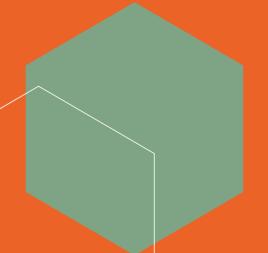


**GNP+ World Aids Day Report 2025** 

# PLHIV Minimum Requirements for Integrated HIV Services



## **Acknowledgements**

# People Living With HIV Minimum Requirements/ Asks for HIV Services Integration Into Primary Health Care for Universal Health Coverage

The Global Network of People Living with HIV (GNP+) extends its deepest gratitude to every person and organisation that made this report possible.

First and foremost, we thank the 1,834 people living with HIV from every region of the world who gave their time, honesty, and lived expertise through the global survey. Your voices are the heartbeat of this document.

We are profoundly grateful to the nine key informants from national and regional PLHIV networks, as well as our partners at WHO and PATH, who shared their insights, experiences, and vision during in-depth interviews.

This report began with the fire and clarity of the more than 80 PLHIV leaders from 18 countries who gathered at the PLHIV Leadership Summit in Nairobi in April 2025. You gave us the mandate, you held us accountable, and you continue to inspire us.

Our sincere thanks go to the GNP+ team and consultants who worked tirelessly to design the research, translate materials into five languages, collect and analyse the data, and shape the findings into this final report. Your skill and commitment turned community voices into powerful evidence for collaborative advocacy and action.

We acknowledge the partners who provided technical and moral support throughout the process, including the WHO, UNAIDS, Global Fund, PATH and the many regional and national networks that mobilised their communities to participate.

Finally, we honour the resilience of networks of people living with HIV everywhere, many of whom carried out this work while facing funding cuts, staff losses, and rapid service transitions. You never stopped showing up for our communities, and this report stands on your shoulders.

This report belongs to all of us. Thank you for trusting GNP+ to carry your voices forward.

#### **Foreword**

# People Living With HIV Minimum Requirements/ Asks for HIV Services Integration Into Primary Health Care for Universal Health Coverage

At the People Living with HIV (PLHIV) Leadership Summit in Nairobi this April, over 80 of us leaders from PLHIV networks in 18 countries and 6 regions came together In Nairobi, Kenya with a shared conviction. The integration of HIV services into primary health care must be led by us, shaped by our realities, and driven by our collective power. You challenged GNP+ to capture our voices and define the minimum standards that will ensure no one is left behind in this period of change, transition and adaptation in the HIV response. We listened. We mobilized. And now, we deliver.

This report is our PLHIV response. A bold blueprint forged from the insights of 1,834 people living with HIV who responded to the survey, and the unyielding expertise of our global networks and key partners. It distills seven essential requirements, from transformative participation that puts us at the heart of decisions, to resilient systems that safeguard treatment and end stigma, to government-led financing that honors our right to health and life.

These are not mere recommendations; they are the foundation for a future where HIV services integration amplifies our strengths, advances self- care and Universal Health Coverage, and accelerates HIV epidemic control. We envision services that are accessible, affirming, and alive with the energy of community-led innovation; where every PLHIV thrives, virally suppressed, and empowered to live fully.

This moment calls for us to come together, PLHIV networks, communities, governments, donors, and partners uniting in purpose. Together, we can turn these standards into action, building health systems that reflect our diversity, honor our leadership, and deliver on the promise we have carried for decades. That of Zero AIDS deaths, Zero new HIV infections and Zero stigma through a truly sustainable and resilient HIV response.



## **Foreword**

# People Living With HIV Minimum Requirements/ Asks for HIV Services Integration Into Primary Health Care for Universal Health Coverage



Andy Seale,

WHO Department of HIV, tuberculosis, viral hepatitis and sexually transmitted infections and WHO Global Coordinator for the UNAIDS Joint Programme

For more than four decades, communities—especially networks of people living with HIV—have been the backbone of the global HIV response. I say this both as someone working within the World Health Organization and as part of the UNAIDS Joint Programme, and as someone who has been living with HIV for 30 years.

Communities of people living with HIV have demonstrated what true leadership looks like: people demanding treatment when systems were silent, defending human rights when stigma and discrimination were loud, and reaching out to those most in need when services fell short. Their courage has made millions of lives—including mine—longer, healthier, and filled with dignity.

Yet today, the gains we fought so hard for feel under threat. Dramatic reductions in external funding are reshaping the landscape of HIV prevention, testing, and treatment across the world. The disruptions outlined in this report are not abstract; they mirror stories I hear from friends, colleagues, and fellow people living with HIV many of whom are ageing with HIV and increasingly needing interconnected, personcentered care. Their experiences confirm what we already know: our response must overcome current challenges and evolve beyond single disease-centered, fragmented approaches if we are to secure long-term sustainability.

To protect our progress—and push closer to ending AIDS as a public health threat—we must continue to further integrate HIV services within resilient, people-centered primary health care and strong community systems where it makes sense for us to do so. And as someone who has relied on specialized and rights-affirming services for three decades, let me be clear: integration must not lead to dilution.

The unique strengths of the HIV response —its respect for dignity, its community-led roots, its insistence on human rights—must not be lost. Instead, integration should amplify these strengths, ensuring that people living with HIV remain at the heart of decision-making and service delivery.

This report arrives at a critical moment. It offers timely evidence and clear guidance, built on the voices of more than 1,800 survey respondents and deep conversations with PLHIV networks, governments, and global partners.

It outlines minimum requirements, that resonate with WHO guidance, for integrated HIV services that are equitable, accessible, and truly grounded in lived experience. The "asks" outlined in this report describe what those of us living with HIV need to maintain treatment continuity, avoid preventable illness and death, and uphold our dignity and rights. One message in particular resonates: PLHIV networks are irreplaceable. Their work on treatment literacy, community-led monitoring, peer support, demand creation and advocacy has helped save countless lives, including my own.

Yet many of these networks now face closures, staff losses, or shrinking operational space. This is unacceptable. The global health community must reaffirm its commitment to protecting, funding, and strengthening their leadership. As the world moves toward universal health coverage, integration gives us a chance to reimagine HIV services as comprehensive, person-centered care. But this will only succeed if we address the full reality of living with HIV: managing comorbidities such as mental health conditions, tuberculosis, cervical cancer, and advanced HIV disease; confronting harmful social determinants; and creating systems grounded in empathy, reliability, and respect.

That requires strong supply chains, reliable data systems, well-trained and compassionate health workers, and—critically—stigma-free environments. And it demands that people living with HIV have meaningful, institutionalized roles in governance, planning, implementation, and accountability. Nothing about us can be sustainable without us.

On behalf of the World Health Organization, I welcome this report as an important contribution to dialogue, policy development, and programmatic action.

Sincere appreciation to GNP+ and every contributor to this report. Sustaining and strengthening the HIV response requires nothing less than centering the voices, leadership, and rights of people living with HIV. As someone both living with HIV and working in global health, I believe that integration, managed sensitively, can be a pathway to stronger systems, healthier communities, and a future where every person receives the services they deserve.

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#### **ACRONYMS & ABBREVIATIONS**

ART Antiretroviral Therapy
ARV Antiretroviral Drugs

CSOs Civil Society Organizations

GNP+ The Global Network of People Living with HIV

HIV Human Immunodeficiency Virus

NASCOP The National AIDS and STI Control Programme

NGO Non-governmental Organisation NCDs Non-communicable Diseases

PATH Program for Appropriate Technology in Health
PEPFAR U.S. President's Emergency Plan for AIDS Relief

PHC Primary Health Care
PLHIV People Living with HIV

TB Tuberculosis

USAID U.S. Agency for International Development

WHO World Health Organization

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#### INTRODUCTION

Significant progress has been achieved in the HIV response through the structured engagement of People living with HIV (PLHIV) in ending AIDS as a public health threat. Their commitment to adherence to treatment has been central to the progress achieved towards achieving the 95-95-95 targets driving down HIV incidence and ending AIDS.

By the end of 2024, the number of new HIV infections was at its lowest point since the mid-1980s, and the number of deaths from AIDS-related causes had dropped to levels last observed in the early 1990s. In 2024, approximately 1.3 million people worldwide became newly infected with HIV, marking a 61% decrease from the epidemic's peak in 1996. This decline represents a 40% reduction since 2010, although it falls short of the global target to reduce new infections to below 370,000 by 2025. AIDS-related deaths also fell significantly, with an estimated 630,000 deaths in 2024—54% fewer than in 2010 and 70% fewer than the peak in 2004.

Despite these advances, HIV remains a major public health challenge, with around 40.8 million people living with the virus globally, including 2.42 million children and adolescents<sup>1</sup>. Sub-Saharan Africa continues to carry the highest HIV globally², even burden of international funding for HIV and broader health responses faces significant cuts. The recent and abrupt US government funding cuts<sup>3</sup>—especially to PEPFAR and USAID have created immediate and severe disruptions to HIV prevention, testing, treatment, and care across Africa. particularly in Eastern and Southern Africa<sup>4-7</sup>, exposing the fragility of HIV response globally. This financial constraint threatens the sustainability of vertical, stand-alone HIV programs underscores the urgency of integrating HIV services into primary and community health care (PHC) systems for Universal Health Coverage (UHC).

To mitigate the impact, countries must urgently mobilize domestic and alternative resources, integrate HIV services into broader healthcare systems, ensure long-term access to ART, and adapt measures to sustain both immediate and long-term responses.

The integration of HIV services into primary health care requires urgent strategic adaptation, maximizing existing resources and infrastructure that is inclusive of networks of people living with HIV (PLHIV) at all levels of decision-making processes.



## **Purpose**

Following recommendations from the PLHIV Leadership Summit in Nairobi, Kenya<sup>8</sup>, the Global Network of People Living with HIV (GNP+) and PLHIV must leverage the unique relationship with governments and the health sector to produce, negotiate, and agree on the bare minimum requirements for integrated HIV services for effective care.

Recognizing the strong community-led infrastructure built from the investment of over two decades of the HIV response, GNP+ and PLHIV networks offer solutions for considerations in adapting and reorganizing national health systems towards long-term availability and accessibility of HIV testing, treatment, and prevention tools. In the current context, with the transition of HIV responses into government systems, PLHIV remain central to the HIV response. Meaningful involvement of PLHIV in the design, implementation, and monitoring of integrated HIV services is essential to ensure that models are effective, equitable, person-centred, and responsive to community needs.

GNP+ and PLHIV are keen to contribute to shaping the HIV services integration agenda, as they seek to evolve and ensure that epidemic control is achieved. PLHIV research is essential in informing policy, generating evidence that is reflective of the experiences, knowledge, and expertise of PLHIV. Therefore, to ensure the involvement and participation of PLHIV in this process, GNP+ and PLHIV networks sought to produce a report that outlines:

- Minimum requirements/asks needed for responsive, integrated HIV services into primary healthcare, ensuring sustained access to quality treatment and viral suppression at the community level.
- 2. Role of PLHIV networks in the integration of HIV services, particularly at the community level, to ensure availability, accessibility, and delivery of person-centred services.
- 3. Solidify PLHIV leadership through the roles of PLHIV networks and service providers in the delivery of integrated service delivery and in ensuring these services remain person-centred.



## **Objectives**

#### This study aimed to:

- 1. Determine the minimum requirements/ask needed for responsive integrated HIV services at the primary healthcare and community levels to ensure sustained access to treatment.
- 2. Explore and understand the role of PLHIV networks in the integration of HIV services, particularly at the community level, to ensure services are delivered as close to the household as possible.
- 3. Solidify PLHIV leadership through the roles of PLHIV networks and service providers in the delivery of integrated service delivery and in ensuring these services remain personcentred.

## Overview of approach

To enrich the findings, the survey employed a mixedmethods approach, combining qualitative and quantitative data collection and analysis.

Quantitative Component– sought to obtain numerical information, such as percentages, ratios, and proportions, to assess quantitative indicators. This was primarily targeted at people living with HIV, globally, and sought to determine their perspectives on the minimum requirements for responsive, integrated HIV services into primary healthcare, ensuring sustained access to treatment and viral suppression at the community level, and the role of PLHIV networks in the integration of HIV services, particularly at the community level, to ensure availability, accessibility, and delivery of personcentred services.

Qualitative Component – a qualitative case study was conducted, aimed at understanding essential aspects of the integration of HIV care from the viewpoint of Networks of PLHIV<sup>8</sup>. This gathered information on the minimum requirements for responsive, integrated HIV services into primary healthcare, ensuring sustained access to treatment and viral suppression at the community level. Additionally, it delved into understanding the role of PLHIV networks in the integration of HIV services, particularly at the community level, to ensure the availability, accessibility, and delivery of person-centred services. Key informant interviews were used to gather information. This data was collected from PLHIV networks and global partners such as WHO, PATH, and GNP+.

## Participant sampling, recruitment, and Data collection

Different sampling methods were used in the selection of participants for the qualitative and quantitative assessments.

Quantitative data were collected using an electronic data collection tool administered through Survey Monkey. The survey ran from 11<sup>th</sup> August to 22<sup>nd</sup> September 2025. The questionnaire was translated into French, Portuguese, Arabic, and Turkish to enhance its reach to people living with HIV across the globe. Further, the questionnaire was circulated via GNP+ platforms, including LinkedIn, Facebook, and Twitter.

The survey included closed-ended questions with a few semi-structured questions to gather perspectives on the minimum requirements/asks needed for responsive integrated HIV services at the primary healthcare and community levels, and the role that PLHIV networks can play in realising the implementation of these integration strategies and models.

For the qualitative component, participants were purposively sampled to take part in the assessment based on their:

- 1. Role as part of networks of PLHIV at the national, regional, or international level, or
- 2. Their work in conceptualising integration for HIV care. They were recruited to take part in assessment through GNP+. Thereafter, data were collected through 9 in-depth interviews using semi-structured interview guides developed with the GNP+ team. All the interviews were virtually conducted over Zoom between 9<sup>th</sup> October and 3<sup>rd</sup> November 2025. On average, the interviews lasted between 45 minutes and 1 hour 20 minutes.

#### Data management and analysis

Quantitative data were exported to Excel, imported into Stata 18, cleaned, and analysed using percentages and crosstabulations. Qualitative interviews were recorded. transcribed verbatim, and managed and coded in NVivo. We conducted a thematic analysis: first familiarising ourselves with the transcripts, generating initial codes, and adding codes informed by literature and guidance on integrating HIV within primary care and across sectors. The research team then mapped and refined key themes, identified relevant quotations, and developed detailed descriptions. Findings from the quantitative and qualitative strands were then merged as presented in the preceding section.

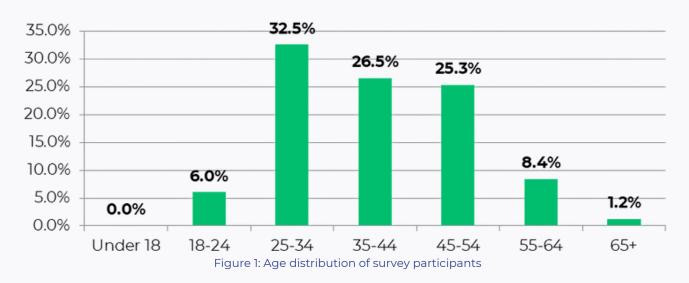
#### Introduction

This section provides an overview of the key findings from the assessment.

## **Participant Characteristics**

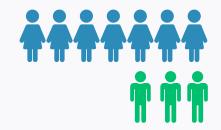
A total of **1,851 participants responded** to the survey, with 1,834 (99.1%) consenting to participate. Figure 1 below shows the age distribution of the participants.

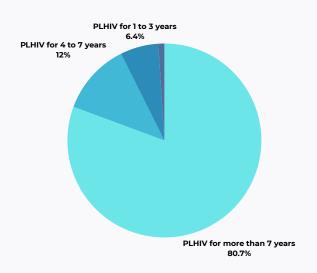
Approximately one-third of the participants were aged between 25-34 years, with more than half of the participants aged between 35 and 54 years.



There were more women (69.5%) than men (28.0%) and non-binary and gender-diverse participants (1.7%). More than half (52.3%) of the participants had a university degree or higher, with 29.8% having secondary education and 15.8% having vocational or technical training.

Most of the participants were employed either full-time (25.2%) or part-time (28.8%). A further 18.9% were self-employed, 19.9% were unemployed, while 4.4% were students and 2.9% were retired. Of the 93.8% of the participants living with HIV, 80.9% have been living with HIV for more than 7 years, 12.0% have been living with HIV for 4-7 years, 6.4% for 1-3 years, and less than 1% for less than a year.





With regard to sexual identity, the distribution of the different populations is shown in Figure 2 below. Proportionally, men who have sex with men (MSMs) represented 13.5% of participants, whereas persons who use drugs represented 11%, sex workers 9.5%, transgender persons 5.5%, migrant or displaced persons 5.2% while persons who have been incarcerated represented 3.1% of participants.

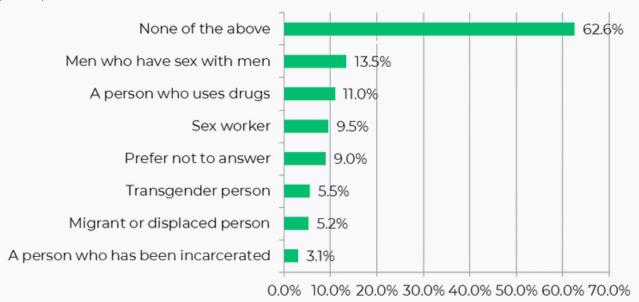


Figure 2: Distribution of key populations among study participants

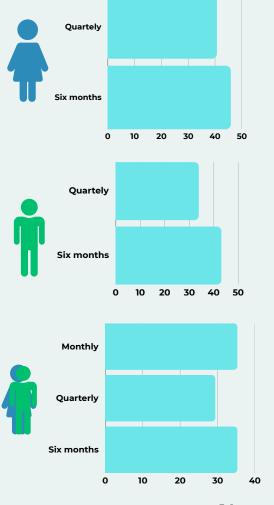
## Most PLHIV access care through public facilities

## Table 2 shows the provision of and access to health services by age.

Most of the participants accessed health services through public health facilities, particularly public hospitals. Approximately six out of ten female and male participants, 59.3% and 59.4%, respectively, accessed HIV services from public hospitals. The majority of non-binary people (42.9%) accessed HIV services from community health centres, with 38.1% accessing them from public hospitals. The HIV clinic was the most common access point for HIV services for both females (72.7%) and males (79.3%).

A few males and females accessed services from private clinics and military, non-governmental, and mission facilities, while none of the non-binary participants accessed HIV services from private clinics or military, non-governmental, and mission facilities.

Regarding the frequency of accessing HIV services, 45.9% of females accessed services every six months, while 40.7% accessed services quarterly. Similarly, among males, the majority accessed services six-monthly (43.1%), with 33.9% accessing HIV services quarterly. Among non-binary participants, most accessed HIV services monthly (35.3%) and six-monthly (35.3%), with 29.4% accessing services quarterly.



## **ART medication is mostly free**

While the majority of participants accessed free HIV services, some participants paid to access HIV services. Most females, 83.6%, and males, 73.1%, accessed free HIV services.

A proportion of both females (16.4%) and males (26.9%), however, did pay for HIV services, with prices ranging from less than \$20 to more than \$100. Among non-binary participants, the majority paid to access HIV services, with one third (33.3%) paying less than \$20, 6.7% paid between \$20-\$50, and 13.3% paid more than \$100. Only 46.7% accessed free HIV services.

## USG funding cuts sparked volatility in service provision

Concerning HIV services provided before and after the USG funding cuts, the provision of some services increased while others declined. Figure 3 shows that among the services that increased post-funding cuts were HIV testing services among non-binary participants, with a slight increase reported among females. An increase in ART service provision was also reported among females, males, and non-binary participants.

An increase in TB screening services was reported across all genders, including those who preferred not to report their gender. Reductions in mental health support services, however, were reported among females, males, and non-binary participants. Females also reported a decline in cervical cancer screening and maternal and child health services after the USG funding cuts.

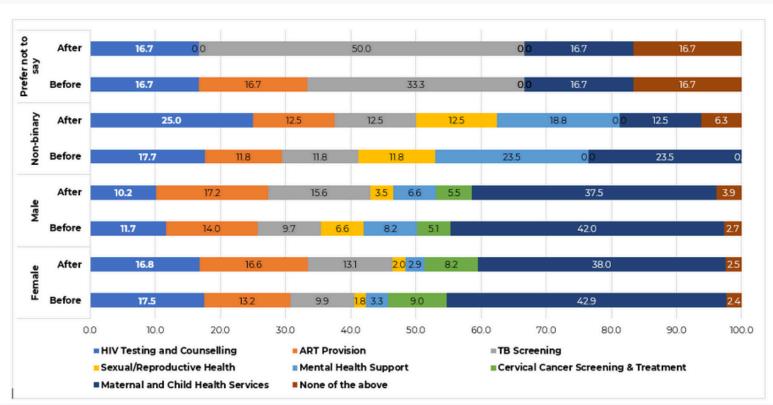


Figure 3: HIV Services provided Before and After the USG funding cuts by Gender

The majority of participants across almost all age groups accessed HIV services from public hospitals. Among participants aged 45–54 years and 35–44 years old, 30.6% and 31.0%, respectively, reported accessing HIV services from public hospitals.

Approximately 22% of participants aged 25-34 years also accessed HIV services from public hospitals, while among participants aged 18-24 years, 9.3% and 9.1%, respectively, accessed HIV services from community health centres and private clinics.

Figure 4 shows a comparison of HIV services provided before and after the funding cuts across participants of different ages. Most of the services remained unchanged pre- and post- the USG funding cuts. However, the provision of some services increased while others reduced. HIV counselling and testing services increased slightly among 25–34-year-olds and either reduced or remained unchanged across other age groups.

Young people (18-24 years), participants aged 45-54, and those 65 years and older reported an increase in ART provision, while the rest either reduced or remained unchanged. Some age groups, 18-24 years and 55 and older, reported increased mental health services after the funding cuts, while all other age groups showed a decline in these services. Regarding cervical cancer screening, only 25-34- and 45-54-year-olds reported increases in the services post the funding cuts.

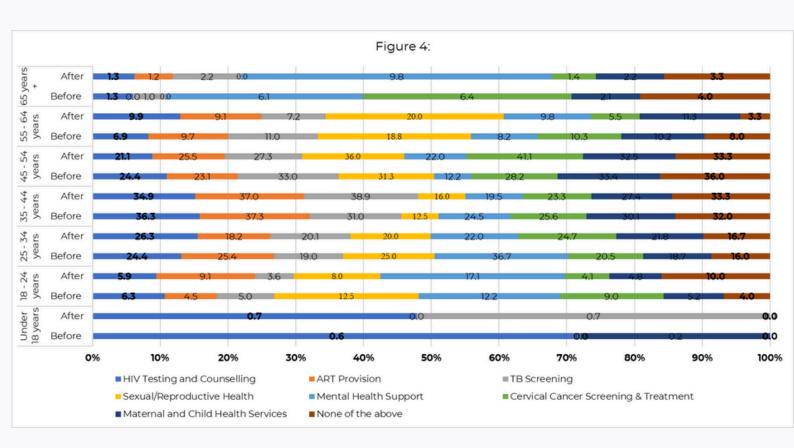


Figure 4: HIV Services provided Before and After the USG funding cuts by Age

## Integrating without transition; Impact of the shifts in the global HIV funding landscape on PLHIV and their networks

The importance of integration in the HIV response has been gradually gaining traction even prior to the withdrawal of funds, especially within the move to promote Universal Health Coverage through Primary Health Care. This is evidenced by **i.** The development of normative guidance documents and case studies on how countries can approach integration; ii. the presence of national-level structures to spearhead integration, including primary healthcare integration frameworks, Integration committees, and working groups; iii. the inclusion of integration as a policy priority in HIV policy documents such as national strategic frameworks and sustainability roadmaps in line with greater country ownership; and iv. National-level integration summits in countries such as Kenya<sup>13,14</sup>. As strategic frameworks designed to guide countries in securing the long-term sustainability of their HIV responses, HIV Response Sustainability Roadmaps also form part of the efforts to integrate HIV services into primary health care. They emphasise a comprehensive approach that embeds HIV prevention, treatment, and care within the broader health system.

However, with the radical shifts in the global HIV funding landscape, person-centred HIV response has evolved in a myriad of ways at national, regional, and international levels. In the following section, we outline different pathways that characterise how countries and PLHIV networks have adjusted to these changes throughout 2025 and their bearing on transitioning to integration<sup>11</sup>.

## Introduction of new policies and structures

As a means of ensuring that there is continuity of care, one key pathway underlying the changes adopted has been the introduction of new policies and structures alongside the already existing structures<sup>11</sup>.

First, there was the development of national standards, briefs, and communiques highlighting the value of integration and the essential elements to be included in integrated service models led by the Integration Committees and Advisory Boards linked to Ministries of Health, as well as Networks of PLHIV, in response to the changes. Additional efforts to develop more detailed implementation blueprints are also underway.



We first of all called upon the Ministry of Health, and for us, that is NASCOP, to come up with a standard guidance on integration. And they did a circular on guidance, which we worked on together, and decided...what is required for integration. And because it was not very detailed. It is just like a letter; counties requested for a blueprint. So right now, we have been working with NASCOP to come up with a blueprint on what helps countries. What defines integration, and what helps countries to know what to do."

(Kenya, PLHIV Network Key Informant)

Secondly, through joint advocacy efforts such as working through the CSO Taskforce, countries such as Uganda were able to engage parliament, which increased budgetary allocations to health as a nod to the need for continued investments in health systems improvements.

As part of their sustainability roadmaps, countries have also included levies and taxes that are expected to generate resources for their HIV response. Governments also adapted to the changing environment by raising funds to cover some of the services, such as ensuring ART is available despite gaps in distribution



"In countries like Indonesia, we have a partnership there. They've done a really nice job of identifying that core life course package for different ages and stages. So, like adolescents, like I mentioned, what I spoke to largely reflects the package of care that must be offered to every adolescent who walks into a primary health care centre or who is screened by a community health worker. So that's some of the work that we're doing with the government of Indonesia to help to actualize this vision. And you know if you're an older individual, then of course you have to be screened for NCDs, you have to also have a mental health screen, so there's these."

(PATH, Key Informant)



"We have added levies in the transport and communication sectors to cater for HIV programming, and for the first year, the government is expecting to collect over 400 billion Tanzanian shillings to support the HIV response at a country level, and they have started collecting in July this year. So as of now, I do not know the status of the collection, but what I know is we have enacted new bills. We call it the finance bill, in which the government accepted the finance bill, where we have added different levies to different services to cater for HIV.... We have added taxes to alcohol, cigarettes, and betting games that are happening at a country level to cater to HIV services."

#### (Tanzania, PLHIV Network Key Informant)

Thirdly, user fees for services that are a barrier to access were introduced. This was compounded by the fact that HIV services were seldom included in benefit packages under health insurance schemes, with the justification that such services tended to be funded. Finally, integration models are also being implemented at the clinic level.

For instance, in Kenya, facilities with HIV clinics have expanded to include non-communicable diseases. Whereas Indonesia has developed a life course package for integration that handles people of different ages and stages of life. Countries had to conduct rapid integration due to the limited time for planned action without having clear operational frameworks. Limiting time for training and institutional-level integration for systems that were typically stand-alone, e.g., the supply chain for HIV and NCDs.

## PLHIV Network closures and scaling down of activities

It was also common for PLHIV networks to report experiencing a decline in the effectiveness of the work they were doing due to the impact of funding withdrawals on their organisational systems<sup>11</sup>. Key interventions led by PLHIV Networks at the community level as part of community outreach and service delivery, outlined in their strategic plans, were discontinued due to the funding cuts.

This included the closure of smaller PLHIV networks; staff layoffs, including community-based volunteers; the halting of activities such as treatment literacy programs and community-led monitoring; reduced support to coordination mechanisms; and the closure of support groups, safe spaces, and youth clubs. More so for services targeted towards key populations. In Tanzania, for instance, the loss of support to peer navigation systems within health facilities meant that younger PLHIV had stopped accessing services



Because even us, as a network of youth living with HIV, as a small organization, employed other people working as peer educators on the ground with the program supported by PEPFAR, which were halted. So, we sent them back home, and the support that they were offering to their fellow young people at the health facilities has been halted. And we see a drop out of young people at the health facilities seeking those services because we are not supporting them anymore."

(Tanzania, PLHIV Network Key Informant)



"The funding withdrawals...were so rapid. As you know, many governments in Africa went for rapid integration. But some already had plans for integration, like Kenya, Uganda...but not the time to really think about how to operationalize it. So, in Uganda, they moved quickly to integrate HIV services into their non-communicable disease or chronic disease clinics, in part. But you know, they didn't have the time for the training of the clinicians, the NCD clinicians to be trained in HIV care. And the supply chains, the HIV supply chains, actually were still pretty decent, but for NCDs, it's always been a problem to get access to basic NCD medicines."

(PATH, Key Informant)

The closure of data repositories meant that there were no opportunities to track efforts being made, as reporting was crippled. Logistics and supply chains, which were also being supported through US funding to strengthen health systems, were also impacted, resulting in poor distribution and stockouts.

Healthcare workers who were previously not engaged in HIV management took on new roles and, without training, did not always provide the most appropriate care for their clients with HIV.

Further, in areas of service provision where gaps already existed, such as paediatric HIV and care for key and vulnerable populations, these gaps became magnified, including instances of stigma and discrimination.



"We had gaps in terms of the coverage, we had gaps among paediatrics too. We had gaps in some of the hard-to-reach areas. We also had key challenges around reaching out to key and vulnerable populations, and the withdrawal of that funding meant that these gaps actually increased. And we were also struggling as a country to adhere to the Abuja declaration for 15% provision of funding on health services."

(Zimbabwe, PLHIV Network Key Informant)



"I think certain things have been compromised; quality of care seems to have gone down. You know, having HIV and living with HIV is not just a matter of access to ARVs. Access to ARVs is not interfered with. ARVs are free, and they are available. But the first thing is, where do you pick them from? If HIV-specific clinics have been closed. If you live in Nairobi, you've been going to an HIV-specific clinic, and now you're told to go to Mama Lucy. Only the brave will go, people who [have] braved stigma and discrimination. Most of the young people have been lost to follow-up because they don't know what to expect. They had built a relationship with the health care workers. Those health care workers are not there. They don't know what to expect, and therefore continuity of] care has been a challenge. We continue to encourage them to avail themselves of medications, but I know it will take time for adjustment."

(Kenya, PLHIV Network Key Informant)



Moreover, in regions such as the Middle East and Northern Africa that were not receiving a lot of US funding, the withdrawals also triggered other funding bodies to pull out their resources.

in a decline in the quality of care. For instance, PLHIV would be redirected to new facilities, and many would opt out of care due to worries of stigma and discrimination and uncertainty over what to expect in the new environment.

All these changes culminated

This severely impacted continuity of care, particularly among young people. To help address these situations, PLHIV networks have been using one-on-one and virtual approaches to reach out to PLHIV and encourage them to stay.

"The MENA region was excluded from the beginning [of] this PEPFAR and the USAID. USAID might be some modest partnership, but PEPFAR was almost never present. It was because for them, the MENA region was not a priority, and since the creation of PEPFAR, when it comes to people living [with] HIV networks, there was no connection already. So that's why there is not a huge impact. But indirectly, because now we are saying that many countries...are following the American example, and they have started to freeze their funds. For example, for us, we had a one-of-a-kind huge project that we had proposed for the ART staff program. We had been preselected, and unfortunately, we were declined at the last minute."

(MENA Region, PLHIV Network Key Informant)

## Restructuring and repurposing of networks and services

Finally, PLHIV Networks had to strategize and convert some of their resources to address new priorities while ensuring that their formal structures remained intact<sup>11</sup>. In Indonesia, they used some of their reserve funds to ensure that community-led monitoring activities were maintained alongside additional support from other funders. While in Uganda, they introduced weekly virtual data update meetings where districts can present their progress and get feedback on their strategies. They have been able to sustain this joint reporting platform for the past 10 months. Further, they are also working with Makerere University School of Public Health and other academic institutions to generate data that can be used to advocate for resources and improve the quality of the HIV response.

In response to the loss of resources, the Networks stated that they have been exploring other resource generation initiatives such as social contracting and social enterprises, e.g., credit and saving societies for PLHIV or health insurance schemes, as a way of building their resilience. Other funds have come from the private sector through their Corporate Social Responsibility Initiatives. The upcoming Global Fund funding cycle was also seen as a good opportunity for the networks also advocate to for community-level implementation and engagement. Despite these challenges, the networks pointed out that they would continue to find ways to remain active because their work is needed.

## **Distress amongst People Living with HIV**

Despite stating that their focus was on integrated models, governments were shutting down HIV clinics without efforts to sensitize communities on integration processes. Fears about the availability of services caused panic as communities were unsure of what HIV services were available to them, leading to disengagement from care, with reported declines in the number of people going into facilities. The additional fees that were being charged by facilities were catastrophic, and the situation was made worse by the rampant stockouts due to the impact of the funding withdrawals on the supply and logistics chains. PLHIV Networks reported an increase in mental health concerns such as depression and anxiety. Many countries are also facing tough socioeconomic times, and PLHIV have to weigh decisions about getting the care they need against meeting their daily needs.



"Our structures and systems, though shaken, we are still engaging. You could even think that we have whole offices in place. We have refused to be erased. We have refused to be deleted. We have refused to not be recognized. We have continued to say, "Here we are," and we continue to demand for action. We continue to inform policy. We continue to mobilize our communities to demand for services. We continue to monitor the services delivery. We continue to do our rapid assessments and research. Even amidst difficulty."

(Uganda, PLHIV Network Key Informant)



"We started to witness that there was, obviously, a high-end rise in terms of mental health issues, including anxiety and depression. That was also covered on one hand by miscommunication but also not knowing what is really happening with relation to the service provision. Again, also, our government didn't really quickly come up with a statement to say what is really going to happen in the aftermath of [the] cessation of funding from the American government. So, there was a lot of anxiety that triggered mental health issues, which were characterized [by] depression and also withdrawal from care."



## Minimum asks required for effective integration

Over two decades of investments in HIV response, proven experience and learned expertise, has equipped PLHIV with solutions that work and will be crucial for considerations in adapting and reorganizing national health systems towards long-term availability and accessibility of HIV testing, treatment, and prevention services. PLHIV detailed various core services that must be integrated into HIV services at the community level to sustain the gains towards ending Aids.

Figure 9 below details these services, which include HIV testing services, HIV treatment services, mental health services, cervical cancer screening, and adolescent support groups.

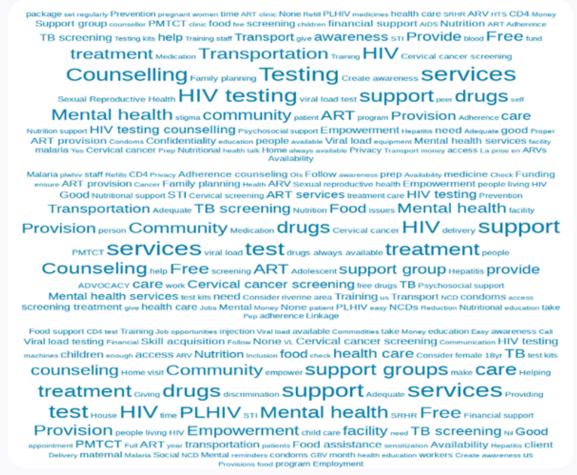


Figure 5: Key Services for inclusion in the Integrated HIV Service package at the Community Level

Beyond these services, PLHIV networks identified the minimum requirements for integration. The asks have been classified according to the type of integration they seek to address, whether they target

- 1. the connections between processes and organisational structures that make it possible for different actors to work together and share information (Structural integration);
- 2. the organisational, interprofessional and sectoral relationships, including PLHIV and PLHIV networks, that are shaped by their shared values and expectations alongside the structural connections (Relational integration); and
- 3. the rules and standards that are shared across all service ecosystems, including goals, work practices, and strategic orientations (Institutional Integration)<sup>12,14</sup>. In addition, for each ask, the strategic and operational levers that will be necessary for its realisation using the Operational Framework for Primary Health Care are described<sup>13</sup>.

## Minimum Ask 1: Institutionalisation of plans to engage PLHIV Networks in adaptations/national HIV integration frameworks.

As HIV services are integrated into primary health care and community health systems, the type of integration must be institutionalised.

#### Type of integration targeted: Relational integration

Though countries may differ in relation to the organisation of their health systems and HIV responses, PLHIV as service users form the foundation of any deliberations on integration. Bureaucratic barriers may limit the active involvement of PLHIV and their networks in the policy-level decision-making, resulting in the formulation of National Action Plans, normative guidance documents, and reports that do not reflect their voices, particularly those of young PLHIV.

Therefore, prioritising the participation and engagement of PLHIV and their networks should not be tokenistic and superficial but should be deliberate, intentional, and transformative. Transformative participation is defined as their involvement in "considering options, making decisions and taking collective action."

This involves working with PLHIV Networks, community-based organisations, peer support groups, and champions who are essential in improving the reach of care to marginalised and criminalized populations, particularly in rights-constrained settings. Through involvement in activities such as peer counselling, health education, active screening, drug collection within community-based differentiated drug delivery models, home visits, adherence support, and treatment literacy.

Their insight is critical for not only identifying what the most suitable approaches for integration should be but also how to ensure that HIV is integrated first into primary care, secondary health services, and the private sector.

In addition, information on user experiences with integrated models can be obtained through community-led monitoring and patient satisfaction surveys, with the feedback being used to continuously improve the quality of services.



Although our participants were active during the meetings, somehow it is really hard for us to ensure that our voice is written into the national action plan drafts. For example, following these meetings, despite the government officers saying that our suggestions or recommendations are being accepted, it's really hard until it's finalized and endorsed... That's one thing that, although we try to push a lot of the agenda, from the community side there's a of complicated bureaucracy in the government to ensure that our needs are being recognized and written into the National Action Plan."

(Indonesia, PLHIV Network Key Informant)

## Minimum Ask 2: Integration should be clearly defined and shaped by local context and realities.

#### Type of integration targeted: Structural integration

An area that was emphasised during the discussions with the PLHIV networks was the need to have clear definitions of integration that are shaped by country-level implementation contexts derived from readiness assessments<sup>12</sup>. Readiness assessments were identified as providing a means through which countries can map their starting points and, afterwards, ensure that they can trace any progress made. Community-based readiness assessments remain lacking in discussions on integration, yet understanding community and household-level dynamics as well as monitoring services at these levels is crucial for good health outcomes and resilient community health systems.

Furthermore, these conceptualisations ought to be drawn from both health and non-health actors who play a critical role in providing holistic care to PLHIV, including those in social protection and economic development. Private sector partners can also be engaged to support integration efforts.



Integration should not only be in health but integration across sectors. Across sectors, not only for HIV health but also for economic development. We also need social support and protection."

(Uganda, PLHIV Network Key Informant)

## Minimum Ask 3: Integration processes and models should be equitable and recognise the diversity and realities of PLHIV.

#### Type of integration targeted: Institutional integration

Due to the diversity of people living with HIV, a key ask from the PLHIV Networks is that all integration processes should be equitable. Health inequities arise from how healthcare interventions and implementation processes are created, implemented, and reproduced during service delivery<sup>1515</sup>.

Therefore, with the move from specialised to more generalised care, it is imperative to ensure that integration models are able to account for the differential needs of PLHIV populations and allay worries that the services provided through primary health care centres are of lesser quality. Integration should be people-centred and tailored to cater for considerations such as human rights, gender, disability, children and young people, and ageing populations.



"Not everyone should be treated the same. It's not easy for any government to have that kind of setup, but I think a concession for women, a concession for young people, should be at least included... I guess in the package if you are trying to have services that are specific to a certain group, the NCDs and probably other, you know, other reproductive health-related services should be taken into consideration also for...different groups. So I think the conclusion here is that even if it's not that easy, a differentiation in terms of services should at the minimum be considered in the integration at the primary health care so that you don't take everyone as the same."

(GNP+, Key Informant)



"Depending on the context that you know, sometimes with HIV prevention in particular but also with HIV care, you know you will inevitably touch on some of the lifestyle/behavioural issues that perhaps were at the heart of transmission risk at the very start. Whether that's linked to sexual health, perhaps drug-using pasts, or ongoing drug use, we need to make sure that everybody who is accessing services can do so appropriately. It becomes more complicated for HIV because, of course, we are linked to criminalized and marginalized populations. And so, the other thing I think we need to do is that when we talk about people living with HIV, we need to always recognize that we're a very heterogeneous group and that within that group, um, particularly if you look at the African context, I think that's a good example where you will have the majority of people will likely come from, you know, heterosexual kinds of...backgrounds. But even within that you will find there are men who have sex with men, transgender people, [and] people who use drugs. And I think it's making sure that we're able to continue to have the levels of specificity needed through however services are organized to make sure that all people living with HIV are represented in the movement, and you know, there are other identities [that] are not erased or invisibilised as we move forward."

The care PLHIV receive should be appropriate for their needs, irrespective of how they come into contact with the system due to factors such as sexual behaviour, injecting drug use, or sex work.

(WHO, Key Informant)

# Minimum Ask 4: The design and delivery of integration models should be comprehensive

#### Type of integration targeted: Wholistic integration

Another key consideration that was highlighted during the discussions with the PLHIV Networks was to ensure that the integration models are comprehensive. First, the models need effectively account for all aspects of HIV care, from treatment, prevention, and adherence within facility and community settings. There was a concern that often, HIV prevention tends to be overlooked in considerations about integrated services. Moreover, even as the HIV services are being integrated into other services such as chronic care clinics, it would be necessary to retain the specialized consideration needed for HIV management. Integration of prevention in HIV services also presents an opportunity for treatment as prevention, particularly the message, which is critical for achieving and maintaining viral load through consistency and adherence to ART. U=U messaging is also an integral part of self-care, as it places PLHIV in charge of their health

Secondly, integration models ought to address a person's HIV-related health needs alongside other health needs. This is associated with an increase in the occurrence of non-communicable diseases such as cancer, hypertension, gastric issues, kidney problems, liver problems, diabetes, mental health issues, and advanced HIV disease among PLHIV. These models should utilise a life-course-based approach to ensure that services provided are relevant to PLHIV at different ages and stages of their lives. Other importance when areas of designing that tend be integration models overlooked, according **PLHIV** to the Networks, include reproductive health. especially women's health concerns such as cervical cancer screening, menopause, and its intersections with HIV, as well as STIs.



"For the time being, I think because treatment works, people have managed to live with HIV. But now these people who are aging with HIV are presenting with the non-communicable diseases. That is hypertension, kidney problems, liver problems, [and] diabetes. So, it does not make sense to be...stuck in the HIV corridor because it is your health. You may have ARVs, [and] you may be virtually suppressed, but non-communicable diseases may still take you out of this world, and that's why for us when the Ministry of Health talked about integration, we welcomed that so that the population that probably [has] non-communicable diseases can also benefit."

(Kenya, PLHIV Network Key Informant)

Thirdly, integrated models should go beyond a focus to also biomedical address psychosocial needs of PLHIV. The networks also encouraged the retention of community-based models, which have traditionally been effective, including the high-impact differentiated service delivery models, multi-month dispensing, dropin centres, shelters, safe spaces, and youthfriendly corners, some of which were closed as a result of funding freezes. As they ensure that the needs of PLHIV from different key populations are catered to.

Additionally, new innovations, including the use of digital platforms in delivering services that complement traditional models, must be explored. Community-based structures should also be strengthened to ensure that services are also available at community levels, through peer and adolescent support groups, Mentor Mother Models, adherence counsellors, or Community HIV champions. Community health workers involved in this work should also receive incentives for their roles.

## Minimum Ask 5: Effective integrated service delivery will be unattainable without resilient health systems.

## **Type of integration targeted:** Institutional integration

It is necessary to design systems and processes at all levels of the health systems (supply chain, information systems, governance and accountability, supervision and support, funding and financing, and human resources) that can ensure that proposed integration models can work optimally<sup>16,17</sup>.

Adopting a systems approach with coordination across operational and strategic levers of the primary care framework would ensure that emerging challenges can be anticipated and planned for, while ensuring that a person-centred approach is maintained. Funding for integrated services should come from different actors through integrated budgets, including those in the private sector.

The physical infrastructure of the facilities should still maintain a level of privacy, particularly for upholding privacy and confidentiality for populations such as people with disabilities, adolescents, and young people.

This could also be accomplished through specific clinics/rooms or differentiated times.

Healthcare providers, particularly those who are unfamiliar with HIV management, require training on how to handle different types of clients as well as clients at different stages of their care, such as first-timers, women attending ANC, or treatment adherence counselling. Their training should also cover integration processes and the minimum standards required to effectively deliver integrated care. A broad range of health workers should also receive training, including dispensing pharmacists who provide medication to PLHIV and need to understand the value of maintaining their privacy.

Further, PLHIV should also be provided with the knowledge on integration so that they can have agency during patient-provider interactions and advocate for better quality care where they feel it is insufficient<sup>16</sup>.



"Another priority that we have called for is to provide training to health care workers. To be sensitized on the issues related to do with HIV. To be sensitized on issues related to do with stigma and discrimination. How to avoid it. To be sensitised on human rights. And that is what has been missing: the specialised care that we used to have in Kenya, that were being supported by USAID and USAID. Although a few of them were recalled, they are not in frontline clinics. So, we have had people who initially did not have the training, and they want to treat HIV like any other condition. And this is a stigmatised condition. So, we have said that training or sensitisation is really very important."

(Kenya, PLHIV Network Key Informant)

Information systems were felt to be one avenue where the privacy and confidentiality of the health records of PLHIV could be lost. Furthermore, the funding withdrawals had led to the collapse of data repositories, making the data needed for decision-making unavailable. Therefore, data systems should be strengthened to account for these concerns while making it possible to still effectively track patients and the breadth and quality of care that they are receiving.

Additional data entry requirements may place a burden on health providers; therefore, data capture systems should be streamlined. Further, operational and implementation research should also be conducted to periodically assess the quality of services, as well as basic research to optimise treatment and diagnostics. Integrated services, particularly laboratory-based tests, on which the nature of services one can receive depends, should also be affordable.

## Minimum Ask 6: Integrated services should be stigma and discrimination-free

#### Type of integration targeted: Institutional integration

A key ask from the PLHIV networks was that integrated services should be stigma and discrimination-free. PLHIV should be able to come into facilities and have their full range of identities and expressions respected and factored into their holistic care plans. Health facilities should strive to maintain the privacy and confidentiality of those accessing care at primary health care levels, as they cater to a large number of clients.

As services shift from a specialist to a generalist approach, health providers who may not have been trained on HIV management, including how to create non-discriminatory environments, can make the encounter with PLHIV unfavourable, leading them to disengage from care.

Provider biases and beliefs may affect how they interact with clients, particularly those who are criminalised, and strategies such as sensitivity training on human rights can help improve their encounters<sup>16</sup>.

Without sufficient training, stigma and discrimination are likely to be embedded within health care systems. Further, lay health workers who were previously not engaged in HIV work also need training on maintaining the privacy and confidentiality of their clients.

## Minimum Ask 7: Governments must take on the responsibility of purchasing HIV treatment

#### Type of integration targeted: Institutional integration

For sustainable, integrated HIV services, governments must take leadership and ownership of the HIV response, not only in driving the agenda but also in financing the response. In particular, governments must not outsource HIV treatment access and must include access to innovative treatments in the pipeline, like long-acting treatments, to close the viral suppression gap both for the health and quality of life for all PLHIV and to drive down HIV incidence (U=U). Governments must commit domestic resources towards procuring ARVs to ensure treatment access is not disrupted.



"Investment is required, and that investment will now not come from the US or [the] Global Fund. That investment must come from our government, the Kenyan government; we are also taxpayers. So when we used to have NHIF, the National Hospital Insurance Fund, HIV was excluded because HIV had funding and adequate funding. And then they came up with the Social Health Authority; HIV was excluded because there was [donor funding. It is our responsibility to remind the government that at the moment, that [donor] funding that made HIV to be excluded is no longer there, and therefore they need to provide resources for covering HIV services. The future of HIV is such that as a chronic medical condition, the minister of health and current government will have to pay. Right now, for the next few years, we have PEPFAR, we have [the] Global Fund, but when we talk about going to 2030, we don't think those will be available. Therefore, the government must take it up."

(Kenya, PLHIV Network Key Informant)

## Opportunities for leveraging PLHIV networks in ensuring responsive integrated HIV services

PLHIV networks are essential in advocacy and delivery of HIV services at the community level. With a deficit of 18 million health workers anticipated globally by 2030<sup>18</sup>, there is an urgent need for innovative strategies that go beyond the conventional health sector response in the delivery of HIV services. This section describes some of the roles that PLHIV networks could play to facilitate the implementation of responsive integrated HIV services.

## **Role of PLHIV Networks in HIV Service Delivery**

#### Cost effective outreach

PLHIV Networks were viewed as playing a key role in the provision of HIV services at the community level. Most of the participants across all ages, sexual identities, and genders affirmed that PLHIV networks assist a great deal in bringing HIV services closer to the households.

HIV services provided by PLHIV networks included peer counselling, treatment access, advocacy, and home visits. As shown in Figure 5, the bulk of the services provided by PLHIV networks were home visits.

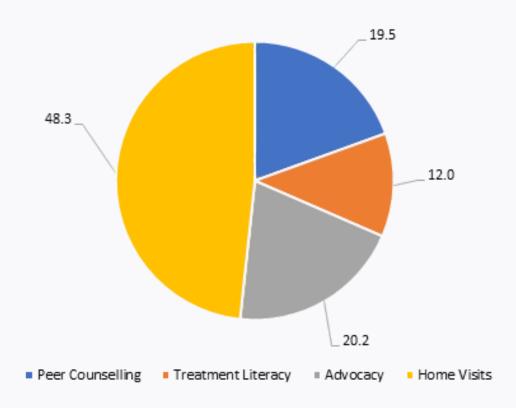


Figure 6: Support services provided by Networks of People Living with HIV

Slightly more than half (51.3%) of participants indicated that PLHIV networks regularly engaged with the community. This was consistent across all age groups except for the elderly, 65 years and older, who reported that networks engaged with communities only occasionally. With regard to key populations, only 37.9% of participants who identified as sex workers reported regular community engagement by PLHIV networks. Almost three in ten (27.6%) reported rare community engagement by PLHIV networks. More than half (55.0%) of incarcerated persons and one-third (33.3%) of persons who use drugs reported only occasional community engagement. The majority of transgender participants (42.9%) also reported occasional community engagement by PLHIV networks.

#### **Self-Care promotion**

Self-care interventions in the delivery of HIV services are a necessity<sup>19</sup>, and studies have demonstrated that PLHIV networks play a critical role in self-care interventions for health and HIV by empowering people living with HIV to actively manage their own health, improve treatment adherence, and adopt health-promoting behaviours<sup>20,21</sup>.

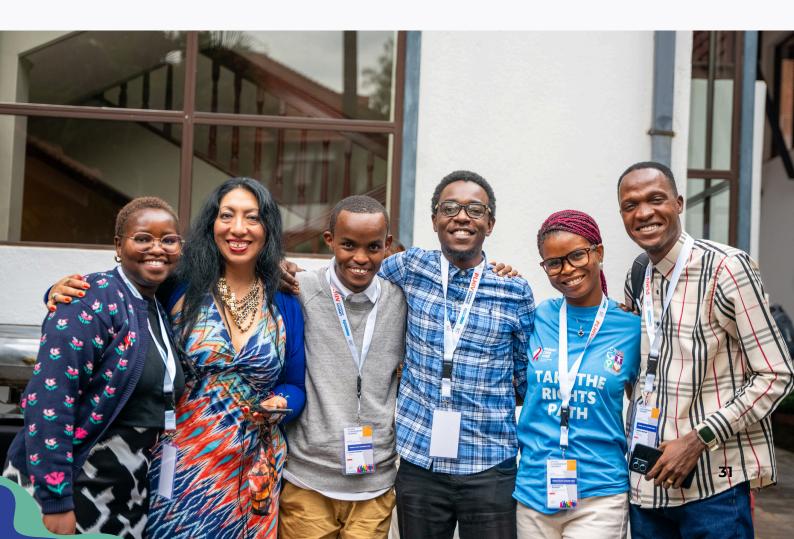
In Kenya, studies show that caregivers and PLHIV who participate in support groups and community-led networks practice essential self-care elements such as infection prevention, nutritional care, psychological support, and care seeking, which improve overall well-being and resilience<sup>22</sup>.

These networks facilitate peer counselling, mental health support, and knowledge-sharing, helping PLHIV overcome stigma and barriers to care while promoting treatment literacy and adherence. Programs like Operation Triple Zero engage young PLHIV as partners in their own care, fostering agency and tailoring services to life-stage needs<sup>23,24</sup>.

Social network-based and community support interventions have been shown to improve retention in care and viral suppression by providing patient-centred and contextually relevant support mechanisms<sup>21</sup>.

As networks play this key role in delivering HIV services, considering the current funding landscape and the shift towards integration, PLHIV networks must also evolve. PLHIV networks must

- ensure they have strong governance, operations and management, including clear succession plans for sustainability;
- 2. pivot to PLHIV-led advocacy that strategically collaborates with governments and partners to ensure HIV services integration is responsive to PLHIV needs;
- 3. be resilient in engaging in community education, demand creation, evidence gathering and CLM to inform national HIV service delivery and programs; and iv) be innovative in identifying institutional resources that emancipate them from donor dependency, including through social enterprising, etc.



## Challenges faced by PLHIV networks in supporting Community-level HIV service delivery

PLHIV networks face various challenges. Figure 6 depicts a word cloud that details the challenges faced by the networks. Among the major challenges were a lack of funding and financial support, stigma and discrimination, and logistical resources, such as transportation. Other challenges faced by the networks include capacity building and commodities.

Inadequate Manque de financement Awareness support government Training Logistics HIV sure Finance Gove Stigmatization Accessibility Limited Good community idea resources provide Discrimination network Transportation Insecurity Support Bad road Stigma Distance Funding Fear Lack Non Stigma discrimination Stigmatized Lack funds Stigmatised Financial Self Money food Financial support know challenge advocacy Transport clients PLHIV Transport fare workers PLHIV networks Na Stigmatisation NA IHV Supports IDPS set sensibilisation viral people living HIV information TRAINED PERSONNEL Stigmatization Insufficient counseling Financial support state Finance care transport High Capacity building idea Non opportunities Distance Provision Stigma discrimination Adherence resources test kits PLHIV Mobility Challenges disclosure Transportation enough Discrimination good community location Funding level Lack Accessibility Stigma drugs HIV testing service Availability SUPPORT Limited funding WORK giving Food program counselling accessing Poor Awareness Financial taken COMMOdities Cooperation people staff Communication Language barrier Support groups Self stigma Insecurity human resources Client Holistic IHV supports Lack proper sensibilisation viral charges ers Disclosure litteracy leading None PLHIV networks feeding health workers Commodities Work patient Engagement provide Capacity building following Non idea Peer Accessibility Access Limited Financial Money care NIII Empowerment people government need PLHIV self stigma Stigma Rejection Funding Good Support barriers Lack information community service delivery challenges Alimentation problems HIV communication services staff capacity training Stigma discrimination Stigmatization Transportation help Fear Insecurities Finance workers Drugs Nil network s Discrimination policy provision available health Distance Financial support Coordination Na c

Figure 7: Main challenges faced by PLHIV networks in supporting community-level service delivery.



## Barriers to PLHIV networks' advocacy for quality HIV services

Beyond the challenges PLHIV networks face in supporting HIV service delivery at the community level, they also face barriers in their advocacy for quality HIV services for recipients of care. Among the major barriers are the lack of financial and logistical resources, stigma and discrimination, community engagement and participation, as well as engagement with governments. These are detailed in Figure 7.

people living HIV Healthcare System facility Funding constraints recognition Political will Limited funding among sure reaching Communication network training policymakers given tot level testing Poor think Good insufficient need cultural financial support long advocacy involvement services facing Stigmatization Yes leaders integration PLIHV IHV access government programs PLHIV integration Lack funds engagement resources rights de listen support drugs Stigma discrimination leadership Funding advocate Lack issues Stigma stakeholders government want community Policy barriers participation people Limited resources Discrimination barriers advocating quality PLHIV leaders health care Finance Transportation challenges key quality HIV services Nit time attitude Financial systems None opportunity know state advocating quality HIV Stigmatisation Non lead Limited even attention Na money knowledge Political Lack awareness sometimes Lack transport Marry capacity building awareness Limited capacity support government Stigma discrimination Limited

Figure 8: Barriers faced by PLHIV Network in advocacy for quality HIV services.

Despite these challenges and barriers, the networks continue to provide HIV services and engage in advocacy. Over 70% of participants rated collaboration between PLHIV networks and healthcare providers as either good (41.8%) or excellent (29.1%). Furthermore, 63.7% of participants also reported that PLHIV networks are involved in planning and decision-making regarding HIV service delivery in their communities, and 69.2% also reported PLHIV networks' involvement in community-led monitoring.



## Strengthening PLHIV Networks to support the delivery of integrated, Person-Centred HIV Services

In view of the challenges and barriers faced by PLHIV networks in advocating for and supporting HIV service delivery at the community level, participants made recommendations on how PLHIV networks can be strengthened. These are shown in Figure 8.

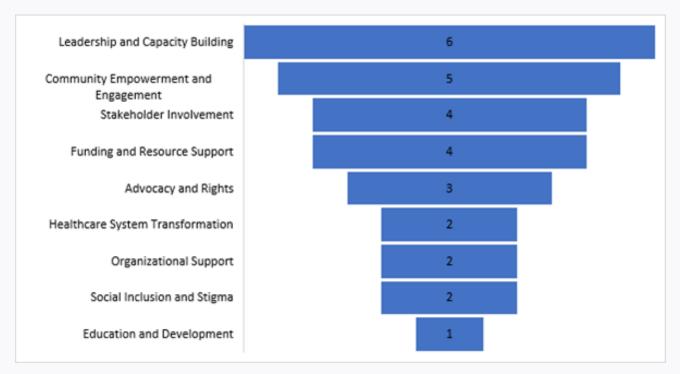


Figure 9: Recommendation to strengthen PLHIV leadership and ensure HIV services remain person-centred

Among the key areas are leadership and capacity building, community empowerment and engagement, stakeholder involvement, and funding and resource support.

#### Leadership and governance of equitable and accessible integrated HIV services

PLHIV Networks are central to the realization of person-centred care as "true local actors" in HIV response at national, regional, and international levels. Therefore, they were seen as being good thought partners to governments, funding organizations, and other implementing partners, as they have first-hand experience with these services.

Though the networks are already part of government-led integration committees and technical working groups, more work needs to be done to strengthen these relationships. They can play a key role in the development of governance and policy tools, such as standards for integrated services. Networks could also develop deliberate plans that outline measures through which the perspectives and needs of PLHIV are taken into account when making decisions about primary health care.



"It would be really good if the national networks took some time to be very deliberate about this. You know, so they develop their own plans for ensuring perspectives and needs of people living with HIV are considered within...the broader piece of primary healthcare approaches that are underway in those countries."

(WHO, Key Informant)

## Advocacy for comprehensive integrated services

The networks need to conduct advocacy on the minimum requirements for integrated services and approaches to ensure that the highest levels of quality are achieved during their implementation. Further, the networks could also advocate for aspects of care that tend to be left out, such as self-care care reduced costs of services, domestic resources to fund services, inclusion of the needs of criminalized and marginalized populations, and ensuring that they are included in strategies and plans.

The networks were also urged to advocate for groups of PLHIV who are often less visible during advocacy initiatives. PLHIV Networks could also advocate for the adoption of new innovations such as long-acting prevention and treatment, as well as dual and multiplex diagnostics as part of integrated models and the inclusion of integrated services into the benefits packages of National Health Insurance Schemes.



PLHIV networks can also play a crucial role in community preparedness for the changes that would be brought on by integration. By solidifying trust through data-driven adaptation experiences and realities of accessing services to improve the quality of health services and strengthening health systems. One of the key gaps that was identified was the lack of familiarity with what integration entails among PLHIV, for which PLHIV networks can conduct demand creation at community levels and sensitize PLHIV on the necessity of the shifts to generalized care at the primary care level and the benefits, such as reduced costs.

They can provide this information through diverse platforms, including digital platforms, using simplified and accessible formats that consider factors such as age, disability status, and literacy levels, ensuring that more people are familiar with integration processes and policies.



"In place to do our advocacy, our engagements, to participate in policy and programming, [engage] in GBV prevention programs and stigma reduction programs, and [ensure] that we have laws and policies that align with the same. Ensuring that our networks and support groups continue to support the integration. Because for us, we are not against integration, but we are about allowing us to provide the education. The information to ensure that our members are able to fit in. And also that we will continue to advocate for specialized services for those who are criminalized, for those who are vulnerable, [and] for those who are hard to reach."

(Uganda, PLHIV Network Key Informant)



"So, our networks still have a role to advocate to ensure the quality of services. Secondly, how to increase the demand and also to capacitate the community. To make sure that the community understands how important it is for them to access services through primary health care rather than [through] the hospitals because of the cost efficiency. The transportation costs can be reduced if their access is at the closest primary health care facility. I think that there are two sides: strengthening the community to increase the demand and also advocating for the government, especially health services, to improve the quality of services."

(Indonesia, PLHIV Network Key Informant)

#### Implementation of integrated HIV services

Moreover, PLHIV Networks should be involved in the implementation of integrated HIV services. They can participate in technical meetings with national governments, including ministries of health, education, and finance. They can participate in the implementation of activities such as health education, demand creation, community mobilization, support groups, treatment literacy programs, training on stigma and discrimination, and community-based drug dispensation, especially during disasters. The members of the networks could participate in task-shifting of roles where healthcare providers are few and do not have time for specialized attention for PLHIV. The networks could also partner with other actors in sectors such as climate-adaptive health programming, economic and livelihood strengthening, as well as capacity building.

Nonetheless, as they rarely receive direct investment from governments, funding models such as social contracting offer an opportunity to support the work they are doing. Despite being found effective, there is a poor understanding of social contracting frameworks and limited political commitment to provide government support to networks. The networks can help in the development of these frameworks, as well as the sensitization of what they are. Despite limited funding, the networks have been able to sustain their work for decades and could also offer best practices as the HIV response is evolving. Examples of India and Kenya demonstrate that social contracting can be successfully implemented<sup>25</sup>.



"If we talk about sustainability, although the government already provides a platform like social contracting for the NGOs in the HIV program [to] access the funding, the mechanism itself is not really being understood by the institutions that are providing the money. Although there's a policy, there are requirements that we are to follow. But the willingness from the government to provide support, especially funding to sustain our program—until now we haven't seen the goodwill from the government to support their own NGOs, especially for the HIV program."

(Indonesia, PLHIV Network Key Informant)

#### Monitoring and Evaluation of integrated HIV services

Finally, PLHIV Networks can play a key role in oversight over the entire spectrum of integration from its design, implementation, and evaluation to highlight where existing strategies are weak and need to be strengthened. They can also highlight best practices that could be candidates for scale-up in other regions.

Feedback on user experiences can be collected through surveys, community-led monitoring, storytelling, or exit interviews on varied dimensions of care, such as fair treatment, respect, and dignity during client-provider encounters, and shared with government ministries for action. Community-led monitoring, which has largely focused on HIV, could also be expanded to incorporate other diseases common in communities, such as TB and malaria.



"We can amplify the best practices because we are in the community. We are the recipients of care. And then we also provide what the gaps are and also engage jointly in monitoring. Community-led monitoring should not only be for HIV, TB, [and] malaria but [also] for, generally, integrated service delivery.

(Uganda, PLHIV Network Key Informant)

Further, while working with other actors such as academic institutions, PLHIV networks can generate data in areas such as HIV stigma research that is useful in addressing some of the challenges associated with integration at a primary care level. As HIV services are integrated into mainstream health systems, this presents an opportunity for PLHIV networks to evolve community-led research to align with the adaptations in health services as they are integrated. This will be key in providing evidence for decision-making regarding the inclusiveness and person-centredness of integrated HIV services, reflecting the experiences of PLHIV. PLHIV-led research can also be used to show the impact of integrated services on HIV outcomes as a use case for greater investment, particularly through domestic resources.



PLHIV networks are foundational to the delivery of responsive HIV services. They play a key role in the HIV response, facilitating the provision of HIV services at the community level and advocating for quality HIV services for recipients of care. PLHIV networks and their constituents must be viewed as a key partner in the provision of HIV services at the community level and in bringing HIV services closer to the households. Among the key services that they provide are peer education, counselling and adherence support, treatment access, demand creation, and home visits. Their peer support services enhance psychosocial outcomes, assist individuals in re-engaging with care, and create a supportive environment that bolsters mental health, achieves viral suppression, and drives down HIV incidence (U=U).

Additionally, they advocate for PLHIV rights and needs, influencing policy and fostering collaboration in health governance and service delivery. In times of crisis, the networks play a critical role in maintaining continuity of care, highlighting their importance in both community and healthcare settings. In view of the effect of disruptions on funding to the HIV response, PLHIV networks and their community have been at the core of ensuring services are still available for recipients of care.

PLHIV Networks face significant challenges in supporting HIV service provision at the community level, especially in resource-limited and marginalized communities. Operationally, networks struggle with inconsistent funding and logistical support, which affects their outreach, succession and sustainability plans. Financial constraints further limit clients' access to necessary resources, while uncoordinated service hours and insufficient supplies hinder effective service delivery.

Stigma and discrimination in both healthcare settings and communities also pose a major challenge for PLHIV networks in their delivery of HIV services. This hampers PLHIV from seeking or maintaining care and is exacerbated by negative staff attitudes and segregated practices that reveal HIV status. Additionally, PLHIV networks face significant leadership and capacity challenges impacting their effectiveness in advocacy and HIV service delivery. There are notable gaps in leadership development, leading to knowledge loss during transitions. A lack of structured mentorship and training further hampers the preparation of new leaders. Governance issues stem from weak management structures and limited policy frameworks, complicating interactions with government and donor entities. Skill deficiencies in areas like project management and financial oversight, alongside high staff turnover, hinder consistent service delivery. Financial constraints restrict capacity building and leadership training, creating a cycle of limitations that prevent networks from scaling their efforts or securing long-term funding.

Despite these challenges, there are opportunities to strengthen and better equip the networks to deliver their health governance, advocacy and HIV services.

Opportunities to strengthen PLHIV networks in delivering HIV services at the community level should focus on leadership development, technical capacity, and resource mobilization. Investing in leadership training and mentorship enables new leaders to emerge, while providing ongoing technical training in project management, service delivery, and monitoring ensures networks deliver consistent, high-quality care.

Building strategic partnerships with health facilities, other community-based organizations, and local governments helps PLHIV networks increase their reach, integrate services, and gain important logistical and technical support.

Expanding community-based service models, such as peer-led adherence clubs, ART distribution, and home visits- improves access, retention, and real-world impact for PLHIV, while task-shifting allows care to be delivered even in underserved or remote areas.

Policy advocacy for formal recognition, supportive funding mechanisms, and enabling environments is crucial to sustain these achievements and ensure community-led activities are prioritized. Finally, equipping PLHIV networks to collect, analyse, and report data allows better monitoring, learning, and resource mobilisation and tailored policy development, which enhances their effectiveness in the evolving HIV response

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PLHIV networks play a vital role in the integration of HIV services at both primary healthcare and community levels.

Their involvement helps design and implement more personcentred and accessible models of care, ensuring that HIV services are not isolated but instead embedded within broader health systems. These networks drive stakeholder engagement, bringing the lived experiences and specific needs of PLHIV to inform integrated programming and policy, which is essential for reducing stigma and tailoring services for young people and key populations. PLHIV networks mobilize and support community health workers, facilitate the care—including uptake comprehensive noncommunicable diseases, and sexual and reproductive health—and enable earlier detection, improved adherence, and care continuity. Their advocacy pushes for supportive policies and resource allocation, while peer support within strenathens social connectedness. improvement, and responsiveness of integrated services. By linking health facilities and community actors, PLHIV networks expand service reach, increase system efficiency, and contribute to achieving universal health coverage and stronger, more equitable health outcomes.

In the current context of global health, with reduced funding towards HIV, integration of HIV services into primary healthcare is being viewed as a solution, as HIV services are streamlined to manage costs and efficiency.

Governments are taking on more financial responsibility for the HIV response and driving the integration of HIV services into primary healthcare. Most government ministries of health developed and costed minimum packages for HIV services. From the perspective of PLHIV networks and recipients of care, there are services that must be included in the minimum packages and integrated into the health system at primary and community levels. PLHIV networks advocate for integrated packages service at the community level, emphasizing key services such as HIV testing, treatment, mental health care, cervical cancer screening, and adolescent support groups. From the perspective of PLHIV networks and recipients of care, integration of HIV services must be based on the following requirements.

**Transformative participation of PLHIV:** A core requirement for integration is the meaningful involvement of PLHIV and their networks at every step, from decision-making to implementation. This goes beyond token representation, demanding transformative participation where PLHIV actively deliberate, shape options, and take collective action to improve services. Their role is central in ensuring community models are responsive, peer-driven, and reach marginalized and criminalized groups through support, education, and advocacy.

**Integration defined and shaped by local realities:** Successful integration requires clear definitions and locally tailored strategies based on rigorous readiness assessments. Country-specific approaches should reflect the realities of health system structures, resources, and the needs of PLHIV, engaging not just health sector actors but also those from social protection, economic development, and the private sector. This holistic planning fosters multisectoral support and ensures sustainability.

**Recognition of PLHIV diversity**: Equity is vital to integrated care, demanding models that recognize and accommodate the heterogeneous needs of PLHIV. This includes attention to key populations, women, children, migrants, and people with disabilities, ensuring no group is left behind or overlooked. Care models must uphold human rights and be sensitive to intersecting vulnerabilities to ensure all PLHIV can access appropriate services.

Comprehensive design and delivery: Integration should account for the full spectrum of health needs—HIV testing, treatment, prevention, adherence, and comorbidities, including noncommunicable and mental health issues. Retaining effective community-based delivery structures, differentiated service models, and peer support mechanisms is crucial to sustain quality, reach, and responsiveness as integration expands.

**Resilient health systems:** Resilient health systems underpin integrated care, including robust supply chains, health information systems, governance, accountability, and financing. Training for healthcare workers on HIV management and integration principles is essential, alongside privacy safeguards and integrated budgets. These systems ensure quality, confidentiality, and efficiency in service delivery.

**Stigma and discrimination-free services:** Eliminating stigma and discrimination from integrated services is a foundational ask. Health workers—both professionals and peers—require sensitivity training to foster safe, accepting environments for all PLHIV. Integrated structures should uphold privacy, respect identity, and continuously monitor for discrimination, with responsive improvements guided by community feedback.

**Government-financed treatment services:** Part of providing integrated ART services involves ensuring that treatment is always available with no disruptions, which must be a priority for governments. Disruptions in treatment, as experienced following the funding cuts, cannot happen again. The responsibility for treatment services must be solely borne by the governments and must not be devolved to donors and other partners. This is crucial for sustained access to treatment, treatment adherence, and viral load suppression.

They stress that integration must be transformative, with PLHIV involved in decision-making, and should be relational meaning meaningful connections between organizations and individuals through shared values and collaboration. Integration should also reflect local realities and require readiness assessments, engage actors from health and nonhealth sectors, and address all aspects of HIV care, along with other health needs such as noncommunicable diseases and reproductive health. PLHIV networks advocate for models that recognize the diversity within their communities, ensuring equitable and comprehensive care regardless of **exposure risk or background**. Effective integrated delivery relies on strong support systems: trained, sensitized health workers, robust data systems with privacy protection, and blended financing mechanisms. Above all, integrated services should be free of stigma and discrimination and delivered by both professionals and peer supporters in safe, accessible Community-led monitoring and settings. feedback mechanisms ensure responsiveness and quality improvement, making PLHIV networks central to successful integration at the primary care and community levels

These core asks reflect both lived experience and evidence-based priorities networks. of PLHIV Integration driven these by minimum requirements will lead to people-centred, equitable, and effective service models. Such integrated approaches will not only improve HIV-related outcomes like testing, treatment retention, and viral suppression, but also enhance responsiveness to broader health needs and advance progress toward universal health coverage. Empowering PLHIV networks to in design, delivery, and monitoring ensures that integrated services are accessible, relevant, sustainable, and resilient.

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# **Annex 1: Results Tables**

Table 1: Participant characteristics

		n=1,399	100
Characteristic		Frequency	Percent
Age	Under 18	3	0.2
-	18-24 years	90	6.4
	25-34 years	314	22.4
	35-44 years	427	30.5
	45-54 years	394	28.2
	55-64 years	142	10.2
	65+ years	29	2.1
Gender	Female	977	69.8
	Male	392	28.0
	Non-binary/Gender Diverse	24	1.7
	Prefer not to say	6	0.4
Highest Education Level	No Formal Education	3	0.2
	Primary School	27	1.9
	Secondary Education	417	29.8
	Vocational/Technical	221	15.8
	Training		
	University Degree or higher	731	52.3
Employment Status	Employed Full-time	352	25.2
	Employed Part-time	403	28.8
	Self-employed	265	18.9
	Unemployed	278	19.9
	Student	61	4.4
	Retired	40	2.9
Primary Caregiver	Yes	601	43.0
	No	798	57.0
Living with HIV	Yes	1,312	93.8
	No	87	6.2
Duration Living with HIV	Less than 1 year	9	0.7
	1 - 3 years	78	6.4
	4-7 years	147	12.0
	More than 7 years	993	80.9
Sexual Identity	MSM	88	7.2
	Transgender	15	1.2
	Sex Worker	63	5.1
	Person who uses drugs	102	8.3
	Migrant or Displaced Person	49	4.0
	Incarcerated	35	2.9
	None of the above	765	62.4
			~ ·

Table 2: Provision of and Access to Health Services by age

	Fe	male	Male Non- P binary		Pre	efer not to say		
	n	%	n	%	n	%	n	%
Health Facility Type								
Primary healthcare facility	131	15.1	44	13. 3	2	9.5	1	16.7
Community health centre	10 2	11.7	40	12.1	9	42.9	0	0.0
Public Hospital	51 6	59.3	19 6	59. 4	8	38.1	5	83.3
Private Hospital	84	9.7	28	8.5	2	9.5	0	0.0
Private clinic	22	2.5	11	3.3	0	0.0	0	0.0
Mission/Military/NGO	15	1.7	11	3.3	0	0.0	Ο	0.0
Department from which service accessed	ces ar	е						
Outpatient department	12 5	17.15	31	11.9	4	23.5	1	16.7
Maternal and Child Health	39	5.4	6	2.3	0	0.0	0	0.0
HIV Clinic	53	72.7	20	79.	12	70.6	5	83.3
	0		7	3				
Other	35	4.8	17	6.5	1	5.9	0	0.0
Frequency of Accessing Services								
Monthly	93	12.8	50	19. 2	6	35.3	0	0.0
Quarterly	29 6	40.7	88	33. 9	5	29.4	1	16.7
Every 6 months	33 4	45.9	112	43. 1	6	35.3	5	83.3
Once a year	4	0.6	10	3.9	0	0.0	0	0.0
Current Payment for HIV Services								
Less than USD20	56	7.7	42	16. 6	5	33.3	0	0.0
USD 20 - USD50	28	3.9	16	6.3	1	6.7	0	0.0
USD50 - USD100	16	2.2	8	3.2	0	0.0	0	0.0
USD100 and above	19	2.6	2	8.0	2	13.3	0	0.0
Services are free	60 5	83.6	18 5	73. 1	7	46.7	6	100.0

Table 3: Access to and payment for HIV Services by Age

	Under years	18	18 - 24 years		25 - 34 years		35 - 44 years		45 - 54 years		55 - 64 years		65 years +	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Health Facility Type														
Primary healthcare facility	1	0.6	5	2.8	41	23.0	66	37.1	48	27.0	13	7	4	2.3
Community health centre	0	0.0	14	9.3	41	27.2	42	27.8	32	21.2	22	15	0	0.0
Public Hospital	1	0.1	47	6.5	140	19.3	225	31.0	222	30.6	73	10	17	2.3
Private Hospital	0	0.0	9	7.9	25	21.9	24	21.1	39	34.2	13	11	4	3.5
Private clinic	0	0.0	3	9.1	8	24.2	8	24.2	5	15.2	8	24	1	3.0
Mission/Military/NGO	0	0.0	2	7.7	4	15.4	10	38.5	7	26.9	2	8	1	3.9
Department from which accessed	service	es are												
Outpatient department	0	0.0	9	5.6	35	21.7	62	38.5	42	26.1	13	8.1	Ο	0.0
Maternal and Child Health	0	0.0	3	6.7	15	33.3	15	33.3	12	26.7	Ο	0.0	0	0.0
HIV Clinic	2	0.3	47	6.2	152	20.2	221	29.3	231	30.6	82	10.9	19	2.5
Other	0	0.0	4	7.6	15	28.3	14	26.4	12	22.6	6	11.3	2	3.8
Frequency of Accessing Services														
Monthly	0	0.0	11	7.4	43	28.9	38	25.5	37	24.8	18	12.1	2	1.3
Quarterly	1	0.3	15	3.9	57	14.6	147	37.7	122	31.3	40	10.3	8	2.1
Every 6 months	1	0.2	32	7.0	113	24.7	125	27.4	137	30.0	38	8.3	11	2.4
Once a year	0	0.0	5	35.7	3	21.4	2	14.3	1	7.1	3	21.4	0	0.0
Payment for HIV services														
Less than USD20	0	0.0	7	6.8	33	32.0	26	25.2	21	20.4	13	12.6	3	2.9
USD 20 - USD50	0	0.0	4	8.9	10	22.2	15	33.3	10	22.2	6	13.3	0	0.0
USD50 - USD100	0	0.0	1	4.2	8	33.3	5	20.8	7	29.2	3	12.5	0	0.0
USD100 and above	0	0.0	2	8.7	5	21.7	8	34.8	7	30.4	1	4.4	0	0.0
Services are free	2	0.3	48	6.0	157	19.6	254	31.6	249	31.0	77	9.6	16	2.0

Table 4: Access to and payment for HIV Services by Key population

		MSM		Tra	ansge ler	Sex Wo	rker	Person use dr		_	ant or laced	Inc ate	arcer d	None of the above		Prefe	er not at ver
		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Health Facil	lity Type																
Primary facility	healthcare	13	14.8	3	20.0	12	19.1	18	17.7	5	10.2	8	22.9	108	14.1	11	10.0
Community centre	health	14	15.9	4	26.7	13	20.6	21	20.6	19	38.8	7	20.0	59	7.7	14	12.7
Public Hosp	ital	48	54. 6	8	53.3	32	50.8	50	49.0	18	36.7	17	48.6	484	63.3	68	61.8
Private Hosp	oital	8	9.1	0	0.0	3	4.8	8	7.8	3	6.1	2	5.7	80	10.5	10	9.1
Private clinic	2	2	2.3	0	0.0	3	4.8	4	3.9	1	2.0	0	0.0	18	2.4	5	4.6
Mission/Milit	tary/NGO	3	3.4	0	0.0	0	0.0	1	1.0	3	6.1	1	2.9	16	2.1	2	1.8
Department	t from which	servic	es are	acc	essed												
Outpatient o	department	10	15.9	1	9.1	13	25.5	14	17.3	10	22.7	2	6.9	103	16.0	8	8.9
Maternal Health	and Child	2	3.2	1	9.1	0	0.0	4	4.9	1	2.3	3	10.3	29	4.5	5	5.6
HIV Clinic		50	79. 4	8	72.7	33	64.7	61	75.3	21	47.7	22	75.9	487	75.6	72	80.0
Other		1	1.6	1	9.1	5	9.8	2	2.5	12	27.3	2	6.9	25	3.9	5	5.6
Frequency of	of Accessing	Servic	es														
Monthly		10	15.9	4	36.4	7	13.7	16	19.8	20	46.5	10	34.5	73	11.4	9	10.0
Quarterly		25	39.7	3	27.3	13	25.5	27	33.3	7	16.3	7	24.1	275	42.8	33	36.7
Every 6 mon	iths	23	36.5	4	36.4	31	60.8	36	44.4	16	37.2	12	41.4	288	44.9	47	52.2
Once a year		5	7.9	0	0.0	0	0.0	2	2.5	0	0.0	0	0.0	6	0.9	1	1.1
<b>Current Pay</b>	ment for HIV	/ Servi	ces														
Less than US	SD20	14	22.6	1	10.0	4	7.8	8	10.1	3	6.8	8	27.6	59	9.3	6	6.7
USD 20 - US	D50	12	19.4	0	0.0	4	7.8	3	3.8	3	6.8	1	3.5	16	2.5	6	6.7
USD50 - USE	D100	2	3.2	1	10.0	1	2.0	2	2.5	5	11.4	1	3.5	10	1.6	2	2.3

USD100 and above	1	1.6	0	0.0	5	9.8	2	2.5	1	2.3	0	0.0	12	1.9	2	2.3
Services are free	33	53.2	8	80.0	37	72.6	64	81.0	32	72.7	19	65.5	537	84.7	73	82.0
HIV Services provided BI	EFORE	<b>fundi</b>	ng d	cuts												
HIV Testing and	11	18.0	3	27.3	10	19.6	10	12.4	16	37.2	3	10.3	93	14.7	14	15.7
Counselling																
ART Provision	13	21.3	3	27.3	5	9.8	15	18.5	5	11.6	4	13.8	80	12.6	9	10.1
TB Screening	3	4.9	1	9.1	5	9.8	15	18.5	3	7.0	3	10.3	59	9.3	11	12.4
Sexual/Reproductive Health	6	9.8	2	18.2	1	2.0	2	2.5	0	0.0	0	0.0	19	3.0	2	2.3
Mental Health Support	7	11.5	1	9.1	10	19.6	6	7.4	2	4.7	2	6.9	19	3.0	2	2.3
Cervical Cancer	2	3.3	0	0.0	4	7.8	7	8.6	Ο	0.0	5	17.2	47	7.4	13	14.6
Screening & Treatment																
Maternal and Child Health Services	17	27.9	1	9.1	15	29.4	22	27.2	15	34.9	12	41.4	306	48.2	34	38.2
None of the above	2	3.3	0	0.0	1	2.0	4	4.9	2	4.7	0	0.0	12	1.9	4	4.5
HIV Services provided Al	FTER f	unding	g cu	ts												
HIV Testing and Counselling	9	14.5	2	18.2	10	19.6	14	17.7	15	34.9	4	13.8	83	13.1	15	16.9
ART Provision	15	24. 2	4	36.4	8	15.7	13	16.5	5	11.6	6	20.7	101	16.0	13	14.6
TB Screening	5	8.1	1	9.1	8	15.7	13	16.5	5	11.6	3	10.3	88	13.9	16	18.0
Sexual/Reproductive Health	3	4.8	1	9.1	2	3.9	2	2.5	1	2.3	0	0.0	13	2.1	3	3.4
Mental Health Support	8	12.9	1	9.1	3	5.9	5	6.3	4	9.3	3	10.3	15	2.4	2	2.3
Cervical Cancer Screening & Treatment	3	4.8	0	0.0	5	9.8	6	7.6	1	2.3	3	10.3	48	7.6	7	7.9
Maternal and Child Health Services	16	25.8	1	9.1	15	29.4	21	26.6	11	25.6	9	31.0	272	43.0	27	30.3
None of the above	3	4.8	1	9.1	0	0.0	5	6.3	1	2.3	1	3.5	13	2.1	6	6.7

Table 5: PLHIV Networks collaboration and participation in planning, decision-making, and Community-led Monitoring

	n	%
PLHIV Networks and Healthcare Provider		
Collaboration Rating		
Excellent	198	29.2
Good	284	41.8
Fair	127	18.7
Poor	58	8.5
Not sure	12	1.8
PLHIV Networks' Involvement in Planning/Decision-ma	aking	
Yes	404	63.7
No	102	16.1
Not sure	128	20.2
PLHIV Networks' Involvement in Community-led Moni	toring	
Yes	439	69.2
No	86	13.6
Not sure	109	17.29

### **Annex 2: Data Collection Tools**

### **Annex 2a: Quantitative Tools**

We are contacting you to request your participation in this critical survey conducted by the Global Network of People Living with HIV (GNP+). Your responses are vital for helping us to better understand the minimum requirements/ask for responsive integrated HIV services at the primary healthcare and community levels to ensure sustained access to treatment and to advocate for better, more integrated, and respectful HIV services in our communities.

Your participation is voluntary, and all your answers will be kept confidential. The data will be combined with other relevant data to create a report on the state of HIV services. No personal identifying information will be shared.

The survey will take approximately 12 minutes to complete.

\* 1. Do you consent to participate in this survey?

If you have questions or would like more information, please contact us at: <a href="mailto:infognp@gnpplus.net">infognp@gnpplus.net</a>.

O Yes
○ No
<u>Demographic Information</u>
* 2. What is your age?
O Under 18
○18-24
○ 25-34
35-44
O 45-54
O 55-64
O 65+
* 3. What is your gender?  © Female
○ Male
O Non-binary/Gender Diverse
O Prefer not to say
* 4. What is the highest level of education you have completed?  O No formal education
O Primary School
O Secondary School
O Vocational/Technical training
O University degree or higher

* 5. What is your current employment status?  © Employed full-time
© Employed part-time
○ Self-employed
$\bigcirc$ Unemployed
○ Student
○ Retired
* 6. Are you the parent or primary caregiver of a child or adolescent (under 18) living with HIV?  O Yes
○ No
* 7. Are you living with HIV?  O Yes
○ No
<u>HIV Status and Network Involvement</u>
* 8. How long have you been living with HIV?  Less than 1 year
○ 1–3 years
$\bigcirc$ 4–7 years
O More than 7 years
* 9. How often do you participate in activities organized by PLHIV networks?
○ Monthly
○ Occasionally
O Never
10. PLHIV from key populations face unique challenges in accessing healthcare. D you identify as a member of any of the following groups? (Select all that apply)
Men who have sex with men
Transgender person
Sex worker
A person who uses drugs
Migrant or displaced person
A person who has been incarcerated
None of the above
Prefer not to answer

### **Healthcare Access and Location**

* 11. What type of healthcare facility do you primarily use for HIV-related services?  O Primary healthcare clinic
O Community health centre
O Public Hospital
O Private Hospital
O Private clinic
Other (please specify)
* 12. How far is the nearest healthcare facility providing HIV services from your home?
O Less than 1 km
○ 1–5 km
○ 6–10 km
O More than 10 km

## **Objective 1: Minimum Requirements for Responsive Integrated HIV Services**

With governments taking on the role of leading and financing the HIV response, integration of HIV services into primary healthcare is seen as the path forward, particularly for the sustainability of the HIV response. In many ways, this has started following changes in the global health financing landscape. In this section, we would like to get your experiences in accessing HIV services following the funding cuts, and what you think should be included as minimum requirements for responsive, integrated HIV services, as integration is standardized.

* 13. Prior to the funding cuts towards HIV programs, which of the following HIV
services were available at your primary healthcare facility?
HIV testing ART provision TB screening Sexual/reproductive health Mental health support Cervical cancer screening and treatment Maternal and child health services None of the above Other (please specify)
* 14. Following the funding cuts towards HIV programs, which of the
following HIV services are available at your primary healthcare facility?
HIV testing
ART provision
TB screening
Sexual/reproductive health
Mental health support
Cervical cancer screening and treatment
Maternal and child health services
None of the above
Other (please specify)
* 15. From which department at the health facility are you receiving HIV services?  Outpatient department
O Maternal and Child Health
O HIV clinic
Other (specify)
16. How often do you access HIV services at your preferred health facility?
○ Monthly
O Quarterly
O Every 6 months
Once a year

17. Following the disruptions to HIV service provision due to US funding cuts, do
you have to pay to access these services?
○Yes
ONo
18. How much do you pay to access HIV services?
O Less than USD20
O USD20 - USD50
O USD50 - USD100
O USD100 and above
19. Prior to the disruptions in HIV services caused by US funding cuts, did
you pay for access to these services?
○Yes
$\bigcirc$ No
20. Currently, how would you rate the accessibility of HIV services at your local clinic? Very accessible
O Somewhat accessible
O Not accessible
21. How long does it now take to receive HIV services after arriving at your facility?  Less than 30 minutes
○30–60 minutes
O More than 1 hour
O Not sure
22. Does it take more time now to receive HIV services compared to before the
funding cuts towards HIV programs?
○Yes
$\bigcirc$ No
O The same
O Not sure
23. How would you rate the quality of integrated HIV services at your local clinic at the moment?  © Excellent
OGood
○ Fair
OPoor
O Not sure

Very easy
O Somewhat easy
Opifficult
O Very difficult
25. Are reminders being sent to HIV clients for their appointments?  O Yes
$\bigcirc$ No
O Not sure
26. Are HIV medications always available when clients need them?  Always
Ousually
Osometimes
Rarely
ONever
O Not sure
27. How satisfied are you with the privacy provided during HIV service delivery? Very satisfied
○ Satisfied
O Neither satisfied nor dissatisfied
○ Dissatisfied
O Very dissatisfied
28. Do you feel that the staff at the facility are adequately trained to provide ntegrated HIV services?
$\bigcirc$ No
29. How confident are you that you can continue accessing your HIV treatment
without interruption at your local facility?
O Very confident
O Somewhat confident
O Not so confident
O Not at all confident

_	recommend your primary	/ healthcare facility	to others
needing HIV se	rvices?		
O No			
O Not sure			
	a what are the three most	t important convice	s that must be
	n, what are the three most		
included in an inc	tegrated HIV package at t	ne community leve	21?
Service 1			
Service 2			
Service 3			
32. Are there any	services you feel are missi	ing from current H	V service offerings at
the primary healt	chcare or community level	!?	
○Yes			
ONo			
33. If your answer	to Question 31 is Yes, plea	ase specify.	
34. What resource	es do you think are most l	acking in your com	nmunity's HIV
service delivery?			
Health wo	rkers and commodities		
	ervices (counselling, ment	al health, etc.)	
Laboratory			
Cervical Ca	ancer screening and or tre	eatment	
35. Are the follow	ing services available and	affirming of your id	dentity at the
same place you g	jet HIV care?		
Yes, and it feels sa	afe and affirming	Yes, but it do	es not feel safe or affirming
	$\bigcirc$	$\circ$	
		Ü	
	O		
	No, it is not av	railable	

Mental health o	r substanc	e use support	Gender-aff	irming			
care (e.g., horr	nones)	0				0	
Harm reduction services (e.g., of needles, OST)		0				0	
Screening for Hepatitis B & C		$\bigcirc$				$\circ$	
36. When you t available and p Yes, at the sam	rovided at t		c and on the		?	child health s	ervices
clinic	е	elsewhere		l am not sure		Not Applicable	
	$\circ$	$\circ$		$\bigcirc$		C	į
Routine childho immunizations Nutrition suppo (e.g., Plumpy'No	ort	na)		$\bigcirc$		$\circ$	
Development		0	$\circ$		0	0	
Treatment fo common chil illnesses (e.g., malaria, diarr	dhood	)	0	0		0	
Treatment Advoca	unselling ent literacy cy	,	etworks pr	ovide in yo	ur area?		
Objective 2: R	ole of PLH	IV Networks	in Commu	ınity-Leve	l Service II	ntegration	
38. How freque about HIV servent Regularles Occasion Rarely Never Not sure	rices? y nally	HIV networks	s engage w	rith commi	unity mem	nbers	

39. To what extent do you think PLHIV networks help bring HIV services
closer to households?
○ A great deal
O A moderate amount
O Very little
O None at all
O Not sure

supporting community-level HIV service delivery?
Challenge 1
Challenge 2
Challenge 3
41. How would you rate the collaboration between PLHIV networks and
healthcare providers in your community?
○ Excellent
○ Good
○ Fair
OPoor
O Not sure
Objective 3: Strengthening PLHIV Leadership and Person-Centred Service Delivery
42. Are PLHIV network members involved in planning or decision-making
for HIV services in your country?
○Yes
○ No
O Not sure
43. Are PLHIV network members involved in Community-led Monitoring (CLM) in
your country?
○Yes
○ No
O Not sure
44. To what extent do you feel that HIV services in your community are person-
centred (i.e., tailored to individual needs)?
○Always
O Usually
○ Sometimes
○ Rarely
○ Never
45. What barriers do PLHIV leaders face in advocating for quality HIV services?

40. What are the top three challenges that PLHIV networks face in

46. What changes would you recommend to strengthen PLHIV leadershi
and ensure HIV services remain person-centred in your community?
47. Is there anything you feel is important that has not been discussed in
this survey that you would like to add?

Thank you for participating in the survey.

### **Annex 2b: Interview guides**

### Introduction/Opening

I would like to encourage all of you to share openly and honestly about any questions you will be asked. Please be assured of this process's absolute confidentiality; your views and opinions will be presented as an aggregated summary, and your views will not be identified in the final report.

Before we start, I will ask for your permission to record this discussion because there will be a lot of information that I will not be able to remember or write down. There will also be times when I will ask follow-up questions so that I can better understand what you are saying. By recording this discussion, we can also make sure that our notes do not leave out the most important information you have shared and don't misquote you. The meaning of your perspectives and experiences will also not change. I would like to assure you that these recordings will be used for research purposes only to help us clearly express your views as an aggregate, as we write our report. This discussion will last about 45 minutes to an hour.

Do you have any questions before we start? [Take time to address all the questions and concerns]

With your permission, I would like to turn on the recorder and begin the interview. [Start recording if permission is granted].

### **Discussion questions**

#### Introduction

- 1. Please introduce yourself and tell me a little bit about the work that you and your network do.
  - o What are your organisation's main focus areas and reach?
  - o How many PLHIV do you serve/have registered in your network? How many networks do you have in the country?
- 2. How would you describe your current engagement with the government in your country in the provision of HIV care?

What would you say have been the most significant strides you have made as part of your collaboration?

- 3. How have the recent global shifts in the HIV funding landscape impacted the work your network does?
  - Would you describe your experiences thus far and the challenges you have faced in ensuring the needs of PLHIV remain at the centre of the HIV Response?
  - Were you able to leverage your relationship with the government agencies to help during the disruption?
- 4. Almost a year into the changes, what are your thoughts on the transition of the HIV response to national government ownership?
- 5. Are there any opportunities that could come out of/could be realised from this shift especially for PLHIV & PLHIV-led organisations that you would like to highlight?

### Minimum asks for Responsive integrated HIV services

- 6. What are some of the opportunities through which HIV services can be better integrated into primary healthcare system and community health systems to ensure person centred care?
  - Probe for Shared decision making, Personalised care and support planning, development of standards, Self-management support, Social prescribing and community-based approaches, enabling choice, health governance and finance, knowledge translation
  - o Are there any areas that you feel have been/continue to be overlooked when envisioning integrating HIV services into primary care and community levels
- 7. Drawing from your experience as a PLHIV network, what would you consider to be the minimum asks from networks to state and non-state actors on integrating HIV into PHC and Community health systems?

If you were to rank them based on importance, which ones would be the most important?

Why do you consider these to be essential?

- 8. What role do you think PLHIV networks can play in the integration of HIV into PHC and Community health systems?
  - What role can PLHIV networks play in the delivery of health services in this integrated health system?
  - o What type of resources (financial, discursive, human, technological, ideological, etc.) would you need to play these roles?
  - Who would be the best individuals/organisations/Institutions with whom you can partner to effectively execute these roles?
- 9. Has your network been implementing any of the integration models in response to local contextual conditions.
  - o What are some of the challenges that you have faced in the implementation of these models and the adaptations you have made to respond to them?

### Advocacy for Responsive integrated HIV services

- 10. Over the past few years, what have your main advocacy goals been as a PLHIV network?
  - o What have been the main approaches that you have used to effectively advocate for your issues of focus?
  - o Have your advocacy goals and approaches shifted as a result of the disruption in funding experienced earlier this year?
- 11. We would like to use your recommendations to co-develop a advocacy toolkit, what would you consider as the key advocacy priorities/goals when it comes to the design or delivery of responsive integrated HIV services at primary care and community levels?
  - o Why is this relevant to ensuring person-centred care for PLHIV i.e., what outcomes do you want to impact?
- 12. What would be the most appropriate channels through which these advocacy priorities can be communicated to partners?
  - o Who should be responsible for the realisation of these advocacy priorities?
- 13. Do you anticipate any resistance to these advocacy priorities? Why and from whom?

#### Conclusion

14. Thank you very much for taking part in our discussion. Do you have any final thoughts on how PLHIV networks can be better involved in integration efforts and work with governments to ensure that the needs of PLHIV are considered in the delivery of patient-centred care and treatment?

### Introduction/Opening

I would like to encourage all of you to share openly and honestly about any questions you will be asked. Please be assured of this process's absolute confidentiality; your views and opinions will be presented as an aggregated summary, and your views will not be identified in the final report.

Before we start, I will ask for your permission to record this discussion because there will be a lot of information that I will not be able to remember or write down. There will also be times when I will ask follow-up questions so that I can better understand what you are saying. By recording this discussion, we can also make sure that our notes do not leave out the most important information you have shared and don't misquote you. The meaning of your perspectives and experiences will also not change. I would like to assure you that these recordings will be used for research purposes only to help us clearly express your views as an aggregate, as we write our report. This discussion will last about 45 minutes to an hour.

Do you have any questions before we start? [Take time to address all the questions and concerns]

With your permission, I would like to turn on the recorder and begin the interview. [Start recording if permission is granted].

### **Discussion questions**

#### Introduction

- 15. Please introduce yourself and tell me a little bit about yourself and the work that you do.
- 16. The recent global shifts in the HIV funding landscape have necessitated the transition from donor-driven to government-led HIV responses. Could you please share your thoughts on the current global landscape and transition to government ownership?
  - Would you describe your experiences thus far and the challenges you have faced in ensuring the needs of PLHIV remain at the centre of the HIV Response?
  - Are there any opportunities that could come out of/could be realised from this shift, especially for PLHIV & PLHIV-led organisations that you would like to highlight?

## Minimum asks for Responsive integrated HIV services

- 2. You recently were part of the development of a report/primer on integration. What prompted this work?
  - o What has its reception been so far?
  - o What lessons have you learnt from its release?
- 3. What are some of the opportunities through which HIV services can be better integrated into primary healthcare system and community health systems to ensure person-centred care?
  - Probe for Shared decision making, Personalised care and support planning, development of standards, Self-management support, Social prescribing and community-based approaches, enabling choice, health governance and finance, knowledge translation
  - o Are there any areas that you feel have been/continue to be overlooked when envisioning integrating HIV services into primary care and community levels
- 4. Drawing from your experience what would you consider to be the minimum asks for responsive integrated HIV services for PLHIV?
  - o If you were to rank them based on importance, which ones would be the most important?
  - o Why do you consider these to be essential?
  - What role do you think PLHIV networks can play in the integration of HIV into PHC and Community health systems?
- 5. Do you have any experience with implementing integration models that you would like to share?
  - o What are some of the challenges that you have faced in the implementation of these models and the adaptations made to respond to them? Best practices?

#### **Advocacy for Responsive integrated HIV services**

- 6. What approaches have you been utilising in advocating for responsive integrated HIV services at primary care and community levels?
  - o What lessons have you learnt from your advocacy efforts so far?
- 7. What recommendations might you have for GNP+ as they develop an advocacy toolkit in terms of advocacy priorities/goals when it comes to the design or delivery of responsive integrated HIV services at primary care and community levels?

- o Why is this relevant to ensuring person-centred care for PLHIV i.e., what outcomes do you want to impact?
- 8. What would be the most appropriate channels through which these advocacy priorities can be communicated to partners?
  - o Who should be responsible for the realisation of these advocacy priorities?
- 9. Do you anticipate any resistance to these advocacy priorities? Why and from whom?

#### Conclusion

10. Thank you very much for taking part in our discussion. Do you have any final thoughts on how PLHIV networks can be better involved in integration efforts and work with governments to ensure that the needs of PLHIV are considered in the delivery of patient-centred care and treatment?



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