. Health workers noted the sensitivity required in ensuring total privacy for adolescents.

Often, families do not want to accept their child's sexual orientation or even sexuality and are not supportive of the adolescent using PrEP or other HIV prevention methods. Health workers seek to support adolescents through these challenges, including guilt induced by religious or conservative parents. Despite challenges accessing the CTC, many clients appreciated that it was not in their local neighborhood because it afforded greater privacy. Some adolescent men who have sex with men also felt that WhatsApp was a good channel to use for maintaining privacy since it was harder for their parents to access than their email or mail.

When the study started distributing PrEP by mail due to COVID-19, some people dropped out, fearing that their families, who were unaware of their PrEP use, might see the medications. Some clients requested in-person appointments throughout the pandemic because their family did not know that they were gay or on PrEP, which the project sought to accommodate.

Accountability

Only one health worker spoke about accountability, reporting that most young people who access services are not aware of their rights or of available complaint mechanisms, which could leave them vulnerable to ill-treatment.

Discussion

PrEP 1519 showed that it is feasible to deliver PrEP to adolescents through Brazil's public health services. It also highlighted the importance of strategies of demand creation, linkage to care, and retention in care. With PrEP now legal for adolescents aged 15 and over, it is critical that the government scale up these services in a way that promotes the engagement and retention of adolescents, including those from marginalized populations. This sub-study has highlighted the human rights dimensions of service delivery that can help inform this scale-up.

The provision of adolescent PrEP is a new concept in Brazil and thus requires investments to prepare facilities, particularly capacity building relating to technical and cultural competency. To

facilitate the integration of adolescent PrEP into routine service delivery in Brazil, it will be useful to integrate PrEP clinical directives within standard health care directives, including pre- and in-service medical education. Attention to each of the human rights standards and principles, and direction on how to operationalize them, will be key.

General recommendations across the areas of health policy, health systems, capacity building, and communication are explored below under the subheadings of the human rights principles explored in the findings.

Availability, accessibility, acceptability, and quality of PrEP services

The Brazilian health system is designed to provide a wide range of integrated services. Many study participants appreciated the range of services available to them beyond PrEP and health workers' efforts to understand them as whole, complicated people rather than just as presenting a single, acontextual medical need, speaking to the importance of this approach.

While participants in our study did not highlight the availability of PrEP as a problem, we were analyzing a situation where adolescent PrEP was available and many demand creation strategies were in place. This is not the case in most places, and scale-up is urgently needed. As with any new health technology, it is critical that new strategies focus on ensuring that the most vulnerable populations can be reached to avoid exacerbating preexisting inequalities. This will require a health systems approach to ensure, for example, a reliable supply chain, sufficient laboratory infrastructure, and a trained workforce, as well as differentiated services and PrEP modalities. Strengthening and expanding other services, including mental health services, may also be needed.

Community health services, community outreach, and demand creation can play important roles in reaching large numbers of adolescents and promoting the availability of adolescent PrEP, including by reducing transport cost and time. However, previous studies have highlighted a need to go beyond the provision of information to ad-

olescents and to support their journey to health services and create a trusting relationship with health professionals.²⁴ Low enrollment in this study may have been due to the limited accessibility of services (i.e., having a single study clinic at the time of this qualitative study), as well as to the dynamics in adolescents' relations that often shape risk perception (e.g., switching between casual sex and steady partners) and concerns over privacy and confidentiality.

Successful programs must address medical distrust and improve physician care to increase PrEP accessibility and acceptability. Many studies reveal the importance of physician-centered programs aimed at improving providers' knowledge surrounding PrEP and their ability to provide affirming care and to reduce stigma-related barriers.²⁵ Improving providers' knowledge ensures that they are fluent in the risks and side effects of PrEP, especially the potential drug interactions with gender-affirming hormones for transgender clients.²⁶

Like many others, our study participants noted the importance of providers using their chosen name and pronoun, but we also found some health workers worrying that they were not sure of the best language and approach to use. Cultural competency training is necessary to improve physicians' ability to provide non-judgmental care for adolescents and to promote the use of inclusive language.²⁷

Our study findings show that recognizing health facility staff as open members of the LGBTQ+ community made participants feel more comfortable and improved their trust in providers. Interventions to ensure that health facilities are seen as safe spaces for health workers and clients in all their diversity can also help promote overall comfort with and trust in these services. Making sure that health workers feel valued is a core piece of this.

Health worker discussions of complex cases and seroconversion of any client on PrEP are a useful quality-control practice that might be adopted in policy relating to all PrEP and combination prevention services. The measures put in place to promote retention in services during the COVID-19 pandemic provide lessons on how to

sustain follow-up on PrEP for different profiles of adolescents.²⁸

Participation

Limited attention to the participation of affected communities in service design and implementation constitutes a weakness of our demonstration study. This is an area for development in future intervention efforts, including government scale-up processes.

Informed decision-making

Health workers should be well-versed in identifying high-risk individuals and providing them PrEP-related information.²⁹ Furthermore, PrEP information should be available to everyone in order to ensure that at-risk individuals are aware of PrEP regardless of whether they feel comfortable disclosing their sexual orientation or gender identity.³⁰ Low knowledge about PrEP among adolescents highlights the need for better communication to reach different adolescent populations, as well as for addressing the social and structural inequalities that drive vulnerability to HIV and limited access to relevant information.³¹

Globally, many programs have successfully addressed PrEP-related stigma by diversifying PrEP messaging. Since most PrEP messaging is targeted toward men who have sex with men, messages could specifically depict and target transgender women and cisgender, heterosexual populations.³² Dissemination of PrEP-related information through leaders in the LGBTQ+ community and peer-education models can also increase access.³³

Social media was found to be a critical channel of communication with adolescents in this study, partly because the study took place during COVID-19 lockdowns, but also because adolescents are so immersed in the world of social media. There is increasing support for the use of social media and dating apps to reach individuals who are not publicly "out."³⁴ As governments make adolescent PrEP increasingly available, social media provides ample opportunities for adolescent-friendly outreach and communication.

In the context of adolescent health service

delivery, capacity building around evolving capacity and informed decision-making is particularly important. Health workers in Latin America have been found to feel ill-equipped to determine adolescents' decision-making capacity, which can impede service provision.³⁵ Helping health workers assess capacity, talk openly about sensitive topics, and trust adolescents' capacity to make informed decisions are central components of capacity building. A socio-relational perspective of autonomy may bring light to the understanding that a person's evolving capacity is unique and is embedded in a social context that is constantly changing and is shaped by emotions, needs for social validation, and the goal of protecting a common good for collective well-being.³⁶ Therefore, rather than health worker capacity building focusing on a single "right" answer that works for everyone, it could be more guided toward building consensus and mapping out sources of support.

Nondiscrimination

Although some interview participants expressed concern about providing adolescent PrEP services for sexual and gender minorities through public health facilities nationwide, even prior to the study this health center already had strong and diverse staffing. The medical doctor was the only new staff member added, as there was no need for a doctor when the health center provided only STI and HIV testing. The project reoriented services to be more people centered—that is, managing health care according to each adolescent's needs and social vulnerability. This included expanding opening hours, redefining some staff roles, and allowing longer and more frequent consultations. This suggests that with training and reorganization, a similar level of service provision would seem feasible in other facilities.

Privacy and confidentiality

Concerns around privacy and confidentiality are often at the forefront for adolescents, particularly in relation to sexual health, HIV, sexuality, and gender identity, which has been found to hinder PrEP adherence among adolescents.³⁷ It is essential that

service providers understand the importance of privacy and confidentiality for adolescents, as well as the legal protections in place that permit them to provide PrEP-related information and services to this age group.

Accountability

There exists a strong legal and policy framework in Brazil within which the government can be held legally accountable for ensuring adolescents' access to PrEP (and associated) services. While conservative political forces have sought to dismantle comprehensive sexuality education and undermine sexual rights in recent years, the election of the current administration in late 2022 signals hope for a reprioritization of health for all within Brazil.³⁸

Limitations

Our study took place in São Paulo, a large city with a high concentration of HIV services compared to most other parts of Brazil. Different or additional challenges with scale-up of adolescent PrEP may be faced in other places.

Even as we know that racial and ethnic identity affect PrEP accessibility and acceptability, and that racial marginalization within the LGBTQ+ community decreases people of color's access to information and resources, we were unable to analyze potential differences in attitudes toward rights-based services by race or ethnicity.³⁹

Conclusion

Given the very limited evidence available on PrEP service delivery for adolescents globally, these lessons might inform countries beyond Brazil as they consider introducing or scaling up adolescent PrEP. The value accorded—by clients and service providers alike—to the human rights principles explored above is clear. Human rights provide a useful framework for assessing system preparedness and capacity for providing youth-friendly services, particularly to marginalized adolescents. Rights also highlight what matters for clients and providers, which can promote better service delivery and improve relationships between clients and providers.

Providing adolescent PrEP, including for sexual and gender minorities, requires taking into account that current generations are characterized by a social representation of HIV as a mild disease, as well as new and more fluid gender and sexual identities. Adolescents and youth pursue greater protagonism in affective and sexual interactions, which includes more frequent use of dating apps and substances in sexual relations. The growing conservatism that has constrained the involvement of different sectors of society and weakened the response to HIV has resulted in a generation with fewer resources to deal with the epidemic.⁴⁰ This study provides useful insights into how countries can design and implement rights-based adolescent-friendly PrEP services that help promote engagement and retention in PrEP services, particularly for marginalized populations. A shift in HIV policy is needed to achieve this goal by prioritizing PrEP in the provision of preventive methods while addressing the social determinants of the HIV epidemic and guaranteeing meaningful participation of adolescents in shaping the policy.⁴¹

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Ethics approval

This study was conducted according to the directives derived from the Brazilian Research Ethics Commission Resolution 466/2012. The protocol was approved by the Research Ethics Review Committee of the World Health Organization (protocol ID: Fiotec-PrEP Adolescent study) and by the University of São Paulo (protocol number 707980173.0000.0065). Written informed consent and assent were asked for those who agreed to participate, and they could withdraw their consent at any stage of the process without penalty, or skip any questions they perceived as too sensitive, personal, or distressing.

Translation

All translations from Portuguese to English were performed by the authors.

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