

# GLOBAL SURVEY

access to and quality of  
**HIV CARE & TREATMENT**

DECEMBER 2019



## About ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

- Treatment education and demand creation (#TreatPeopleRight)
- Intellectual property and access to medicines (#MakeMedicinesAffordable)
- Community monitoring and accountability (#WatchWhatMatters)

To learn more about ITPC and our work, visit [www.itpcglobal.org](http://www.itpcglobal.org).

## About this Report

ITPC's 2019 Global Treatment Access Survey focused on barriers to quality HIV care and treatment across 14 low- and middle-income countries covering seven regions of the world. The report summarizes findings of our peer-led research, conducted between April and December 2018. The survey has identified access barriers and gaps, along with poor quality of services experienced by people living with HIV.

## Acknowledgements

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## Regional Partners

- ARASA - AIDS and Rights Alliance for Southern Africa
- ITPC WA - West Africa
- ITPCru - Eastern Europe and Central Asia
- ITPC LATCA - Latin America and the Caribbean
- ITPC MENA - Middle East and Northern Africa
- ITPC EA - East Africa
- ITPC South Asia / Delhi Network of Positive People (DNP+) - Southeast Asia

## National Partners

- All-Ukrainian Network of People Living with HIV/AIDS, Ukraine
- Association African Solidarité (AAS), Burkina Faso
- Fundación Llanto, Valor y Esfuerzo (LLAVES), Honduras
- Marsa Sexual Health Center, Lebanon
- Partnership Network, Kyrgyzstan
- Persaudaraan Korban Napza Indonesia (PKNI), Indonesia
- Red Nacional de Jóvenes Viviendo con VIH (REDNAJCER), Dominican Republic
- Treatment Advocacy and Literacy Campaign (TALC), Zambia
- Uganda Harm Reduction Network (UHRN), Uganda
- Viet Nam Network of People Living with HIV (VNP+), Viet Nam
- Zimbabwe National Network of People Living with HIV (ZNNP+)

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# ABBREVIATIONS AND ACRONYMS

<b>AIDS</b>	Acquired immunodeficiency syndrome
<b>ART</b>	Antiretroviral therapy
<b>ARV</b>	Antiretroviral
<b>BTG</b>	Bridging the Gaps programme
<b>CBO</b>	Community-based organization
<b>CTO</b>	Community treatment observatory
<b>DSD</b>	Differentiated service delivery
<b>EFV</b>	Efavirenz
<b>HBV</b>	Hepatitis B virus
<b>HCV</b>	Hepatitis C virus
<b>HIV</b>	Human immunodeficiency virus
<b>HPV</b>	Human papillomavirus
<b>IRIS</b>	Immune reconstitution inflammatory syndrome
<b>ITPC</b>	International Treatment Preparedness Coalition
<b>IUD</b>	Intrauterine device
<b>KP</b>	Key populations
<b>LMIC</b>	Low- and middle-income countries
<b>MENA</b>	Middle East and Northern Africa
<b>MSM</b>	Men who have sex with men
<b>NGO</b>	Non-governmental organization
<b>NVP</b>	Nevirapine
<b>OI</b>	Opportunistic infection
<b>PLHIV</b>	People living with HIV
<b>PWID</b>	People who inject drugs
<b>RVLT</b>	Routine viral load testing
<b>SW</b>	Sex worker
<b>TB</b>	Tuberculosis
<b>TG</b>	Transgender person
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>WHO</b>	World Health Organization

# FOREWORD

The world has committed to ending AIDS by 2030, by meeting the Joint United Nations Programme on HIV/AIDS (UNAIDS) 95-95-95 targets: 95% of people living with HIV knowing their HIV status; 95% of people who know their status on treatment; and 95% of people on treatment with suppressed viral loads. In reality, while the HIV response has been effective in reducing AIDS-related deaths, it has failed to significantly decrease new infections. This is especially worrisome for young people, who, according to the 2019 Goalkeepers Report<sup>1</sup>, may see an increase in new HIV infections if we do not intervene now. In many countries, the average person living with HIV still faces crippling blockages to treatment. As of 2018, only 62% of the world's 37.9 million people living with HIV (PLHIV) were accessing antiretroviral therapy (ART).<sup>2</sup>

Our survey data show that an overwhelming number of recipients of care are presenting at clinics with advanced HIV disease. If people are unwilling to seek healthcare due to stigma-related barriers, then they will continue to show up only when they are gravely ill. We must address stigma and discrimination—including self-stigma, anticipated stigma and actual criminalisation—as persistent and deadly barriers to treatment access. Survey results also underscored the critical need for treatment education along the continuum of care. People living with HIV must be able to make informed choices in order to fully access their right to health.

By the end of 2020, 92% of low- and middle-income countries (LMICs) are expected to adopt the World Health Organization's HIV 'treat-all' recommendation.<sup>3</sup> As the healthcare system prepares to scale-up and differentiate HIV service delivery, it must be increasingly responsive to the needs of key populations (KP). Yet, as coverage is expanding, the actual quality of treatment remains sub-optimal. Viral load testing has yet to be fully integrated into HIV service delivery in many places. All people living with HIV have the right to access routine viral load testing, and to know whether their ART is working. Keeping people on a failing regimen obstructs efforts to "end AIDS", as it creates opportunities for the virus to become drug resistant.

It is equally important to tackle structural weaknesses impinging on HIV treatment, as people can get the best HIV medicines but still die from non-communicable diseases, such as cancer and diabetes, because of failing primary healthcare systems.

This Global Survey Report uncovers several sub-optimal aspects of care that highlight our recommendations, which are based on perspectives shared by people living with HIV and healthcare workers in these parts of the world.

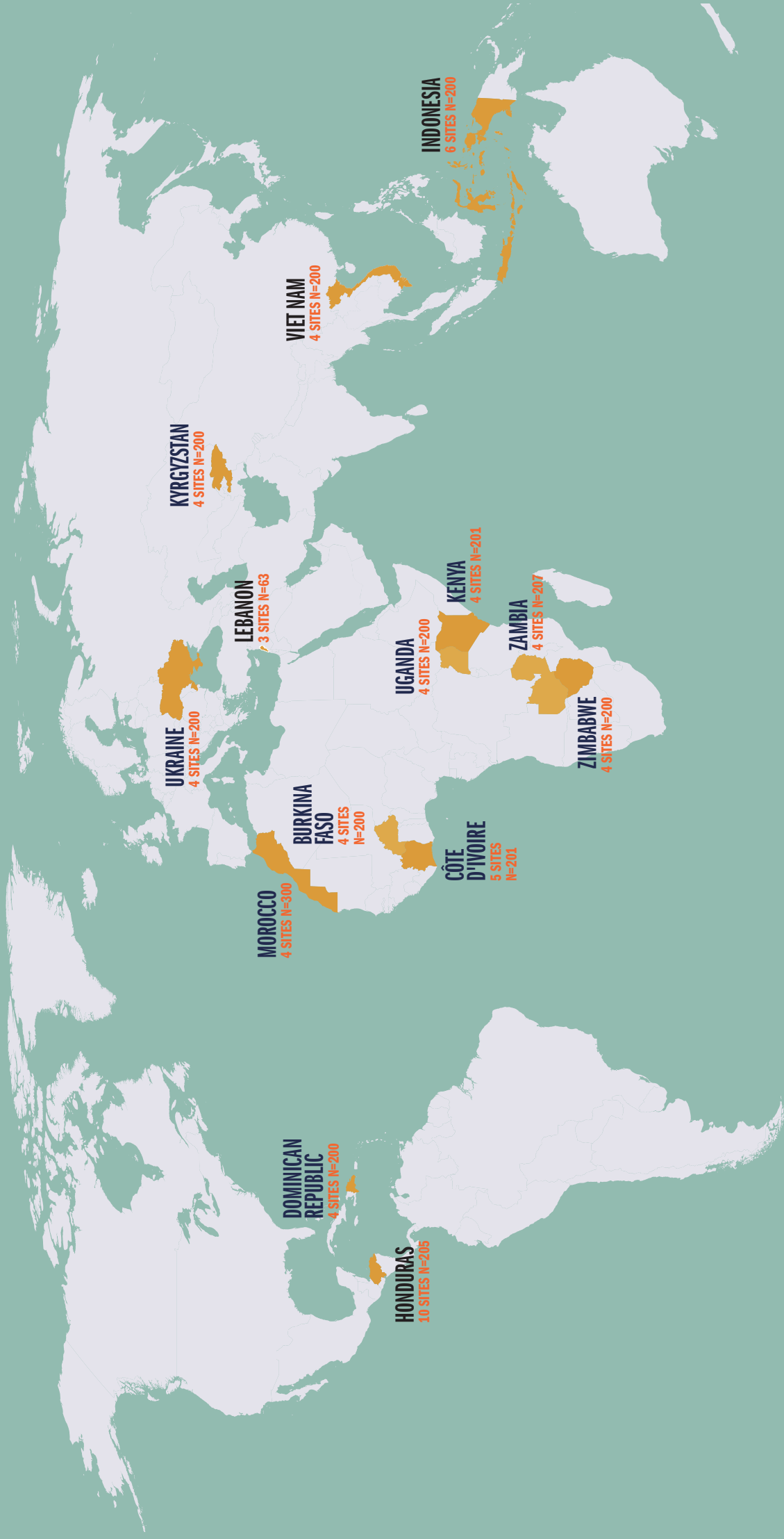
A main finding of our survey is that community-led approaches empower the beneficiaries of HIV treatment to monitor and improve the quality of healthcare that they receive. This finding comes on the heels of the 2019 results of the HIV Prevention Trials Network (HPTN) Population Effects of Antiretroviral Therapy to Reduce HIV Transmission 071 (PopART) study, which showed a 30% decline in new HIV infections in places where HIV prevention included home-based counselling and testing.<sup>4</sup> The evidence is clear: services must be delivered where people are, instead of waiting for them to come to clinics. Although community-based services are effective, they remain sorely underfunded. If we are to ever reach 30% coverage by community-led HIV programs, as committed in the 2016 United Nations Political Declaration on HIV and AIDS,<sup>5</sup> communities must have the resources to deliver services, conduct advocacy and lead programs that address their needs.

We can't change the game if we keep doing business as usual; we need to put the money where the evidence is!

In solidarity,

Solange Baptiste  
ITPC Executive Director

## Countries, Sites and People Living with HIV Included in the Survey



# EXECUTIVE SUMMARY

This community-based survey details barriers faced by 2,777 recipients of care (RoCs) from 14 countries, along with perspectives from their healthcare providers and national-level stakeholders. A third of the respondents included in the quantitative survey were members of a key population, namely men who have sex with men (MSM), transgender people (TG), people who inject drugs (PWID) and sex workers (SW).

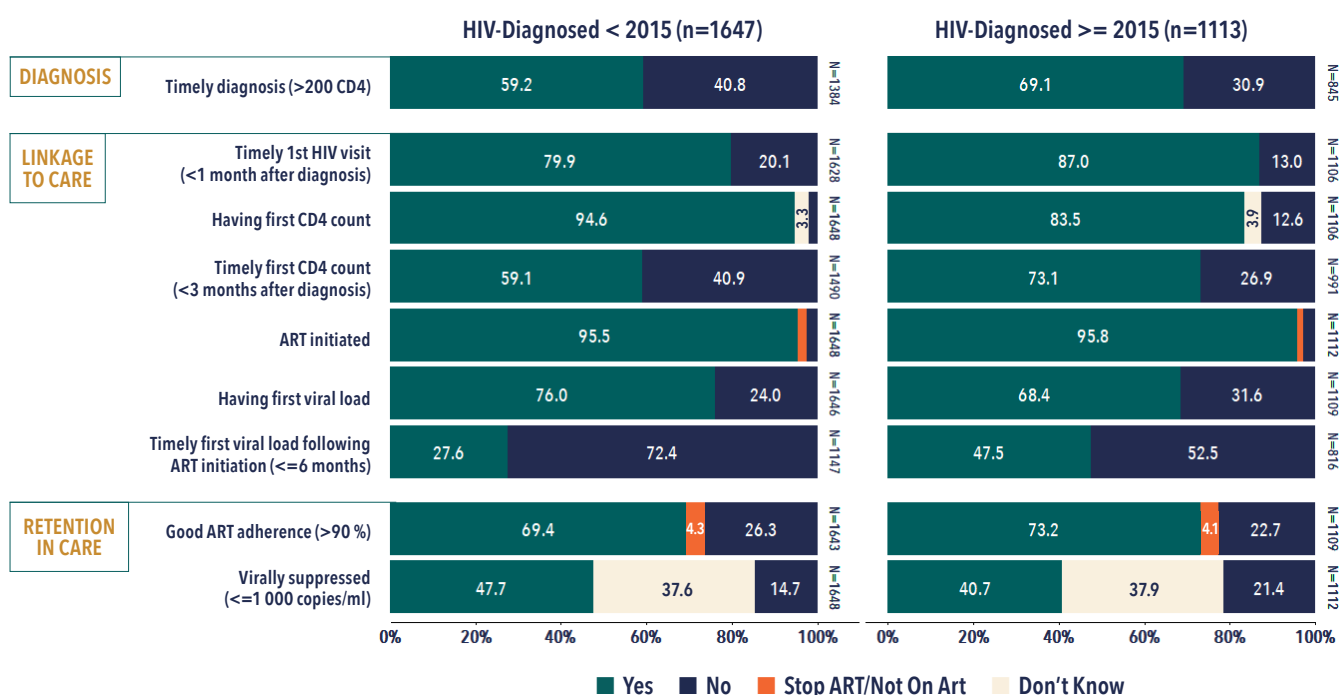
Stigma is still a pervasive deterrent to testing, engaging in care and ART adherence; addressing it is essential for the health and welfare of people living with HIV and their communities—and for ending AIDS by 2030. Study respondents who reported anticipated stigma were more likely to be diagnosed with advanced HIV disease; the fear of being seen at an ART clinic and concerns about confidentiality prevented many people from engaging in care, while those in care experienced HIV-related stigma from healthcare workers.

Our study revealed significant gaps in services—and missed opportunities across the continuum of care (Figure 1). The top reason for testing remained illness

and suspected HIV-related symptoms. The number of people who were diagnosed with advanced HIV was unacceptably high across settings, even among those diagnosed after 2015; their health was further endangered by delayed linkage to and gaps in care.

There were significant differences between countries and populations around timely linkage to care and CD4 testing. People were more likely to be linked to care within 30 days in Indonesia, Honduras and Uganda. In all countries, people who inject drugs and people in rural settings were significantly less likely to enter care within 30 days of diagnosis. Those diagnosed before 2015 were more likely to have a CD4 cell count than people diagnosed

**FIGURE 1: Timing of ART Initiation, Retention into HIV Care and Treatment Services and Adherence, by Year of Diagnosis**





after 2015, even though baseline CD4 testing is still recommended as an essential part of clinical management.

Most countries in this study have implemented the World Health Organization's (WHO) 'treat-all' recommendation. Over a third of study participants who were diagnosed in the 'treat-all' era, between 2016 and 2018, started ART on the same day that they were diagnosed. However, nearly half of them felt they were not given enough time to decide whether they felt ready to initiate treatment.

The survey confirmed that access to viral load testing is suboptimal in many countries; in countries where viral load monitoring is available, people do not always receive results—and they are often not acted upon. Only half of the survey participants received a viral load test six months after ART initiation, despite the World Health Organization recommendation for doing so. People diagnosed in a publicly-funded setting had poorer access to viral load testing than those who were diagnosed through private care and non-governmental organizations (NGOs). A considerable number of respondents didn't know whether their viral load was suppressed, and qualitative interviews established other important knowledge gaps around routine viral load testing.

Overall, 74% of survey respondents reported sub-optimal ART adherence (defined as <90% by

visual analog scale). Factors associated with poor adherence included stigma and discrimination from healthcare workers; inconvenient clinic hours and long waiting times for consults; ART side effects; lack of financial resources and/or health insurance; low education level; lack of social support; younger age; and drug use.

Many ART centres do not have the capacity to diagnose and/or treat recipients of care for opportunistic infections (OI). A quarter of survey participants reported that testing for OIs was unavailable at their healthcare site, forcing them to travel to a different health centre. Furthermore, almost one in five women reported lack of access to condoms, and roughly a third reported lack of access to hormonal contraception. Suboptimal care threatens the health and survival of people living with HIV—and undermines the success of global efforts to end AIDS.

Through qualitative interviews, healthcare providers cited numerous barriers to delivery of optimal HIV services, including infrastructure, drug and diagnostic stock-outs, understaffing, cumbersome record keeping systems, a heavy workload, low wages and a lack of HIV-specific training. They also provided key recommendations such as strengthening collaboration with NGOs and community health workers, and rolling out differentiated service delivery (DSD) for stable patients.

More than a third of survey respondents diagnosed with HIV between 2016 and 2018 started ART on the same day. However, nearly half of them felt they were not given enough time to decide whether they felt ready to do so.



# SUMMARY OF KEY RECOMMENDATIONS

- **PROVIDE TREATMENT EDUCATION** to recipients of care and healthcare workers, essential for supporting adherence, particularly with the advent of 'treat-all', as more people who are asymptomatic are diagnosed and initiated on ART.
- **SCALE-UP DIFFERENTIATED SERVICE DELIVERY** to improve access to culturally competent HIV care, treatment and support services based on the needs of recipients of care.
- **EXPAND VIRAL LOAD TESTING** including prompt delivery of results and indicated actions, through decentralized point of care testing VL testing.
- **PROVIDE FULLY INTEGRATED HEALTHCARE CARE** without user fees, through the co-location of screening and treatment services.
- **IMPLEMENT COMMUNITY TREATMENT OBSERVATORIES (CTOs)** to improve access to quality and consistent supply of HIV services, treatment and commodities through community-led monitoring mechanisms.
- **MAINTAIN BASELINE CD4 TESTING** (and monitoring, when indicated), to identify people who are presenting or returning to care with advanced HIV.
- **INCREASE SUPPORT FOR AND BREADTH OF COMMUNITY-LED APPROACHES**, to increase linkage to and engagement in HIV services.
- **PROMOTE THE RIGHTS OF PEOPLE LIVING WITH HIV (PLHIV)** and key populations, through rights-based approaches.
- **MAKE MEDICINES AFFORDABLE**, ensuring optimal treatment regimens are available at more affordable prices.

**ITPC's regional partners were closely involved with selecting national partners and the development of the research protocol and objectives. Data collectors were trained by national focal points who had been trained by ITPC. Data were collected by civil society organizations, most of them networks of people living with HIV.**

This research included a quantitative survey and a qualitative survey. The quantitative survey evaluated access and barriers to HIV services among recipients of care. Data concerned indicators to measure access and quality of HIV treatment and factors potentially associated with access to health services (e.g. clinical data, socio-demographic characteristics, social support, general health, health behaviour, etc.) The qualitative survey characterized challenges to accessing and delivering HIV care among a convenience sample of PLHIV, health workers and political stakeholders selected at each country site. Data were collected about the barriers survey respondents encountered in providing or receiving HIV services across the continuum from diagnosis to clinical care and monitoring.

After the study was approved by national ethics committees, participants were given information about the study verbally and in writing; they provided informed consent and agreed to share additional information from their medical records (although it was not required for study inclusion). A standardized questionnaire was used to collect data before each interview.

Interviews were recorded and transcribed, and all identifying information was erased during transcription. Recorded interviews were erased after transcription to ensure confidentiality. The questionnaires and interview transcripts were entered into a password-protected database.



Data collectors during implementation workshop and training in Marrakech, Morocco.



## 1.1. Study Population

A third of the 2,777 recipients of care included in the quantitative survey (Table 1) were members of a key population (men who have sex with men [MSM], sex workers [SW], transgender people [TG] and people who inject drugs [PWID]).

The qualitative survey enrolled 47 people living with HIV (including key populations and other populations at risk of HIV), 62 healthcare providers (nurses, doctors, infectious disease specialists, social workers and counsellors) and 13 stakeholders involved in regional- or national-level HIV policy.

**TABLE 1. Baseline Characteristics among Recipients of Care**

<b>BASELINE CHARACTERISTICS</b>	<b>NA*</b>	<b>TOTAL</b>	<b>%</b>
<b>GENDER</b>			
Male		1169	42.1
Female		1585	57.1
Transgender		23	0.8
<b>AGE</b>	NA= 2		
18-29		504	18.1
30-44		1472	53.0
>44		799	28.8
<b>AREA</b>	NA= 16		
Rural		500	18.1
Semi/peri-urban		854	30.9
Urban		1407	51.0
<b>KEY POPULATIONS</b>			
PWID	NA=0	481	17.3
MSM	NA=4	345	12.4
SW	NA=9	319	11.4
TG	NA=0	36	1.3
<b>OTHER POPULATIONS</b> (clients of sex workers, refugees, international migrants, prisoners, truck drivers and having a partner from a key population.) <sup>7</sup>			
Do not belong to an identified risk group		1512	54.5
<b>MARITAL STATUS</b>	NA= 8		
Married		925	33.4
In relationship (not married)		429	15.5
Single		802	29.0
Separated		288	10.4
Widowed		325	11.7
<b>EDUCATION</b>	NA= 34		
Primary/ No formal education		954	34.8
Secondary		1337	48.7
Tertiary		452	16.5
<b>INCOME-GENERATING ACTIVITY</b>	NA= 11		
Yes		1668	60.3
No		1098	39.7
<b>HEALTH INSURANCE</b>	NA= 5		
Yes		817	29.5
No/ Don't know		1955	70.5

\*Not Available

## 1.2. Quantitative Survey

The survey was based on interviews with 2,777 recipients of care recruited from public and private health centres, hospitals and facilities run by NGOs in urban, semi-rural and rural areas. Efforts were made to diversify the selection of health facilities by location, size and type of population served. In each setting, every third RoC was invited to participate in an interview until 50 people had been enrolled.\*

Data on population- and health system-level factors were collected and analysed, including: demographics, knowledge and beliefs, enabling factors, reasons for HIV testing, and site of HIV diagnosis, whether they were referred to a doctor for HIV care- and relationships with healthcare providers. When possible, self-reported access to care indicators (dates of diagnosis, initial CD4 cell count, ART initiation and viral load testing) were confirmed by medical records.

\* Based on logistics and national contexts, the number of health facilities and PLHIV surveyed per facility differed by country.

**TABLE 2: Access to Care Indicators**

	INDICATOR	MEASUREMENT
ENTRY TO CARE	Late presentation	Diagnosed with advanced HIV (CD4 cell count of <200 cells /mm <sup>3</sup> )
	Timely first HIV care visit	Appointment within 30 days of HIV diagnosis
LINKAGE TO CARE	Timely CD4 testing	A CD4 count within three months of receiving an HIV diagnosis
	ART initiation	Number of people who initiated ART (based on eligibility under national guidelines)
	Timely viral load count following ART initiation	At least one viral load test within six months of ART initiation
RETENTION IN CARE	Engaged in care	At least one HIV appointment within four months of the initial visit
	ART adherence Viral suppression	Assessed by visual analog scale <1000 copies/mL



The survey measured access and quality of HIV care. As shown on Table 2, indicators covered entry to care, linkage to care and retention in care, as well as data on population- and health system-level factors.

## 1.3. Qualitative Survey

Participants were selected through local networks or organizations that have partnered with ITPC, with priority given to members of key populations and the organizations serving them.

The qualitative study included interviews with 122 participants from 14 countries, including 47 people living with HIV, 13 key informants (members of regional or national health committee and leadership from local NGOs), and 62 healthcare workers. Healthcare workers and other stakeholders were selected by local partners, based on their experience working with PLHIV and their knowledge of national and regional barriers to accessing care and treatment.

Interviews with RoCs focused on experiences with their HIV diagnosis, subsequent care pathway, and the barriers they encountered. These were compared between people diagnosed before and after 2015.

Healthcare workers were asked about their motivation for delivering HIV care and their knowledge of national and World Health Organization (WHO) guidelines, as well as the barriers they experienced to providing care and implementing ART guidelines.

The key informant interviews covered knowledge of national and WHO guidelines, the barriers—including at the political level—they faced in implementing them and delivering quality HIV care treatment.

The All-Ukrainian Network of People Living with HIV/AIDS implemented the survey in four health facilities, where over half of the survey respondents were people who currently inject drugs or people who formerly injected drugs.









## 2.1. Stigma: A Pervasive—and Deadly—Barrier

Stigma was cited as a major barrier to all HIV services across the continuum of care, and to ART adherence. People who reported anticipated stigma—the belief that they would be treated unfairly and/or poorly by others based on their HIV status—delayed or avoided testing, and they were 1.2 times more likely to be diagnosed with advanced HIV disease. Once diagnosed, the fear of being seen at an ART clinic and concerns about confidentiality in a healthcare setting prevented some people from engaging in care, while those in care reported that HIV-related stigma from healthcare workers was common.

Criminalization continues to foster stigma. Members of key populations were especially vulnerable to stigma from healthcare workers, since many live in countries where same-sex relationships, drug use and/or sex work are illegal (see Table 3). For example, MSM and SW reported that they were significantly more likely to be denied health services due to their HIV status than other people living with HIV.

**TABLE 3. Criminalization of Key Populations by Region and Country**

REGION	COUNTRY	CRIMINALIZED KEY POPULATIONS
LATIN AMERICA AND THE CARIBBEAN	Dominican Republic	PWID
	Honduras	PWID
EASTERN EUROPE AND CENTRAL ASIA	Ukraine	SW & PWID**
	Kyrgyzstan	PWID, MSM**, SW**
SOUTHEAST ASIA	Viet Nam**	SW, PWID
	Indonesia**	SW, MSM, TG
WEST AFRICA	Côte d'Ivoire	SW, PWID
	Burkina Faso	SW, PWID, TG**
EAST AFRICA	Uganda	SW, MSM, PWID, TG
	Kenya	SW, MSM, PWID
SOUTHERN AFRICA	Zimbabwe	SW, MSM, TG, PWID
	Zambia	SW, MSM, TG**, PWID
MIDDLE EAST AND NORTHERN AFRICA	Morocco	MSM, SW, PWID, TG
	Lebanon**	MSM, SW, PWID

Source: UNAIDS 2018 “Miles to Go” report (34)

\*\* Source: ITPC Treatment Survey qualitative interview

“I don’t want to tell people at my work that I need to go to the hospital or AIDS centre because I could be fired. I am afraid that my bosses will think that I am too sick to perform my job.”

—Man living with HIV, Ukraine



“I hide my pills at work in a key-locked cabinet, for which only I have the key. I always wait for my wife to leave the room. She’s seen me before and asked what I’m taking but I’ve said that I had food poisoning.”

—Man living with HIV, Burkina Faso

Roughly two-thirds (64.6%) of all survey participants experienced anticipated stigma during the previous 12 months. Overall, 20.7% reported avoiding social gatherings and 23.9% didn't disclose their HIV status to any family members.

Over a third of participants (37.8%) experienced external stigma over the previous year, most commonly being the subject of gossip (28.3%) and harassment (14.9%), while 10.8% reported job loss and 6.2% were assaulted. More than half of the survey participants (56.7%) reported internalized stigma—self-blame for HIV status, decision not to have sex or not to have children based on their HIV status.



*Health care workers used to ask me some funny questions like are you a boy or a girl? They call each other to come and see me and I think it is discrimination and they start laughing.*

—Transgender Woman, Zimbabwe



*I am gay and when I ask for lubricants, I become the topic that day. This makes me hate coming here for my ARVs. They should offer KP-friendly services and also not threaten to report us to police. I am treated differently and even ignored. Sometimes I am sent from one room to another and the staff sometimes tells me they don't have time for people like me.*

—Man living with HIV, Uganda



Criminalization continues to foster stigma. In Burkina Faso, men who have sex with men, people who use drugs and transgender people were especially vulnerable to stigma from healthcare workers.

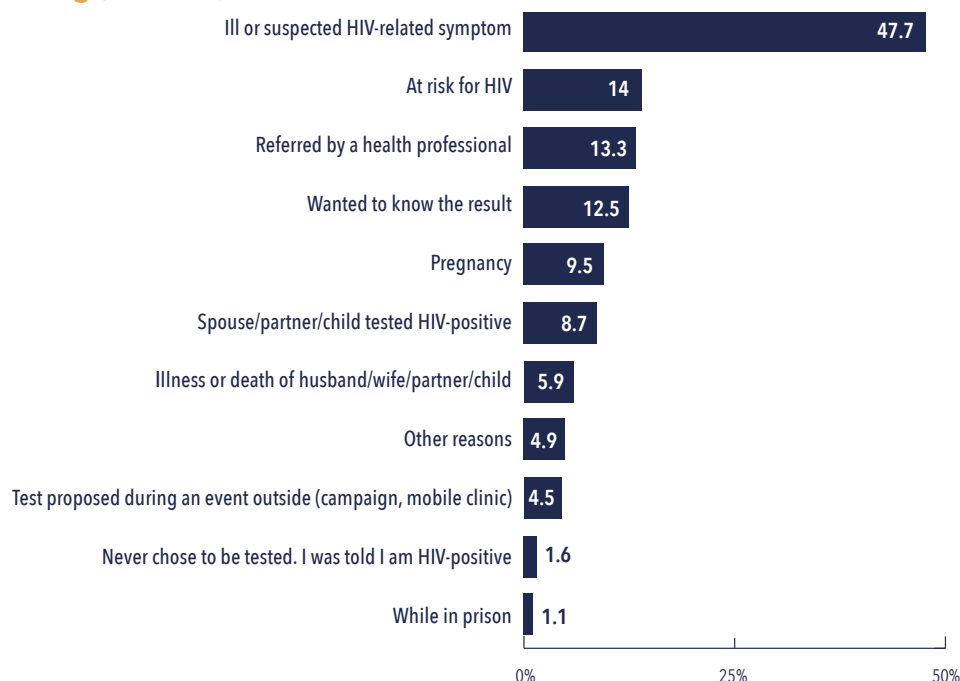


## 2.2. HIV Testing

Nearly half (47.7%) of survey participants were tested for HIV because they were ill (Figure 3). The other most common reasons for testing included having been at risk for HIV and referral by a healthcare provider. Overall, people were most likely to be tested at public,

government-funded facilities than through private healthcare (67.8% versus 14.1%), especially those with advanced HIV (a CD4 cell count of < 200 cells/mm<sup>3</sup>). Only 10.9% were tested at an NGO.

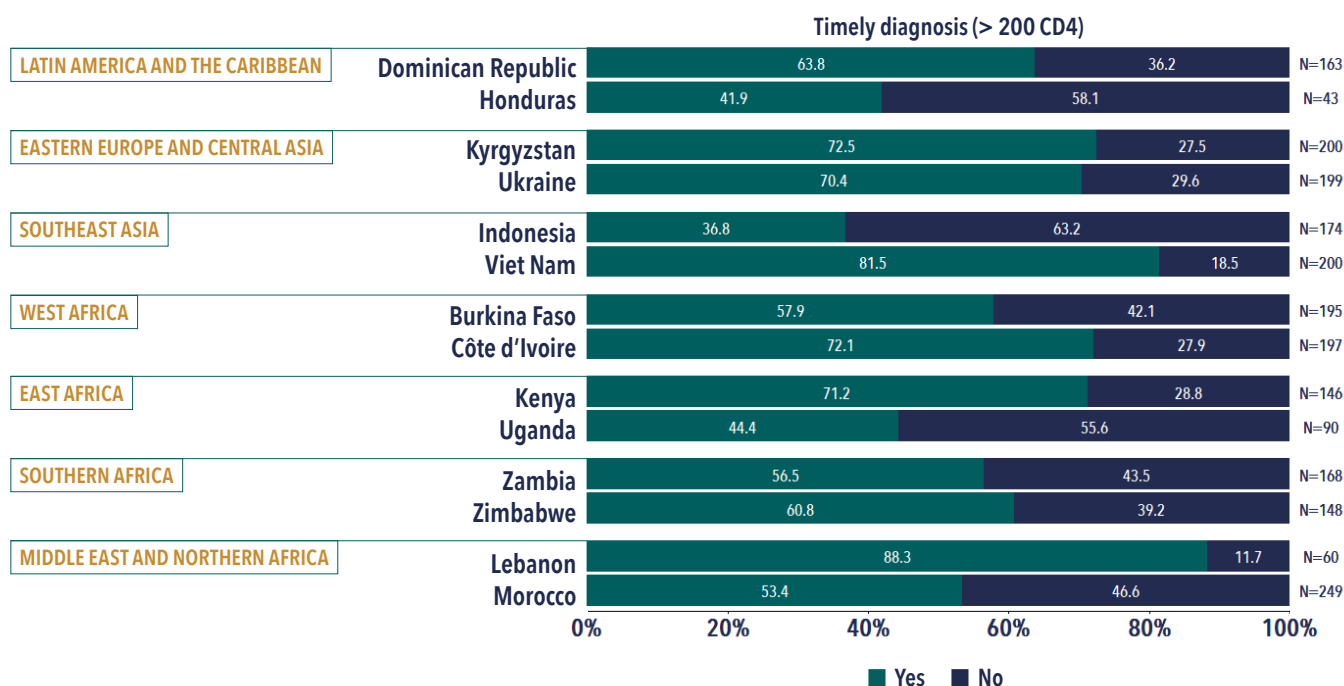
**FIGURE 3. Reasons for HIV Testing (n=2777)**



The study revealed significant gaps in service—and missed opportunities. The number of people who were diagnosed with advanced HIV varied by country and region, but it remained unacceptably high across settings. Notably, people were more likely

to be diagnosed with advanced HIV in Honduras, Indonesia, Morocco and Uganda, and more likely to be diagnosed with a higher CD4 cell count in Côte d'Ivoire, Dominican Republic, Kenya, Kyrgyzstan, Lebanon, Viet Nam and Ukraine (Figure 4).

**FIGURE 4. Timely Diagnosis, by Region and Country (n=2 242)**



Overall, more than a third (37.1%) of survey participants presented with advanced HIV disease, especially those diagnosed before 2015 (40.9% versus 30.9%), putting them at high risk for death—even after ART initiation.<sup>6</sup> Transgender people who were members of other key populations were significantly more likely to be diagnosed late than other key populations or the general public. Surprisingly, people in urban and peri-urban areas were more likely to be diagnosed late than people living in rural areas.

Some participants reported that they were only offered HIV testing after being treated for other conditions, such as malaria.



*“It took about 10 months of being sick until someone thought of HIV.”*

*—Woman living with HIV in Kenya, where she was treated for various ailments, including headaches, fever, and malaria before her doctor offered an HIV test.*



ITPC MENA implemented the survey in Morocco, where approximately half of the respondents presented with advanced HIV disease.



*The patient doesn't have the money to buy the drug especially antibiotic that you want to prescribe because it is not offered at the facility. Mostly expensive medicines are not in the facility for free. This also includes some tests which patients must pay for them, but they don't have money.*

*—Doctor, Kenya*

## 2.3. Linkage to and Quality of Care

The 'second 95'—receipt of ART—is often used as a proxy for linkage to, and engagement in care, but information on the timeliness, quality, and scope of care available to people living with HIV is limited. Our survey uncovered several sub-optimal aspects of care. For example, RoC often did not receive CD4 testing, or baseline CD4 testing and prophylaxis for opportunistic infections when indicated. Clinics did

not have necessary tests or treatment for opportunistic infections (OI), sometimes due to drug stock-outs. User fees also presented a barrier to HIV care. Although access to viral load testing is increasing, it is unclear whether and when recipients of care consistently receive—and understand—their results, and what actions are taken when viral load is detectable.

### ENTRY TO HIV CARE

Overall, timely linkage to care (a medical visit within a month of receiving an HIV diagnosis) increased among people diagnosed after 2015 (87% vs. 79.8%), although there were significant differences between countries (Figure 5).

People living in urban areas and those with social

support were more likely to enter care within 30 days of their diagnosis, while people who inject drugs, married people, people in rural settings, those who experienced stigma at least once during the previous 12 months, and people who did not think their medical files were confidential were less likely to enter care within 30 days of diagnosis.

### PERSPECTIVES FROM HEALTHCARE PROVIDERS

Healthcare providers are the backbone of the response to HIV and essential to its success. Yet their voices are seldom heard. In this survey, they cited numerous barriers to delivery of optimal HIV services, including infrastructure (lack of access to nearby labs, insufficient private, appropriately sized spaces

to deliver care, inadequate or broken equipment) drug and diagnostic stock-outs, understaffing, cumbersome record keeping systems, a heavy workload, low wages and a lack of HIV-specific training, including about treatment guidelines, and on counselling for key populations.

Key recommendations from healthcare providers to address barriers to HIV services:

- Strengthen collaboration with NGOs and community health workers, including people living with HIV and key population staff, peer educators and social workers;
- Expand integrated care delivery for HIV/TB services, condoms, testing and treatment for sexually transmitted infections;
- Define health insurance policies and promote free care and treatment and examinations;
- Roll out differentiated service delivery (DSD) for stable patients: mobile units, key population-specific schedules, decentralization at local structures, delegation to nurses and collaboration with local health facilities that do not provide HIV services;
- Improve availability of treatments and machines, particularly for viral load testing;
- Implement treat-all policy;
- Improve social and psychosocial support for PLHIV (including home visits, counselling, community support, multi-lingual staff for migrants);
- Tackle stigma and discrimination through key population programmes and trainings to health care workers (including those who are not delivering HIV care);
- Promote HIV self-testing;
- Roll out campaigns for prevention of mother to child transmission;
- Support healthcare workers by increasing staff, reducing paperwork and increasing wages, providing standard protocols for care delivery and improving their knowledge of HIV treatment.

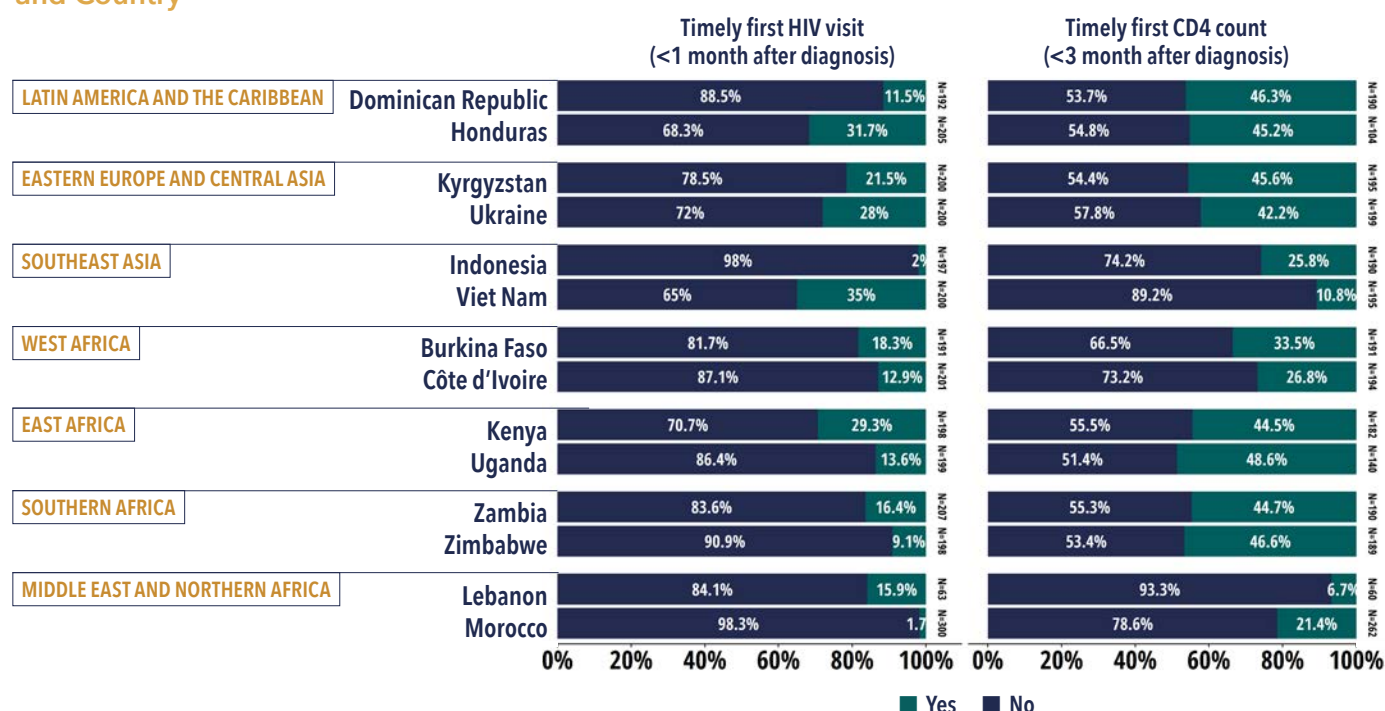


## CD4 COUNT

Although CD4 cell count is no longer needed for determining treatment eligibility in many countries, it is still important for clinical management, since people living with advanced HIV disease require specialized care.<sup>vi</sup> People who were diagnosed before 2015 were

more likely to have a CD4 cell count than people diagnosed after 2015. However, those diagnosed after 2015 were more likely to have a CD4 cell count within 3 months of starting ART.

**FIGURE 5. Timing of HIV Care Visit and CD4 Cell Count After an HIV Diagnosis, by Region and Country**



Overall, 17.8% of survey respondents did not have a CD4 cell count until over a month after ART initiation, leaving those with a low CD4 cell count vulnerable to

immune reconstitution inflammatory syndrome (IRIS)—either the worsening of a previously treated infection or the unmasking of an underlying, undiagnosed infection.

## ART INITIATION

In 2015, WHO recommended that all infants, children, adolescents and adults receive ART, based on data demonstrating the health and survival benefits of

ART—at any CD4 cell count.<sup>7,8,9</sup> In our survey, 71% of respondents were diagnosed before 2016.

## NATIONAL-LEVEL ELIGIBILITY FOR, AND ACCESS TO ART

Most of the 14 LMICs in this study have implemented the WHO 'treat-all' recommendation (Table 4). As of 2016, Kenya, Kyrgyzstan, Ukraine, Zambia and Zimbabwe offered ART regardless of CD4 cell count. By 2017, Burkina Faso, Côte d'Ivoire and Honduras had adopted 'treat-all' and by 2018, the Dominican Republic followed suit. In Indonesia, ART eligibility is still determined by CD4 cell count. The delay between HIV diagnosis and ART initiation varied greatly across countries (Figure 6).



**After the diagnosis, no treatment was prescribed; there was no treatment at all in the country.**

*- Male drug user in Kyrgyzstan, who was diagnosed in 2001 but wasn't able to access ART until 2007.*

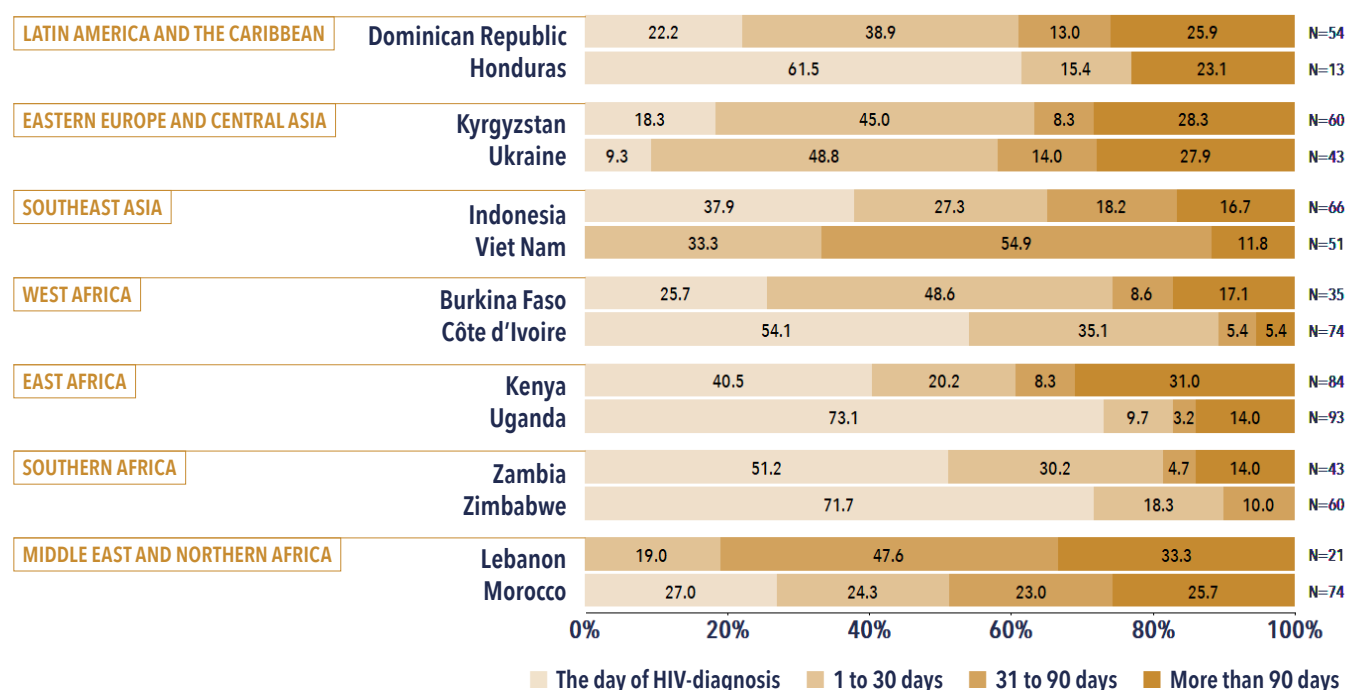
**TABLE 4. National ART Guidelines, and out-of-pocket costs for ART and viral load**

REGION	COUNTRY	'TREAT-ALL' ADOPTED / CD4 THRESHOLD FOR ART ELIGIBILITY	DATE	COST ART	COST VIRAL LOAD
LATIN AMERICA AND THE CARIBBEAN	Dominican Republic	None	2018	Free	Free
	Honduras	None	2017	Free	Free
EASTERN EUROPE AND CENTRAL ASIA	Ukraine	None	2016	Free	Free
	Kyrgyzstan	None	2016	Free	Free
SOUTHEAST ASIA	Viet Nam	None	2017	Free	Free
	Indonesia	≤ 350	2014	Free	Charge
WEST AFRICA	Côte d'Ivoire	None	2017	Free	Free
	Burkina Faso	None	2017	Free	Free
EAST AFRICA	Uganda	None	2016	Free	Free (1 per year)
	Kenya	None	2016	Free	Free (1 per year)
SOUTHERN AFRICA	Zimbabwe	None	2016	Free	Free
	Zambia	None	2016	Free	Free
MIDDLE EAST AND NORTHERN AFRICA	Morocco	None	2016	Free	Free
	Lebanon	None	2017	Free	Charge



Initiating HIV treatment took more than a month for a quarter of respondents in Burkina Faso, who were diagnosed between 2016 and 2018.

**FIGURE 6. Delay between HIV diagnosis and ART initiation among PLHIV (HIV diagnosis 2016-2018)**



Overall, 67.1% of people who were diagnosed between 2016 and 2018 started ART less than a month after diagnosis. Among the 771 people diagnosed during this period, 38.4% started ART on the same day,

but nearly half of this group (48.1%) felt they were not given enough time to decide whether they felt ready to initiate treatment.

## 2.4. Viral Load Testing

WHO recommends routine viral load testing (RVLT) at 6 and 12 months after ART initiation and every 12 months thereafter, but access to viral load testing is sub-optimal in many countries. In places where RVLT is available, people do not always receive results, and they are often not acted upon.

People living with HIV have the right to know whether their ART is working by accessing RVLT; this knowledge also supports ART adherence, and flags the need for a switch to new effective regimen when treatment is

failing. Keeping people on a failing regimen puts them at risk for opportunistic infections and can intensify drug resistance.

In theory, RVLT is available at no charge in every country that was surveyed, except Lebanon, where user fees are usually above 160 US dollars. Yet in practice, only 72.5% of survey respondents reported having a viral load test, with 55.1% receiving timely viral load testing (6 months after ART initiation).

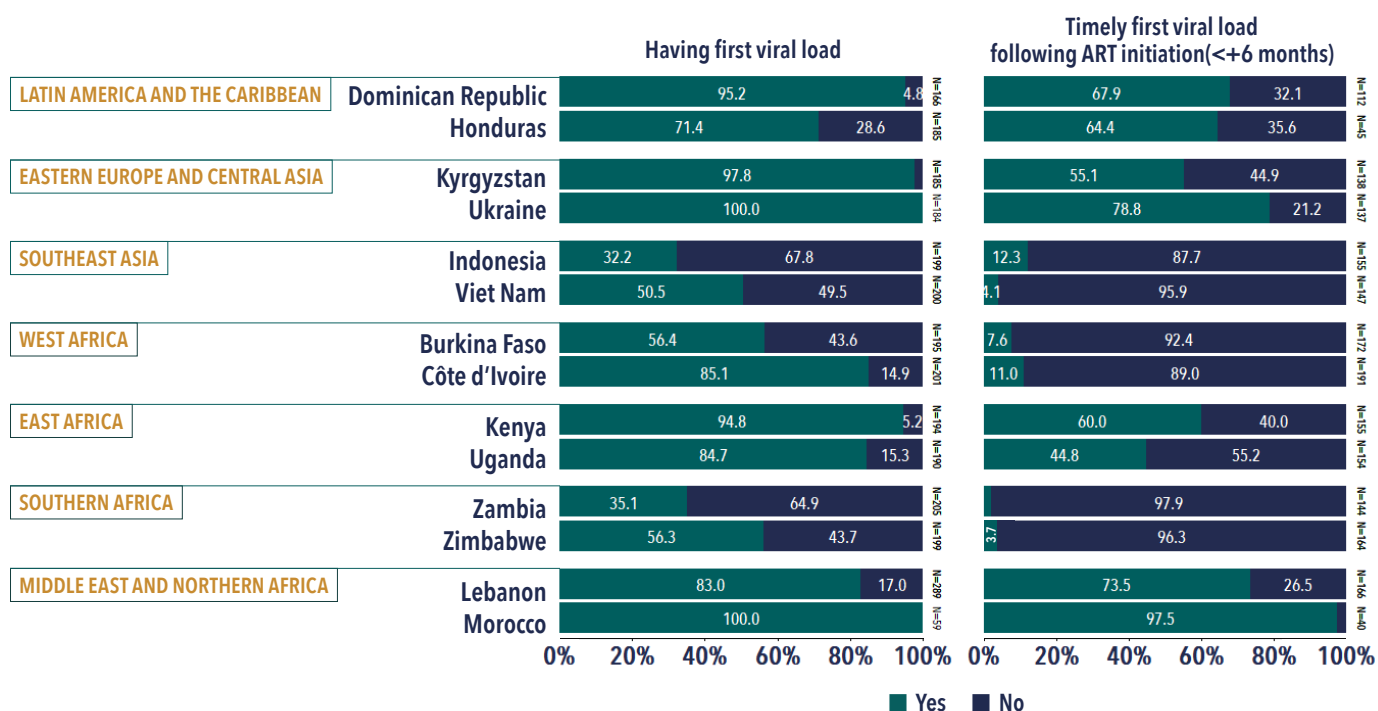
## HIV DRUG RESISTANCE

The prevalence of pre-treatment and acquired HIV drug resistance is increasing. In 12 of 18 LMIC surveyed by WHO, over 10% of adults (and nearly twice as many women as men) had pre-treatment resistance to efavirenz (EFV) and/or nevirapine (NVP).<sup>10</sup>

In these countries, the rate of resistance to EFV and/or NVP among people who were not virally suppressed ranged from 50% to 97%, indicating the need for viral load testing and prompt switching to second-line ART. Genotypic testing remains

unavailable and/or prohibitively expensive in many places. Instead, viral load testing, which has been recommended by WHO since 2013, is used to detect treatment failure and identify people who may need adherence support and/or a new antiretroviral regimen.<sup>11</sup>

**FIGURE 7. Access to Viral load Testing by Country**



Access to viral load testing varied across regions and countries (Figure 7) and improved significantly after 2015; the number of people who had viral load testing within 6 months of ART initiation nearly doubled, from 27.6% to 47.6%. However, 14.4% of survey

respondents did not know the result of their most recent viral load test and only 53.3% of people with viral suppression were informed that their viral load was undetectable (Figure 8).

**FIGURE 8. Viral Load Testing and Viral Suppression**

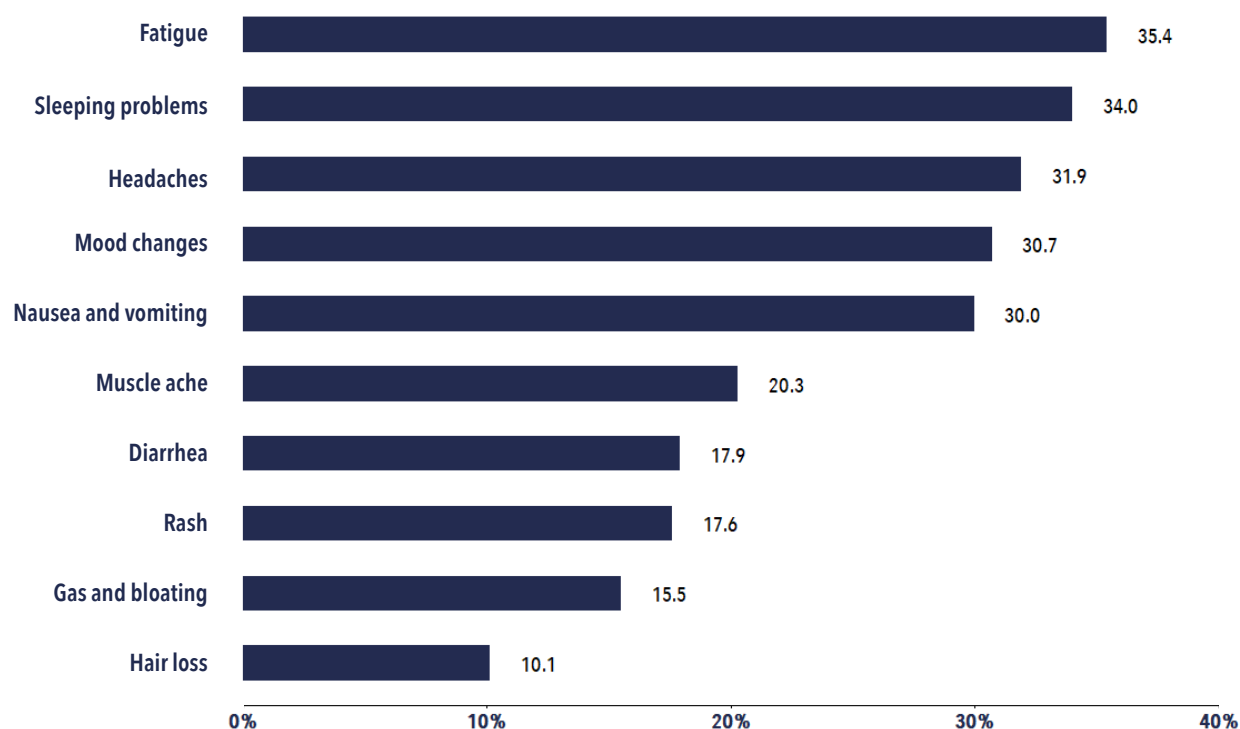




For the 15.6% of respondents with a detectable viral load after at least six months of ART, the opportunity to act on this information was often missed. Among them, 75.2% were still on a first-line treatment and 65.1% had never changed their regimen. Less than half (41%)

reported poor adherence (<90% by visual scale), while more than a third reported treatment interruptions, mostly because of ART side effects such as fatigue, mood changes and sleeping problems (Figure 9).

**FIGURE 9. Side effects in the previous 4 months as reported by PLHIV with a detectable viral load, 6 months after initiating ART (n=315)**



In some countries, a considerable number of PLHIV didn't know whether their viral load was suppressed; this was mainly driven by lack of access to viral load testing, particularly in West and Southern Africa, Southeast Asia, Latin America and the Caribbean. Overall, 2.8% of participants did not know what a viral load test was and 6.1% did not know if they had already had the test done. Qualitative interviews confirmed a lack of knowledge among recipients of care—most interviewees didn't know their viral status or what a viral load test was.

People who were diagnosed in a publicly-funded setting had poorer access to viral load testing than those diagnosed through privately-funded care and NGOs (69.9% vs. 83.7%). Barriers to timely viral load testing included lack of equipment (machines and reagents) or broken equipment, high demand, delayed results (from 1 to 6 months), user fees and lack of information about viral load testing.



*CD4 count and viral load are important in monitoring and treatment of patients but not yet available in my area.*

—Doctor, Viet Nam



*Few viral load machines dotted across the country. Rural health facilities usually have no CD4 count machines.*

—Member of Health Services Committee, Zambia

## 2.5. Adherence

Adherence to ART is essential for achieving and maintaining viral suppression, but it is challenging for many reasons. Currently, ART is lifelong and has side effects; its use may result in stigma.

Adherence data were collected from survey participants using a single-item visual analog scale. When available, medical records were reviewed to obtain information on viral suppression. Optimal adherence was defined as a score of >90%.

Overall, 80% of participants who were virally suppressed reported optimal adherence, versus 63.7% of those not virally suppressed. Suboptimal adherence was reported by 26% of participants, for various reasons. These included stigma and discrimination from healthcare workers; inconvenient clinic hours and/or long lines and waiting times for consults, exams and test results at ART centres; experiencing at least two short-term ART side effects; living in a peri-urban area; employment; lack of financial resources for transportation to the clinic and food; lack of health insurance; low education level; lack of social support (including access to counselling and support groups); language barriers; younger age; and drug use—all of which were significantly associated with poor adherence.

Overall, 70% of survey participants remained on their first-line regimen; the main reasons for switching were side effects (48.9%) and drug resistance (18.2%). Treatment interruptions, mainly due to ART side



*I haven't means to provide myself for food[...] Often, I have to stop my treatment during a period because I don't have means, as I said. Dose is strong, so I have to eat well.*

*—Woman living with HIV, Côte d'Ivoire*



*I want to be followed more closely, that someone calls me from time to time to remind me to take my pills, that they send me messages to encourage me. They know my number*

*—Woman living with HIV, Côte d'Ivoire*

effects, were reported by 37.3% of survey participants. In addition, participants cited relocating, missed appointments and feeling healthy as reasons for interrupting their treatment.

In contrast, participants who had good relationships with their healthcare provider and those who felt that their confidentiality was protected were more likely to be adherent. Although men reported better adherence than women did, they were not more likely to be virally suppressed.



In the Dominican Republic, a considerable number of PLHIV didn't know whether their viral load was suppressed. Qualitative interviews confirmed a lack of knowledge about RVLT among recipients of care.

People living with HIV have described the value of community ART groups for several reasons, including for supporting adherence.<sup>12,13</sup> Yet 51.3% of survey

participants with a detectable viral load after at least six months on treatment had never participated in an ART adherence group.

## 2.6. Overall Quality of Care

Healthcare for people living with HIV involves more than antiretroviral therapy. Sub-optimal care threatens the health and survival of PLHIV—and undermines the success of global efforts to end AIDS. This survey found that people received inadequate healthcare, including lack of or limited access to sexual and reproductive health services; testing and treatment for OI and common co-morbidities, including non-communicable diseases; palliative care and social services (Figure 10).

“

*But often, when we are sick, we come to AIDS Centre, there is no drug.*

– Woman living with HIV, Côte d'Ivoire

“

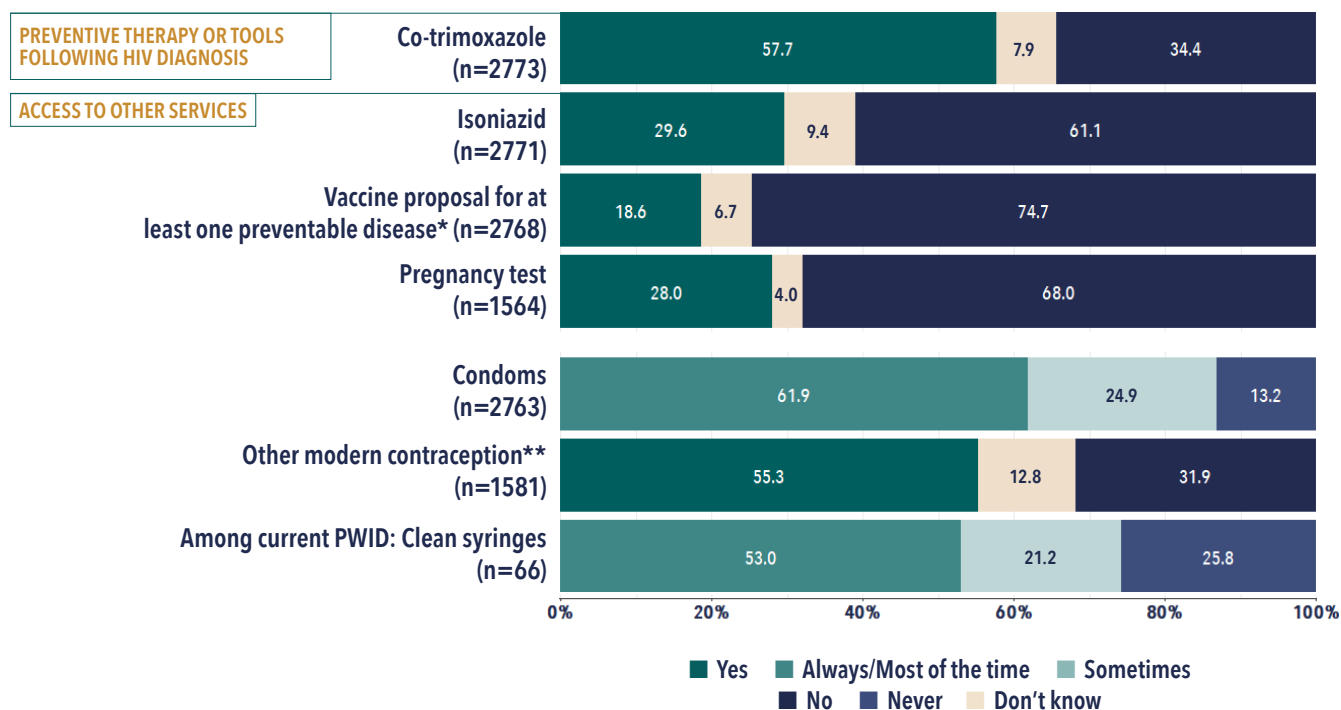
*The staff should be educated on stigma towards gay men and not doctors telling everyone about you.*

–Man living with HIV, Kenya

In Ukraine, odds of being virally suppressed were higher among people living with HIV who visited ARV clinics regularly compared to those who did not.



**FIGURE 10. Access to Holistic Healthcare Services for PLHIV**



\*Hepatitis B virus, influenza, pneumococcal disease, tetanus, human papillomavirus

\*\*Voluntary sterilization, oral hormonal pills, the intra-uterine device (IUD), injectables, the implant, vaginal barrier methods and emergency contraception.

In particular, 17.7% of women reported lack of access to condoms (vs. 7.2% of men). Moreover, 31.9% of female participants reported lack of access to other forms of modern contraception (e.g. hormonal contraception, IUD)

which is particularly concerning in the context of WHO HIV treatment guidelines, which call for a women-centred approach to health care, and for offering effective contraception to women and adolescent girls of child-bearing potential.<sup>14</sup>



Almost one in five women in the survey reported lack of access to condoms and over a third of them reported lack of access to modern contraception. This is particularly concerning considering that WHO calls for a women-centred approach to health care.

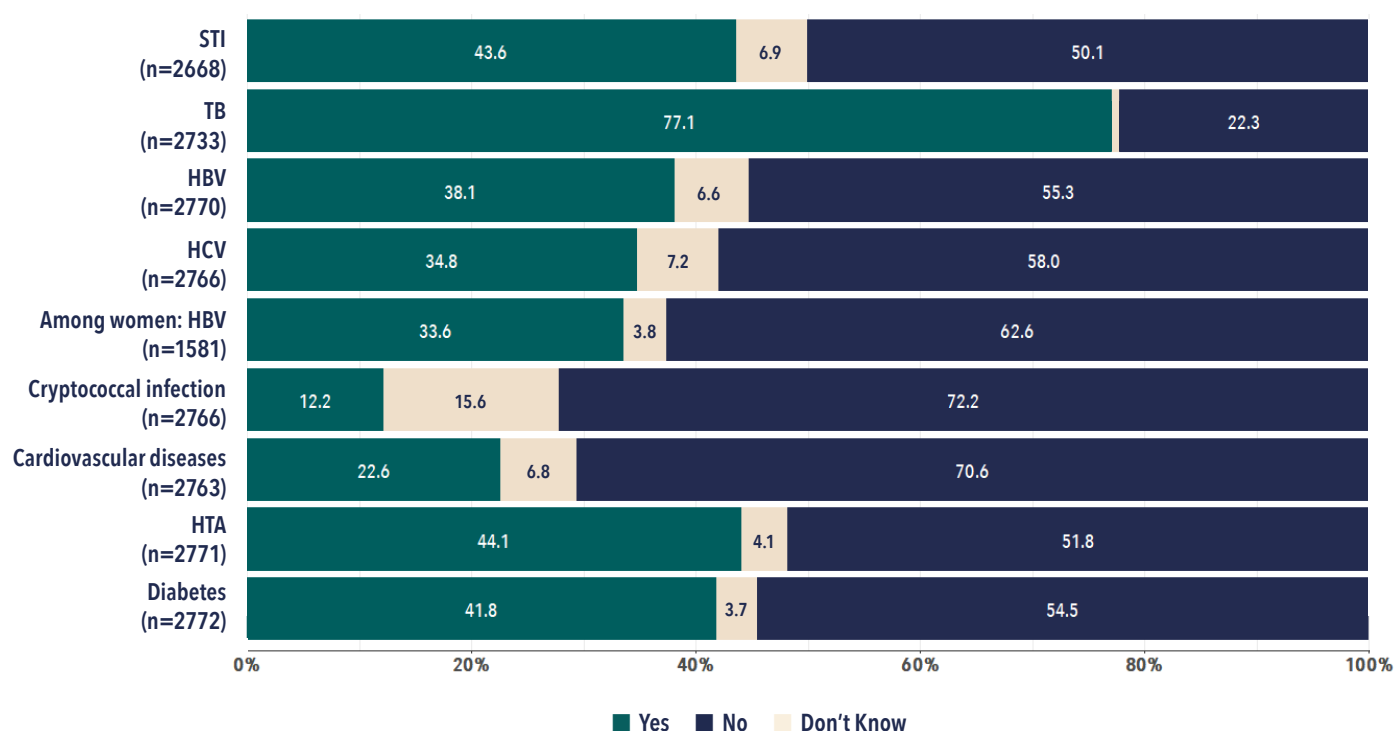


Many ART centres do not have the capacity to diagnose and/or treat recipients of care for OI. When people needed prophylaxis or treatment for an OI—or a common co-morbidity—medicines were not always available; healthcare workers in sub-Saharan African countries consistently cited drug stock-outs. Overall, 26.1% of survey respondents reported that testing was unavailable at their healthcare site, forcing them to travel to a different health centre, where they frequently experienced stigma and discrimination from healthcare workers who were not involved with providing HIV care. In addition, there are financial barriers to care: in some places, testing and treatment for OI are not included in the free package of care for people living with HIV. User fees were a barrier for 33.8% of survey participants.

Tuberculosis (TB), although preventable and curable, is the leading cause of death among people living with HIV. The WHO recommends that all PLHIV be screened periodically for TB. Yet only 77.1% of survey participants reported being asked about symptoms (coughing, night sweats, weight loss or fever for more than 3 weeks) and whether they had had recent contact with a person who had TB.

Roughly a third of survey respondents were screened for common co-morbidities, such as hepatitis B virus (HBV), hepatitis C virus (HCV) and diabetes; an even smaller proportion were screened for human papilloma virus (HPV), cryptococcal disease and cardiovascular disease (Figure 11).

**FIGURE 11. Screening for Common Co-morbidities**



# 3

## SURVEY LIMITATIONS

The quantitative study was cross-sectional, so temporal or casual effects were not considered. The survey presents a bias towards those who agreed to participate. By recruiting participants directly at the health facilities, it overestimates access to health services by people living with HIV.

There were difficulties gaining access to medical records; in some facilities, files were incomplete or missing. In these instances, participants provided their own medical information.

Our sample is not representative at country-level, since we were unable to randomly select healthcare facilities where the survey was performed. Instead, selection was based on diversity in location, size and populations served. Some countries had difficulties recruiting participants. In such cases, we lowered the number of respondents.

“Although there have been great achievements in the fight against HIV and AIDS, our survey uncovers several sub-optimal aspects of care that are common to all regions of the world. Furthermore, because we recruited participants directly at health facilities, the situation might be actually worse, in terms of access to health services” -

Alma de León - ITPC LATCA Regional Director



In health facilities where medical records were incomplete or unavailable, participants provided their own medical information.







Significant progress has been made in the response to HIV. However, our survey reflects persistent access gaps and shortfalls in the quality of care that people living with HIV face. Based on the findings of the study, ITPC recommends the following key steps to be taken to improve access to and quality of HIV services, which will bring the world closer to ending AIDS:

■ **PROVIDE TREATMENT EDUCATION TO RECIPIENTS OF CARE AND HEALTHCARE WORKERS:** People living with HIV have the right to, and benefit from HIV treatment education. It is essential for supporting adherence, particularly with the advent of 'treat-all', as more people who are asymptomatic are diagnosed and initiated on ART. Programs that offer parallel information can help to empower recipients of care and their healthcare providers, dispel stigma, and improve these relationships towards collective development and implementation of solutions that motivate health systems strengthening.

■ **SCALE-UP DIFFERENTIATED ART SERVICE DELIVERY:** Implement DSD frameworks that seek to improve access to culturally competent HIV care, treatment and support services based on the needs of recipients of care. The DSD frameworks call for availability of both facility and community-based service delivery to improve access and quality of services. For example, the International AIDS

Society DSD framework<sup>15</sup> notes that by decentralizing ART delivery to the community (i.e. drop-in centres), access to HIV services for key populations may be enhanced. Other health system, social and structural barriers such as long waiting times, confidentiality breach, stigma and discrimination, inconvenient health facility hours and others can be addressed through the implementation of DSD models.

■ **EXPAND ROUTINE VIRAL LOAD TESTING, PROMPT DELIVERY OF RESULTS AND INDICATED ACTIONS:** Shifting to decentralized point-of-care viral load testing could increase access to RVLT, reduce turnaround time, facilitate DSD for stable recipients of care and community-based ART delivery. In tandem, it is essential to ensure that recipients of care receive and understand their results, that measures are taken based on results, such as identifying treatment failure, switching regimens and supporting adherence.

## ■ **PROVIDE FULLY INTEGRATED HEALTHCARE WITHOUT USER FEES:**

Increase integration of holistic prevention, testing, care and treatment services, through the co-location of screening and treatment services for common HIV-related co-morbidities and opportunistic infections, sexual and reproductive health (i.e. access to contraception, condoms, lubricants, HBV and HPV vaccines), harm reduction (i.e. access to clean needles/syringes, opioid substitution therapy), testing for and management of non-communicable diseases, social support.

## ■ **MAINTAIN BASELINE CD4 TESTING (AND MONITORING, WHEN INDICATED):**

to identify people who are presenting or returning to care with advanced HIV, since they are at increased risk of death even after starting ART and require a WHO-recommended package of care.

## ■ **INCREASE SUPPORT FOR AND BREADTH OF COMMUNITY-LED APPROACHES:**

Service delivery and care models that are led / driven by communities, have proven to be effective. To increase linkage to and engagement in HIV services, recipients of care and communities must be involved in policy development and the design, delivery and monitoring of health services.

## ■ **IMPLEMENT COMMUNITY TREATMENT**

**OBSERVATORIES:** to improve access to, and quality and consistency of HIV services, treatment and commodities through community-led monitoring mechanisms. These should be integrated into national programs and structures to facilitate routine collection of data, identify persistent challenges to health systems and service delivery, and foster collective engagement between healthcare workers and recipients of care in the development and implementation of sustainable solutions, such as addressing stock-outs by identifying and resolving supply chain management.

## ■ **PROMOTE THE HUMAN RIGHTS OF PEOPLE LIVING WITH, AND VULNERABLE**

**TO HIV:** including key populations through legal and policy interventions to eliminate discrimination, overcome structural barriers, protect confidentiality and privacy and create an enabling environment for universal, high quality health care.

## ■ **MAKE MEDICINES**

**AFFORDABLE:** Ensure that WHO-recommended, optimal treatment regimens are available and affordable everywhere, by addressing intellectual property and regulatory barriers to market entry of generic products, and by increasing competition between generics producers.

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ITPC's Global Survey is part of  
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data on access to and quality of  
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