Austin Journal of HIV/AIDS Research

Open Access

Austin Publishing Group

Research Article

Community-Led Monitoring of Youth-Friendly HIV Services in Rwanda: Learnings from a National Dialogue with Young People Living with HIV

Gerard Kaberuka[1]*, Jean Berchmans Tugirimana[1], Deo Mutambuka[1], Anne Pirotte[2], Gallican Nshogoza Rwibasira[3], Jelena Bozinovski[4], Susan Perez[5], Soeurette Policar[6] and Tapiwanashe Kujing[7]

[1]Rwanda Network of People Living with HIV/AIDS (RRP+), Kigali, Rwanda, University of Rwanda, Kigali, Rwanda

[2]Deutsche Gesellschaft für Internationale Zusammenarbeit GmbH (GIZ), Strengthening the Rights-Based Approach in Civil Society Organisations, Kigali, Rwanda

[3]Rwanda Biomedical Center, Kigali, Rwanda

[4]Community Data & Advocacy Manager, International Treatment Preparedness Coalition - ITPC Global

[5]Specialist, Community-led Monitoring (CLM), Community, Rights and Gender Department, Global Fund to Fight AIDS, Tuberculosis and Malaria, Geneva, Switzerland

[6]CLM Coordinator for the Civil Society Forum, Port - au-Prince, Haiti

[7]Director, Pan-African Treatment Access Movement (PATAM), Harare, Zimbabwe

***Corresponding author:** Gerard Kaberuka, Rwanda Network of People Living with HIV/AIDS (RRP+), Kigali, Rwanda, University of Rwanda, Kigali, Rwanda

Email: kagerard2005@gmail.com

Received: December 03, 2025
Accepted: December 25, 2025
Published: December 31, 2025

Abstract

Background: Young people living with HIV (YPLHIV) in Rwanda face significant challenges in accessing and consistently engaging with HIV services. This disconnects between policy intentions for youth-friendly care and their lived realities often leads to inadequate service delivery. Existing services frequently fail to address the unique needs and concerns of this vulnerable population. This Community-Led Monitoring (CLM) initiative aimed to identify barriers and facilitators encountered by YPLHIV in accessing and utilizing HIV services in Rwanda. CLM is a community-driven process where affected communities systematically collect, analyze, and use data to advocate for improved health services; it was chosen for this initiative to empower YPLHIV as leaders in monitoring and shaping solutions based on their lived experiences. To achieve this, a multi-step participatory dialogue process was employed to synthesize program learnings and insights. This process involved focus group discussions with YPLHIV across seven districts, community dialogues, and a national dialogue. The national dialogue utilized a marketplace format for presentations and plenary discussions, fostering shared ownership and consensus on recommendations.

Methods: This Community-Led Monitoring (CLM) approach employed qualitative, descriptive, and participatory program learning methods to triangulate perspectives, validate findings, and ensure recommendations were grounded in both youth experiences and stakeholder expertise. As part of the CLM process, Young People Living with HIV were actively engaged through focus group discussions across seven districts, community dialogues, and a culminating national dialogue. The national dialogue used a marketplace format for presentations and plenary discussions, fostering shared ownership and consensus around co-created recommendations from youth.

Findings: Through this Community-Led Monitoring process, Young People Living with HIV actively revealed that current youth-oriented HIV services in Rwanda often lack true youth-friendliness. Key barriers identified by youth included pervasive stigma and discrimination, breaches of confidentiality and lack of privacy in service delivery (e.g., shared waiting areas and co-located services), judgmental attitudes and inadequate communication from healthcare providers, and operational inefficiencies within health facilities (e.g., long waiting times and mixed appointments with adults). Conversely, crucial facilitators of engagement and adherence emerged from these youth-led dialogues, including the provision of comprehensive psychosocial support and mental health services, the effectiveness of youth-led and peer-supported approaches, and the need for accurate, youth-friendly information and messaging. The participatory CLM process culminated in actionable recommendations co-created with youth, including establishing confidential ARV service points, implementing dedicated youth-friendly testing days, expanding youth-targeted counseling and mental health support, and scaling up youth-led peer education initiatives

Conclusion: The actionable recommendations, co-created with young people living with HIV through participatory dialogue, provide a clear roadmap to improve the accessibility, quality, and youth-friendliness of HIV services in Rwanda. Grounded in youth experiences and priorities, and centering on youth-friendly spaces, integrated mental health support, peer-led initiatives, and accurate information, these recommendations address their comprehensive needs. Findings were shared with health facility leadership, national program managers, and relevant decision-makers during validation and dissemination workshops. In response, actions were agreed to and began, including confidential ARV service points, dedicated youth-friendly testing days, expanded youth-focused counseling and mental health support, and scaling up youth-led peer education. As these actions are implemented, YPLHIV are experiencing more private, youth-centered services, enhanced psychosocial support, and clearer information, which are contributing to improved engagement in care and better health outcomes.

Citation: Gerard Kaberuka, Jean Berchmans Tugirimana, Deo Mutambuka, Anne Pirotte, et al. Community-Led Monitoring of Youth-Friendly HIV Services in Rwanda: Learnings from a National Dialogue with Young People Living with HIV. Austin J HIV/AIDS Res. 2025; 11(1): 1059.

Introduction

Globally, significant strides have been made in the fight against HIV, with expanded access to antiretroviral therapy contributing to a substantial reduction in AIDS-related deaths and improved quality of life for many living with the virus [1]. Despite this progress, new HIV infections persist, particularly among adolescents and young people aged 15-24 years, who accounted for approximately 27% of new global infections in 2022 [2]. Young women in particular bear a disproportionate burden, with adolescent girls and young women representing 66% of new infections among adults aged 15 and older [3]. These demographic trends highlight a critical challenge in achieving the UNAIDS 95-95-95 targets, which aim to ensure that 95% of people living with HIV are aware of their status, 95% of those diagnosed are on antiretroviral therapy (ART), and 95% of those on ART achieve viral suppression [4,5].

The challenge is especially acute in sub-Saharan Africa, which continues to bear the highest global burden of HIV [6]. In 2023, an estimated 89% of the 1.47 million adolescents and young people living with HIV worldwide were in SSA. This region sees adolescent deaths from HIV continue to rise, even as they decline in other age groups. Young people living with HIV in SSA often experience poorer treatment outcomes, including lower rates of viral suppression and higher rates of mortality and loss to follow-up, compared to adults. This can be attributed to a confluence of factors including pervasive HIV-related stigma [6-8], judgmental or discriminatory attitudes from health providers, food insecurity which can impact ART adherence, and a critical lack of tailored psychosocial support [9,10]. Mental health issues, such as depression and anxiety, are prevalent among YPLHIV in SSA and can adversely affect ART adherence [11,12]. These complex barriers necessitate context-specific and youth-centered interventions, as one-size-fits-all prevention programs are often ineffective.

Rwanda has made substantial strides in its national HIV response, yet young people living with HIV continue to encounter specific obstacles [13]. These challenges include pervasive stigma, judgmental services, and socioeconomic issues such as food insecurity, which impede their access to quality care, treatment adherence, and overall well-being [14,15]. Moreover, young people living with HIV in Rwanda often grapple with emotional distress, including suffering, depression, and isolation, highlighting the urgent need for accessible psychosocial support [16]. Despite national guidelines emphasizing accessible, acceptable, appropriate, and effective adolescent-friendly services, their practical implementation frequently falls short.

Historically, the direct involvement of youth in assessing service barriers and developing solutions in Rwanda has been limited, resulting in a disconnect between policy intentions and their lived experiences [13,17]. Recognizing the need for youth engagement and directly incorporating their insights, the Rwanda Network of People Living with HIV/AIDS (RRP+) partnered with the Rwanda Biomedical Center and the Deutsche Gesellschaft für Internationale Zusammenarbeit GmbH (GIZ) to implement Community-Led Monitoring (CLM). Using a cycle of community-driven data collection, analysis, and advocacy, CLM fostered shared ownership and collaboration between youth and stakeholders. By documenting youth experiences within the CLM framework and co-creating context-specific strategies, this manuscript presents the learnings and prioritized recommendations from young people living with HIV to guide the development of truly youth-friendly HIV services in Rwanda.

Objectives

Main Objective

To synthesize program learning from a nationwide participatory dialogue with young people living with HIV in Rwanda and to generate actionable recommendations for strengthening youth-friendly HIV services.

1. 3.2. Specific ObjectivesTo identify and describe the barriers and facilitators faced by young people living with HIV in accessing and using HIV services in Rwanda.

2. To document the key learnings and insights from the multi-step participatory dialogue process with young people living with HIV and key stakeholders in Rwanda.

3. To synthesize and prioritize Actionable recommendations co-created during the national dialogue to improve the accessibility, quality, and youth-friendliness of HIV services in Rwanda.

Methods

Qualitative Approach and Research framework

This initiative adopted a qualitative, descriptive, and community-led monitoring (CLM) approach, framing its participatory program learning to deeply explore the lived experiences, challenges, and co-created solutions of young people living with HIV in Rwanda concerning HIV services. CLM methods, including focus group discussions, community dialogues, and national dialogues, were deliberately chosen to ensure the comprehensive collection of data directly from diverse youth voices and to foster meaningful engagement between YPLHIV as community monitors and stakeholders at various levels. The overarching aim was to facilitate a national dialogue where community-identified solutions could be validated and prioritized. The entire design was fundamentally aligned with CLM principles, underscoring the active and meaningful engagement of YPLHIV as partners and leaders in identifying service barriers and collaboratively developing strategies to enhance youth-friendly services.

Characteristics and Reflexivity of the Work

The research team comprised individuals affiliated with the RRP+, the Rwanda Biomedical Center, and the University of Rwanda. Researchers from RRP+ and RBC were integral to the design and implementation of the multi-step participatory process. RRP+ is an organization dedicated to advocating for the rights of people living with HIV in Rwanda, and its involvement reflects a commitment to empowering the voices of YPLHIV. Similarly, the RBC, as a key government health institution, served as a duty bearer in this program learning initiative, fostering collaboration between youth and policymakers.

This embedded positionality meant that the researchers were not detached observers but actively engaged facilitators and stakeholders, working with participants to co-produce knowledge and recommendations. This approach was intentional, aimed at building trust and fostering meaningful dialogue, consistent with principles of good participatory practice that emphasize "working with youth as partners" rather than merely as beneficiaries. The researchers' experience in public health, advocacy, and community engagement in Rwanda shaped the design and execution of the dialogues, enabling culturally sensitive and relevant interactions. Reflexivity was maintained by transparently acknowledging this participatory role and focusing on validating findings through multi-stakeholder consensus at the national dialogue, ensuring that the insights generated were directly reflective of the participants' experiences and priorities.

Context Setting/Site

This community-led monitoring initiative took place in Rwanda, a nation actively working to combat its HIV epidemic through community engagement. The study involved a multi-phased engagement process, beginning with local community-led dialogues in seven high-prevalence districts: Kicukiro, Nyarugenge, Gasabo, Kayonza, Muhanga, Musanze, and Rubavu. These were followed by broader community dialogues led by YPLHIV in four rural districts: Kayonza, Muhanga, Musanze, and Rubavu. The process culminated in a national dialogue in Kigali, where community monitors presented their findings and recommendations to national stakeholders. The study's context is defined by Rwanda's commitment to UNAIDS targets, particularly for vulnerable populations, and the ongoing effort to bridge the gap between national guidelines for adolescent-friendly services and their practical implementation through community oversight.

Sampling Strategy

Purposive sampling was used to select YPLHIV to serve as community monitors for the initial focus group discussions, ensuring representation from diverse backgrounds and vulnerable populations within the selected high-prevalence districts. This approach aimed to gather rich, varied perspectives directly from the community. The phased approach, moving from local discussions to broader community and then national dialogues, facilitated a comprehensive understanding and community validation of identified themes and proposed solutions. Recruitment focused on achieving representation across different age groups and genders, reflecting the diversity within the YPLHIV community.

Ethical Issues Pertaining to Human Subjects

This Community-Led Monitoring (CLM) initiative strictly adhered to ethical guidelines and CLM principles, prioritizing the safety, dignity, autonomy, and empowerment of all YPLHIV community monitors in line with rights-based approaches. Approval was obtained from the Rwanda Biomedical Center (RBC) HIV division to conduct this CLM process. All participants provided informed consent, with minors offering assent alongside parental or guardian consent, ensuring they clearly understood their roles as monitors and advocates. Participants were fully informed of their rights, including the voluntary nature of involvement and the ability to withdraw at any time without repercussions. To uphold CLM standards of confidentiality and anonymity, no personally identifiable information was collected; instead, unique identifiers were used, and all data were anonymized to protect community monitors' identities. Strict data security measures, such as secure storage and password protection, were implemented to safeguard sensitive information, with findings reported in aggregate form to preserve individual privacy while amplifying collective community-led insights for advocacy.

Data Collection Methods

Data collection for this CLM initiative took place between April and November 2022 through a multi-phased participatory process aligned with CLM principles of community empowerment and systematic monitoring. Initial focus group discussions were conducted with youth living with HIV across seven districts to identify barriers and propose solutions related to UNAIDS 95-95-95 objectives, incorporating data on youth mental health challenges. These were followed by community dialogues in four rural districts, which convened "duty bearers" (such as policymakers and service providers) and "rights holders" (youth living with HIV) to discuss service gaps and refine recommendations collaboratively. The process culminated in a national dialogue held in November 2022 in Kigali, gathering key stakeholders in a "marketplace format" for presentations and discussions on barriers to youth-friendly services, including youth testimonies, leading to plenary sessions that formulated and prioritized conclusions and recommendations for advocacy and service improvement.

Data Collection Instruments and Technologies

For FGDs, the interview guide was developed by RRP+, focusing on the UNAIDS 95s objectives. Digital audio recorders captured data during FGDs, complemented by notes.

Units of Study

The initiative's primary units were young people living with HIV (YPLHIV) serving as community monitors, who participated in focus group discussions (FGDs) and subsequent dialogues. Initial FGDs involved youth from seven districts, followed by community dialogues that included youth and duty bearers from four rural districts. The national dialogue incorporated a wider array of key stakeholders. Recruitment focused on ensuring representation from vulnerable and key populations in high-prevalence areas to amplify diverse community voices.

Data Processing

After data collection, experienced transcribers transcribed verbatim all audio-recorded discussions from focus groups and community dialogues to accurately capture participants' expressions. Transcripts were organized and managed using qualitative data analysis software. To protect confidentiality and privacy, identifiable information was de-identified or anonymized during transcription and processing. Data integrity was maintained through secure, password-protected storage, with access limited to authorized personnel.

Data Analysis

Data analysis employed a community-led thematic approach, aligned with the participatory CLM initiative. This iterative process integrated community insights into an evolving analytical framework for ongoing refinement. In collaboration with community representatives, researchers coded key ideas, concepts, and themes based on YPLHIV's lived experiences and service interactions. Codes were grouped into broader categories and themes through collective sense-making. The analysis synthesized community-identified findings presented at the national dialogue for rights-holders and duty-bearers to jointly formulate and prioritize actionable recommendations, advancing an advocacy agenda. This community-driven method ensured the analysis reflected YPLHIV's realities and priorities, promoting accountability in service delivery.

Techniques to Enhance Trustworthiness

To enhance the trustworthiness and credibility of the study findings, several techniques were employed. The multi-phased approach, which included focus group discussions, community dialogues, and a national dialogue, served as a form of triangulation. This allowed for the cross-validation of themes and perspectives across different participant groups and engagement levels. The participatory nature of the study, particularly the national dialogue, functioned as a form of member checking. Preliminary findings and proposed recommendations were presented back to the community and key stakeholders for validation, refinement, and prioritization. This ensured that the interpretations accurately reflected the participants' experiences and priorities. Additionally, a comprehensive description of the study methodology, including context, sampling, and data collection procedures, was maintained to establish dependability. This allowed for the potential audit of the research process. The researchers' embedded positionality as stakeholders within the HIV response in Rwanda also fostered a deeper contextual understanding, contributing to the credibility of the findings.

Findings

Summary of Findings

Qualitative findings from Focus Group Discussions with young people living with HIV across seven districts and from the National Dialogue with duty bearers, rights holders, and service providers consistently reveal a disconnect. The current delivery of youth-oriented HIV services in Rwanda often falls short of what young people themselves perceive as "youth-friendly." Participants emphasize the importance of confidentiality, privacy, and trusted, non-stigmatizing care as fundamental enablers for HIV testing, initiating antiretroviral therapy, and maintaining adherence. However, significant barriers emerge around concerns about confidentiality breaches, the pervasive presence of stigma, and the physical and organizational design of services. Shared waiting areas and the co-location of ART services inadvertently disclose a young person's status or mix them with adults. Stakeholders at the national level corroborated these findings, advocating for structural adaptations guided by the World Health Organization's principles of youth-friendly services. These principles emphasize the importance of time, space, and staff to ensure services are more accessible, acceptable, and appropriate for young people living with HIV. The subsequent sections delve into these enablers and barriers, illustrated by direct quotes from participants.

Demographic Characteristics of Participants

The research involved 133 young individuals aged 18 to 24 years, selected from various high-risk and HIV-positive groups. The sample included several important subgroups: female sex workers, individuals who are both female sex workers and teen mothers, men who have sex with men, and teen mothers. This composition offers a comprehensive analysis of the barriers and facilitators to youth-friendly HIV services from various perspectives, emphasising a crucial life stage for managing sexual health and HIV services.

Barriers and Facilitators Encountered by Young People Living with HIV in Accessing and Utilizing HIV Services in Rwanda

Pervasive Stigma and Discrimination: A fundamental barrier across all engagement platforms was the deeply ingrained stigma and discrimination associated with HIV. This stigma, both internalized by YPLHIV and externalized through societal and sometimes institutional attitudes, significantly impacted mental well-being, disclosure decisions, and consistent engagement with care. The fear of being identified as HIV-positive often led to avoidance of health services.

"I knew that I am HIV positive when I was 12 years old, now I am 25 years old. It was not easy to me to understand how HIV chose me among other siblings. My adherence was so bad and consequently I failed the first line."

This sentiment highlights how early diagnosis coupled with perceived societal judgment can lead to profound self-stigma, directly affecting treatment adherence and health outcomes. Furthermore, the fear of judgment from peers intensifies this burden:

"The stigma among adolescents and youth may be higher because this is a sexually active group and everyone who knows my status and sees me chatting with a boy looks me in lenses of infecting that boy."

The social implications of disclosure often outweigh the health benefits in the minds of young people, compelling them to maintain secrecy at considerable personal cost. This fear of gossip and social ostracization directly influences their willingness to seek and consistently use services.

"They gossip about you if you go to the health centre."

Such experiences underscore the intense social pressure and fear of public shaming that YPLHIV face, discouraging them from accessing vital health services.

Breaches of Confidentiality and Lack of Privacy: Experiences of inadequate confidentiality and privacy within healthcare settings were frequently cited as significant deterrents. Young people expressed profound discomfort and anxiety about accidental or intentional disclosure of their HIV status, leading them to avoid clinics and travel to distant facilities where they remain unknown.

"A youth girl from the countryside was waiting in the ARV service in the health facility when she saw her neighbour entering the same waiting room. Each of them thus knew the status of the other, which was unbearable for her. She decided to leave her family and her village and travel to Kigali to 'hide' herself where nobody would know that she is HIV+. To make a living, she had no other choice but to become -and is up to now- a female sex worker."

This powerful anecdote illustrates the devastating consequences of confidentiality breaches, forcing individuals into extreme measures to protect their privacy, sometimes leading to heightened vulnerability.

The physical design and operational practices of health facilities often exacerbate this issue:

"The waiting rooms are not separated; young people wait with adults, increasing the risk of being seen by someone they know, leading to discomfort and fear of disclosure."

The lack of separate waiting areas, coupled with shared spaces for different services, means that young people attending HIV clinics are often visibly identifiable, fostering auto-stigma and deterring consistent care-seeking.

"I do not like at all being mixed together with adults in the ARV waiting room. It makes me worry that my HIV+ status is displayed to adults who know neighbors or friends."

This concern about public display of their status actively discourages young people from attending appointments, leading to potential treatment interruptions.

Judgmental Attitudes and Inadequate Communication from Healthcare Providers

Many YPLHIV reported encountering judgmental, disrespectful, and unsupportive attitudes from healthcare providers. This contributes to a feeling of being undervalued and unwelcome, eroding trust in the healthcare system. The quality of communication also varied, with many young people feeling that their concerns were not adequately addressed or that they were not treated with dignity.

"A youth shared that she felt that the HCP talking more nicely to others who were better dressed. Being dressed as a female-sex worker, she feels not respected, not as well treated as others and even harassed. The drugs are distributed to her without explanations or encouraging words, after a long waiting time. The schedule for appointments is not respected."

Such experiences of differential treatment based on appearance or perceived social status create significant barriers. The fear of parental disclosure by healthcare providers who know their families also fuels distrust:

"If I go for an HIV test and find there a nurse who knows my parents, you will think that she/he will tell them about your status."

This highlights a critical breach of trust and an ethical dilemma for young people seeking care in their local communities.

"Sometimes the health workers are rude, they scold us if we come late, or if we ask too many questions. We feel judged."

These interactions demonstrate a lack of empathy and youth-friendly communication, further alienating young people from the services designed to help them.

Operational Inefficiencies within Health Facilities

- Beyond attitudinal issues, several practical and systemic challenges within health facilities impede youth access. The**Long waiting times and overcrowding:** These issues were consistently reported, making clinic visits arduous and difficult to fit into school schedules or other daily commitments.

"We spend too much time waiting, and sometimes we miss school because of it."

- **Mixed appointments with adults:** The lack of dedicated appointment slots or separate service times for young people reduces their comfort and privacy, making them feel less prioritized.

"Waiting in ARV services mixed with adults"

- **Insufficient counselling and limited educational materials:** Young people often expressed a need for more comprehensive information about their condition, treatment, and sexual and reproductive health, which current counselling services sometimes fail to provide.

"We don't get enough information about how to live with HIV, especially about relationships and having children."

- **Inadequate number of health care providers:** Staff shortages lead to rushed consultations, less personalized care, and an inability to address the unique needs of young people effectively.

- **Lack of dedicated "Special times for adolescents"**: Despite recommendations in national guidelines, the implementation of specific times for youth services is often absent, further limiting accessibility.

Facilitators and Enablers of Youth-Friendly Services

Despite these significant barriers, several factors emerged as crucial facilitators for promoting engagement and improving the experiences of YPLHIV:

- **Peer Support and Empathetic Staff:** The presence of peer support networks and understanding healthcare providers significantly enhances young people's comfort and adherence. Connecting with others who share similar experiences provides immense psychological and emotional relief.

"When I attended adolescents' support group, I got comfort and started my HIV status."

Young people also expressed a strong preference for interacting with younger, more empathetic healthcare workers:

"If I find there a youth like me, I will be free to talk. For the youth it's easier to give him/her information compared to an elder."

This highlights the importance of shared identity and experience in building trust.

"Nurses who do not display status are good; they make us feel safe."

This quote reinforces the critical role of discreet and professional behavior from healthcare providers in fostering a sense of security and trust among YPLHIV.

- **Targeted Interventions for Self-Stigma:** Programs specifically designed to address self-stigma, such as the Wakakosha Program, were recognized for their positive impact on resilience and well-being among YPLHIV, helping them to navigate internal struggles related to their status.

- **Comprehensive National Guidelines:** Rwanda's national guidelines explicitly outline the characteristics of youth-friendly services, emphasizing accessibility, acceptability, appropriateness, and effectiveness. These guidelines provide a foundational framework, even if their implementation is inconsistent. Key recommendations within these guidelines, such as "Special times for adolescents" to reduce waiting times, "Adequate space and sufficient privacy" in consultation rooms, and "Trained staff" with specific skills for adolescent care, offer clear pathways for improvement.

- **Community-Based Communication and Linkages:** Suggestions from youth themselves included innovative communication strategies to ensure information reaches all YPLHIV and the establishment of robust referral systems with follow-ups, linking individuals to family and community support structures.

"We need more youth ambassadors to reach out to others in our communities."

Training YPLHIV to mentor and support younger infected peers was also identified as a highly valuable strategy, fostering leadership and shared responsibility within the community.

"When youth are involved in helping other youth, they listen more."

This indicates the power of peer-to-peer support in improving engagement.

Lessons learnt: Key Program Learnings and Insights from the Participatory Dialogue Process

The multi-step participatory dialogue process, involving young people living with HIV and key stakeholders, served as a valuable learning ground. It yielded invaluable insights that went beyond simply identifying barriers and facilitators. This approach itself demonstrated the transformative power of genuine youth engagement, providing a framework for developing more effective, youth-centered HIV programs.

Lesson 1: Privacy, Confidentiality, and the Physical Design of ARV/Testing Spaces Shape Youth Engagement

The participatory process consistently emphasized the significance of privacy and confidentiality in fostering youth comfort and their continued engagement in care. Young individuals expressed significant discomfort in ARV waiting areas where adults are present or where ARV services are co-located with other non-youth services. One youth shared their apprehension, stating,

"I detest being mixed with adults in the ARV waiting room. It makes me anxious that my HIV+ status is revealed to adults who are aware, such as neighbors or friends. On the other hand, being with other youth is acceptable to me."

This concern was echoed in discussions about "waiting in ARV services mixed with adults" and the broader issue of the "ARV waiting room shared with other services," which heightened concerns about status disclosure and stigma, actively deterring timely testing and follow-up. The discussions throughout the marketplace-style national dialogue underscored that the location and visibility of ARV services can inadvertently expose youth, contributing to their reluctance to engage. This highlighted the urgent need for dedicated, confidential testing spaces and youth-friendly service points to reduce perceived exposure and stigma, thereby enhancing attendance and adherence. Additionally, the importance of discretion by health professionals was acknowledged, with young individuals expressing a preference for "nurses who do not display status." The recurring suggestion for specific provisions, such as "special days for testing youths," further reinforced the demand for tailored, private service delivery.

Lesson 2: Psychosocial Support and Mental Health Are Integral to ART Initiation and Adherence

The dialogues identified mental health as a pivotal lever for engagement in care, revealing that psychological well-being and a supportive therapeutic environment are essential for young people to initiate ART and sustain adherence. The process emphasized that adolescents and young people living with HIV often carry profound emotional burdens that directly influence their decisions about treatment initiation and daily adherence. This reinforced the critical need for integrated psychosocial support within youth-friendly HIV services. The impact of psychological support was clearly articulated, with participants stating that "psychological support helps much to start the treatment." This support fosters motivation, which participants identified as deeply linked to mental health, confirming that "motivation is a positive factor linked to mental health, directly influencing adherence." A sense of community and solidarity also played a crucial role in supporting mental health, as conveyed by the sentiment "know that you are not alone as YLHIV." Furthermore, the importance of guidance from healthcare providers was highlighted as a component of this support, with participants acknowledging "you need to follow the advice of the health care providers."

Lesson 3: Youth-Led and Peer-Supported Approaches Enhance Motivation, Belonging, and Adherence:

Across the Focus Group Discussions and the national dialogue, young people consistently highlighted the significant role of peer influence, youth-led education, and visible role models in fostering engagement in care. These insights underscored the need to strengthen youth-led peer education groups and ensure that youth ambassadors and mentors are integral to program design and implementation. These approaches were recognized for their ability to combat isolation and provide relatable examples of successful adherence, ultimately leading to improved retention in care and higher rates of viral suppression. For some, motivation was deeply personal and tied to future responsibilities, as expressed by one participant: "We need to find motivation; I have a child, and I want to be there for them." For others, particularly Female Sex Workers, the motivation was linked to their professional identity: "Get healthy by taking your medications. Otherwise, you won't have any clients." The power of shared experience and community was also repeatedly emphasized, fostering a sense of belonging through the realization that they are not alone as Young People Living with HIV. These findings led to clear recommendations for scaling up such initiatives, including the call for "RRP+ to support more youth-led PE groups and role models in PE groups."

Lesson 4: Accurate, Youth-Friendly Information and Messaging Around ART, Side Effects, and Transmission Are Essential

The dissemination of clear, non-stigmatizing, and specifically tailored information to young people emerged as a crucial factor in their engagement with HIV services. Rumors and misinformation about ART, such as concerns about weight gain or perceived lack of efficacy, were identified as significant barriers to initiation and consistent adherence. In contrast, accurate and empowering messaging about ART benefits, the importance of adherence, and the “Undetectable = Untransmittable” (U=U) concept was recognized as a powerful tool to reduce stigma and motivate continued engagement in care. The need for clear communication and trust in providers was evident, as exemplified by the statement: “Testing is better at HF. The nurse knows how to take care of you.” Confidentiality was emphasized as paramount for information exchange, with participants underscoring its significance. The positive impact of understanding the health benefits was highlighted, including the knowledge that one will be in good health and able to prevent opportunistic diseases. Conversely, participants acknowledged the severe implications of stopping ART for their partners, necessitating comprehensive information about transmission due to the difficulty of disclosing HIV+ status. The U=U message was particularly impactful in reducing stigma and promoting engagement.

Lesson 5: Community and Health-System Alignment Is Needed to Address Structural Barriers

Participants acknowledged that structural determinants, such as "food insecurity" and broader resource constraints, significantly influence adherence to ART and overall access to services. While much of the discussion focused on direct service delivery, there was a clear recognition that the broader social determinants of health including nutrition, economic stability, and consistent access to youth-friendly resources must be comprehensively addressed to enable sustained engagement in care. The participatory process suggested integrating psychosocial and economic supports with clinical services to create a more holistic, youth-centered HIV program. The overall consensus emphasized that "structural determinants need to be considered in a comprehensive approach to improving the youth experience within HIV programs," advocating for "integrated care that acknowledges emotional burden and life planning."

Lesson 6: Prioritization of Concrete, Actionable Service Delivery Changes Emerged from National Dialogue

The prioritization exercise conducted at the national dialogue yielded a clear set of concrete, actionable recommendations aimed at making services more youth-friendly. These included the implementation of "dedicated youth-friendly testing days," the establishment of "confidential ARV service points," the expansion of youth-targeted counseling and mental health support, and the scaling up of "youth-led PE groups." There was also a broad call for "strengthening privacy in service delivery." The process powerfully demonstrated that when young people and duty bearers collaboratively identify and prioritize solutions, the resulting recommendations are inherently grounded in both practical feasibility and direct relevance to the lived realities of young people.

Lesson 7: Stakeholder Collaboration and Reflexive Learning Strengthen Program Legitimacy and Uptake

The multi-step methodological process, encompassing Focus Group Discussions, community dialogues, and the national dialogue, proved instrumental in facilitating a triangulation of perspectives among young people, duty bearers, and health providers. This inclusive design, exemplified by "(marketplace format) presentations and plenary discussions for validation," helped to validate the findings and ensured that the resulting recommendations reflected a joint understanding of the barriers, facilitators, and feasible solutions. This "multi-step participatory process with youth and stakeholders" ultimately led to "consensus at the national dialogue," which instilled greater confidence in the collective recommendations and increased the likelihood of their uptake and implementation.

Recommendations

Recommendation 1: Establish and sustain youth-friendly spaces within HIV service delivery to protect confidentiality and reduce stigma

Youth participants highlighted confidentiality concerns and fear of status disclosure when waiting in mixed spaces with adults, which undermines engagement in testing and care. The national dialogue recommended discreet access and, where feasible, dedicated youth-friendly clinics or time slots to safeguard privacy and minimize exposure to stigma. To operationalize this, pilot separate youth waiting areas or defined youth-access hours, ensure staff training on non-stigmatizing attitudes, and develop clear privacy protocols, with a system to monitor privacy breaches and respond rapidly. A representative quote captures the imperative: “I do not like at all being mixed together with adults in the ARV waiting room. It makes me worry that my HIV+ status is displayed to adults who know me.”

Recommendation 2: Scale confidential testing options and youth-focused counselling to support testing, linkage, and ART initiation

Youth expressed preference for confidential testing locations with trained staff and underscored the pivotal role of counseling in initiating treatment. The national dialogue suggested youth-friendly testing days or campaigns that protect privacy while expanding access. Action steps include expanding facility- and community-based testing with confidential procedures, implementing youth-only testing days, ensuring rapid linkage to care, and strengthening pre- and post-test counselling with youth-adapted materials. As youth noted, “Testing is better at HF. The nurse knows how to take care of you,” and “Confidentiality is essential.”

Recommendation 3: Integrate robust mental health and psychosocial support as a core component of HIV services for youth

Mental health issues and psychosocial stress emerged as key determinants of engagement in care and adherence. Youth emphasized the value of psychological support and peer connections. Scaling up requires embedding routine mental health screening in HIV care for youth, establishing youth-led peer support groups, and providing ongoing training for counselors in adolescent mental health and trauma-informed care, with clear referral pathways for clinical services when needed. A supporting quote: “Psychological support helps much to start the treatment.”

Recommendation 4: Strengthen adherence support and U=U–oriented messaging through youth-led strategies

Adherence was driven by personal motivation, stigma, and correct information about ART and transmission. Youth proposed leveraging peer education to reinforce adherence and U=U concepts in formats that resonate with young people. Action steps include developing youth-tailored adherence modules (including digital and peer-led formats), disseminating U=U messaging in youth-friendly ways, and creating individualized adherence plans with youth input while ensuring privacy-friendly incentive approaches. A guiding quote: "Know the consequences for the partners if the ARV is stopped, because it is difficult to display HIV+ status."

Recommendation 5: Expand youth-led engagement and peer education as central pillars of service delivery and accountability

The program learning highlighted the potential of peer educators (PE) to improve testing uptake, linkage, adherence, and psychosocial support, with youth calling for stronger youth-led groups. Action focuses on formalizing youth PE networks with clear roles and supervision, integrating PE into service workflows, and establishing formal feedback loops so youth inputs influence policy decisions and resource allocation. A representative line from youth: "You are not alone as YLHIV," which underscores the value of peer support.

Recommendation 6: Increase access through diversified service modalities, including community-based testing, ART initiation, and follow-up

Location-related barriers and long wait times prompted calls for diversified modalities beyond fixed facilities, including mobile or community-based testing and ART initiation. Implementation entails piloting community-based HIV testing and same-day ART initiation, ensuring robust referral and follow-up systems, and maintaining data capture across modalities for consistent monitoring.

Recommendation 7: Implement a formal, multi-stakeholder accountability mechanism that centers youth voices

Youth want tangible evidence that their input drives change; a structured mechanism is needed to track commitments and outcomes. Steps include establishing a standing youth advisory group linked to the health system, publishing regular progress reports on actions taken in response to youth recommendations, and ensuring transparent prioritization and resource allocation aligned with youth-identified needs.

Recommendation 8: Align financing to sustain integrated youth-friendly HIV services.

Sustainable funding is essential to maintain confidentiality enhancements, mental health integration, PE programs, and diversified service delivery. Action points include securing dedicated budgets for adolescent/youth-friendly services, exploring integration with broader youth health initiatives for efficiency, and monitoring cost-effectiveness and impact on the 95-95-95 targets.

Discussion

This study employed a multi-step participatory dialogue process to synthesize program learnings and co-create actionable recommendations for strengthening youth-friendly HIV services in Rwanda. The findings from Focus Group Discussions with young people living with HIV and a National Dialogue with key stakeholders revealed critical barriers and facilitators, highlighting a persistent disconnect between existing policy intentions and the lived experiences of youth. These insights align with broader literature on young people living with HIV (YPLHIV) in Sub-Saharan Africa, where young people often face poorer treatment outcomes due to pervasive stigma, judgmental attitudes, and a lack of tailored psychosocial support. This contextually relevant blueprint provides a framework for service improvement [18,19].

A central theme that emerges from the study is the pervasive impact of stigma, confidentiality breaches, and a lack of privacy on the engagement of young people living with HIV (YPLHIV) in HIV services [20]. Young people expressed significant discomfort in shared waiting areas and co-located services, where the risk of status disclosure is high. This discomfort led to avoidance of care or extreme measures to protect privacy. This finding aligns with broader observations that deeply ingrained stigma and discrimination profoundly affect YPLHIV's mental well-being, disclosure decisions, and consistent engagement with care [21]. The participatory process reinforced the need for intentional redesign of physical spaces and rigorous adherence to privacy protocols to address these deeply ingrained issues. This was explicitly called for in the co-created recommendations from the national dialogue, which prioritized the implementation of "confidential ARV service points," "dedicated youth-friendly testing days," and "strengthening privacy in service delivery."

The study further emphasized the crucial role of psychosocial support and mental health in initiating and maintaining adherence to antiretroviral therapy (ART) among young people living with HIV (YPLHIV). The experiences of the participants underscored the profound emotional burdens that YPLHIV carry, which directly influence their treatment decisions. This finding aligns with existing literature that highlights the prevalence of mental health issues, such as depression and anxiety, among YPLHIV in sub-Saharan Africa and their adverse impact on ART adherence. This underscores the urgent need for accessible psychosocial support [10]. Rwanda's national HIV response acknowledges this need and is actively working to strengthen psychosocial care and train peer educators to provide such support. Rwanda's comprehensive HIV treatment approach emphasizes psychosocial support and adherence counseling to help PLHIV cope with the lifelong nature of the disease. However, the study's findings suggest that these services need to be more deeply integrated and accessible. Participants emphasized the significant role of psychological support in initiating treatment and the positive correlation between motivation and mental health, which directly influences adherence. Consequently, the co-created recommendations emphasize the integration of comprehensive psychosocial support and mental health services into routine HIV care for YPLHIV.

Furthermore, the study consistently highlighted the effectiveness of youth-led and peer-supported approaches as powerful facilitators of motivation, belonging, and adherence. The study found that when youth are involved in helping other youth, they tend to listen more attentively, leveraging the credibility and relatability of peers. This is further supported by evidence that adequate parental, familial, community, school, and peer support is essential for promoting informed decision-making. among youth." The success of peer education groups and the training of peer educators in Rwanda further validates this approach, with peer educators trained to support YPLHIV psychosocially. The co-created recommendations advocate for scaling up these initiatives, including strengthening existing "youth-led peer education groups" and integrating "youth ambassadors and mentors into program design and implementation." This underscores a shift towards empowering youth as active agents in their own care and in supporting their peers [22-24].

The multi-step participatory dialogue process itself proved to be a critical learning and empowering mechanism. Historically, "the direct involvement of youth in assessing service barriers and developing solutions in Rwanda has been limited, resulting in a disconnect between policy intentions and their lived experiences." This study's approach, described as a "multi-step participatory process with youth and stakeholders," aimed "to learn from the program by fostering shared ownership and collaboration between youth and stakeholders" and ultimately led to "consensus at the national dialogue." While Rwanda has national guidelines for adolescent-friendly services, their practical implementation often falls short. This is further highlighted by observations that SRH services were often "designed for the general population without specialized adolescents SRH healthcare providers." The participatory methodology not only identified existing gaps but also generated practical, context-specific recommendations directly informed by young people, thereby "bridging the gap between policy and practice." This iterative approach, which included FGDs, community dialogues, and a national dialogue with "marketplace format presentations and plenary discussions for validation," enhanced the legitimacy and likelihood of uptake of the co-created recommendations by ensuring they were grounded in both youth realities and stakeholder consensus.

In conclusion, the findings from this participatory study underscore that while Rwanda has made strides in its HIV response, significant challenges persist for YPLHIV due to pervasive stigma, confidentiality concerns, and gaps in psychosocial support. The co-created recommendations, born from a robust and inclusive participatory process, offer an actionable roadmap for enhancing the accessibility, quality, and youth-friendliness of HIV services. Implementing these prioritized recommendations, which advocate for youth-friendly spaces, integrated mental health support, peer-led initiatives, and accurate information, is essential for truly meeting the needs of YPLHIV and achieving sustainable improvements in their health outcomes.

Limitations

While methodological measures such as triangulation through multi-phased focus group discussions, community dialogues, and national dialogue, along with member checking and detailed documentation, enhanced the trustworthiness of this Community-Led Monitoring (CLM) initiative, several inherent limitations remain. The qualitative and participatory design limits generalizability beyond the seven sampled districts and primarily rural settings, potentially overlooking nuances among YPLHIV in urban or other subpopulations. Additionally, reliance on self-reported experiences and community-led interpretations may introduce subjectivity, though it is mitigated by collaborative validation. The initiative's focus on qualitative insights also precludes quantitative metrics for broader epidemiological trends, and recruitment emphasis on high-prevalence areas might underrepresent less affected groups. Despite these constraints, the youth-driven approach ensures relevance to lived realities and actionable advocacy in Rwanda's HIV context.

Generalizability

The findings of this Community-Led Monitoring (CLM) initiative, while detailed and contextualized within Rwanda, may not generalize broadly to all young people living with HIV in varying geographical or socio-cultural contexts. Qualitative approaches like this typically examine barriers within specific populations, highlighting the need for quantitative studies to assess the extent of these barriers across larger groups.

Potential for Bias

Social desirability bias may have influenced responses on sensitive HIV-related topics, with participants potentially under- or over-reporting psychosocial experiences to meet social or peer expectations, a risk heightened in adolescent qualitative settings prone to validity issues. Selection bias could also occur despite efforts for diversity, as purposive sampling might favor those already in support programs or facilities, missing perspectives from disengaged or highly marginalized YPLHIV. Furthermore, the focus on qualitative depth, though valuable, lacks quantitative data to assess the prevalence or scale of barriers and facilitators, limiting insights for prioritizing interventions.

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