



GLOSSARY

Antiretroviral treatment (ART)

Medications used to treat or prevent HIV; can reduce the amount of virus in blood to undetectable levels, preventing HIV-related illness or transmission

Comorbidity

A condition that exists at the same time as another condition

HCPs

Healthcare providers

MLHIV

Men living with HIV

MSM

Men who have sex with men

MSW

Men who have sex with women

PLHIV

People living with HIV

Polypharmacy

Taking multiple medications – defined in Positive Perspectives 2 as taking five or more pills a day or taking medicines for five or

more health conditions

QoL

Quality of life

WLHIV

Women living with HIV



FOREWORD

The way people living with HIV (PLHIV) are cared for is evolving. While there is still more work to be done to ensure universal access to antiretroviral treatment (ART), thanks to medication innovations, HIV is now a long-term, treatable health condition and many PLHIV are living longer, healthier lives than before.

As HIV care has evolved, the focus has moved away from surviving HIV to living and ageing well with HIV, with improved quality of life (QoL) being the desired goal. Long-term QoL is becoming a critical priority in the care of PLHIV, a factor that is embedded within the UNAIDS 2025 AIDS targets, along with tackling inequalities in HIV care.

However, few international HIV studies capture the experiences of PLHIV beyond viral suppression. The Positives Perspectives study, Wave 2 (Positive Perspectives 2) is one of the largest, global, HIV patient-reported outcomes studies to date. Staying true to the goal of meaningful involvement of PLHIV in HIV care from the Denver Principles, the Positive Perspectives 2 research provides perspectives and opinions from a diverse group of PLHIV across the world.

Patient reported data from the Positive Perspectives 2 study provide first-hand information about how care and treatment affect the health and wellbeing of PLHIV beyond viral suppression and offer in-depth insights into the challenges that impact the QoL of PLHIV.

As many PLHIV now live longer than before, a collaborative and holistic approach to HIV care that facilitates ongoing communication between PLHIV and HCPs can help improve health outcomes and QoL.



Garry Brough

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ABOUT THIS REPORT

Building on the unique knowledge gained from the initial Positive Perspectives survey, Wave 1 (Positive Perspectives 1) undertaken in 2017, this report focusses on results from the Positive Perspectives study, Wave 2 (Positive Perspectives 2). It investigates how PLHIV rate their own health, how living with HIV impacts their lives and affects their outlook for the future, as well as examining their interactions and relationships with HCPs and their experiences with ART. The in-depth insights gained from the study can help us address the unmet treatment needs and challenges faced by PLHIV and contribute towards improving QoL. All results in this report are based solely on responses from PLHIV involved in the study.

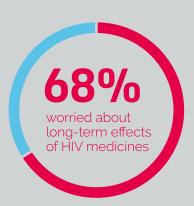
Report updated in July 2021.

KEY INSIGHTS

Positive Perspectives 2 results confirm the importance of a holistic approach to HIV care. Empowered PLHIV who are involved in open and active dialogue and joint decision-making with their HPCs were more likely to report undetectable viral load and, more importantly, improved aspects of their QoL than those who did not report such dialogue.

POLYPHARMACY

multiple treatments and HIV



(1,425/2,112*) of PLHIV in the study were worried about the long-term effects of HIV medicines¹



57% concerned about multiple medicines

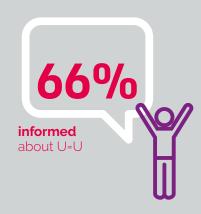
(1,195/2,112*) of PLHIV were concerned about taking more medicines as they grow older¹

OPEN & ACTIVE DIALOGUE



(1,556/2,389) of PLHIV agreed that they would like to be more involved in decisions about their HIV treatment²

UNDETECTABLE = UNTRANSMITTABLE (U=U)



Those who reported being informed of U=U by their HCPs (1,588/2,389) had more favourable health outcomes than those who reported not being informed³

KEY INSIGHTS

TREATMENT CHALLENGES



(1,056/2,389) of participants were fully satisfied with their HIV medication⁴



(1,842/2,389) believed that future advances in HIV will improve their overall health and wellbeing⁴

Improvements to HIV medicine ranked as either first or second most important were:4

'Reduced long-term impact on my body' (47%) 'Longer-lasting medicine so I don't have to take it every day' (43%) 'Fewer side effects' (41%)

'Less HIV medicine every day but just as effective' (25%)

HIV IN SPECIFIC GROUPS

Ageing well with HIV



Almost one-quarter (23%, 161/699) of PLHIV aged ≥50 years reported suboptimal health on all domains (physical/mental/sexual/overall)⁵

HIV & women:



50% (285/571) of WLHIV reported suboptimal health compared to 42% (609/1,486) of MLHIV⁶

Men who have sex with women



88% (421/479) of men who have sex with women (MSW) reported perceived barriers to discussing concerns with their HCPs, compared with 73% (506/696) of WLHIV and 59% (601/1,081) of men who have sex with men (MSM)⁷



EXPERT PANEL

ADVISORY COMMITTEE MEMBERS

The study was run by ViiV Healthcare in collaboration with an international, multi-disciplinary Advisory Committee of experts, including PLHIV, representatives from HIV support groups and HIV physicians.

The Advisory Committee was instrumental to the development of the study themes, as well as being involved in the analysis and communication of the Positive Perspectives 2 study results.



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STUDY METHODOLOGY

Positive Perspectives 2 is an international, cross-sectional study conducted in the same countries as Positive Perspectives 1 but also extended to include South Africa and countries in Latin America and the Asia Pacific region. In total, 2,389 PLHIV aged 18 – 84 from 25 countries participated in the study:



Mexico (n=63), Brazil (n=58),

Argentina (n=50), Chile (n=50)

The study was conducted between April 2019 and January 2020. Some data included in this report are based on an interim analysis carried out in September 2019 including 2,112 participants; most of this report is based on the full sample size of 2,389 participants.

The study aimed to include a diverse cross-section of PLHIV within each country sample and participants were recruited through:

- Existing panels of PLHIV
- Referrals by respondents
- Working with national charities
- → PLHIV support groups and non-governmental organisations
- (NGOs) HIV online communities
- Promoting the research via social media networks

PLHIV were eligible to join the study if they were over the age of 18, diagnosed with HIV and currently receiving ART.



POLYPHARMACY multiple treatments and HIV



POLYPHARMACY

multiple treatments and HIV

Thanks to advances in HIV treatment, the majority of PLHIV who have access to ART now live longer. This also makes the likelihood of 'polypharmacy' (defined in Positive Perspectives 2 as taking five or more pills a day or taking medicines for five or more health conditions), where multiple medications are needed to manage other health conditions (known as comorbidities), more common. Polypharmacy can increase the likelihood of decreased medication adherence and can also increase the risk of serious adverse events.⁸

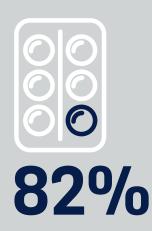
Positive Perspectives 2 evaluates the relationship between polypharmacy and overall quality of life. The findings also emphasise that, as the treatment needs of PLHIV evolve, ongoing communication between PLHIV and HCPs is critical. A proactive treatment plan that considers the totality of treatments can result in a more holistic care pathway that optimises health outcomes for PLHIV.¹



Positive Perspectives 2 data show that many PLHIV in the study reported polypharmacy or were taking other medicines in addition to their ART: Taking multiple medications shouldn't compromise QoL. Positive Perspectives 2 data show that PLHIV worry about aspects of their HIV care related to polypharmacy:



Overall prevalence of polypharmacy amongst PLHIV in the study¹ (887/2,112*)



(1,731/2,112*) of PLHIV reported taking at least one non-HIV pill daily¹



(1,425/2,112*) of PLHIV were worried about the long-term effects of HIV medicines¹



(1,195/2,112*) of PLHIV were concerned about taking more medicines as they grow older¹

After controlling for the presence of comorbidities, Positive Perspectives 2 results also show that polypharmacy is strongly associated with poorer QoL.

Even among those study participants who self-reported that their HIV was virologically-controlled, polypharmacy was associated with less favourable health outcomes and treatment satisfaction.¹

Conversely, after controlling for the presence of comorbidities, optimal overall health is almost 20% higher among those without polypharmacy - 63% (1,322/2,112*) vs 47% (984/2,112*), regardless of reported virologic control.¹

730/0
PLHIV were open to taking an HIV treatment with fewer medicines

Positive Perspectives 2 data show that 73% (1,544/2,112*) of PLHIV were willing to switch to an HIV treatment composed of fewer medicines (as long as their viral load remains suppressed)¹

The top three reasons cited for switching treatment were to reduce:1



Among those in the study who had been living with HIV ≥ 2 years (1,841), a comparison of treatment priorities at the time of initiating ART, versus at the time of the study, revealed that the three treatment priorities with the largest increase in importance over time were:



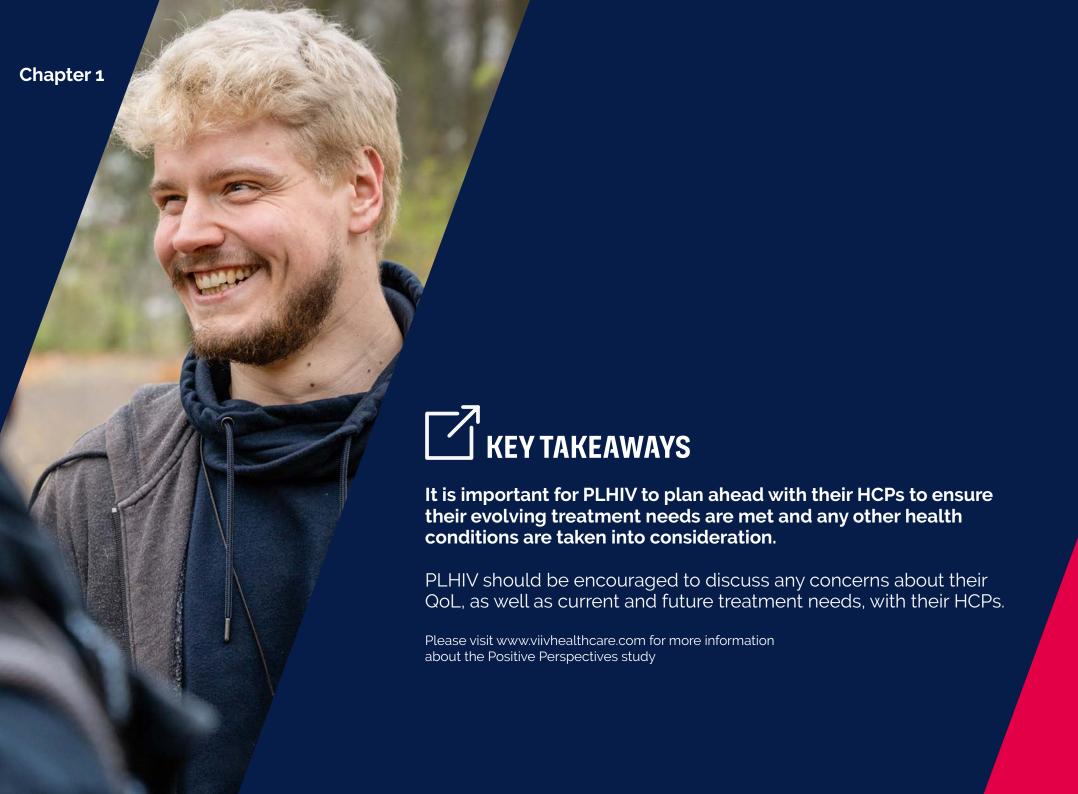
Minimizing the long-term impact of HIV treatment - 16 percentage points difference (44% vs 60%)¹



Keeping the number of medicines in the HIV treatment to a minimum - 15 percentage points difference (34% vs 49%)¹



Ensuring minimal side effects
- 12 percentage points
difference (55% vs 67%)¹





OPEN AND ACTIVE DIALOGUE

While suppressing the HIV virus is the main goal of HIV treatment, PLHIV can also work with their HCPs to aim for care that considers physical and emotional needs and also helps improve QoL.

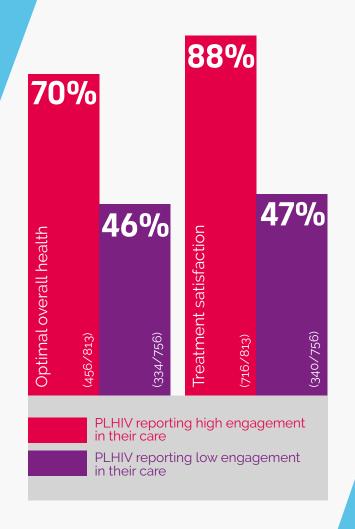
This all-encompassing approach, which also includes peer support, is known as 'holistic care'. Open and active dialogue between HCPs and PLHIV, coupled with support from peers and community organisations, can enable PLHIV to feel comfortable discussing their treatment desires and concerns as well as their lifestyles and to collaborate with their HCPs to effectively manage their HIV.^{9,10}

Data from the initial Positive Perspectives 1 survey showed that having open discussions with their HCPs helps PLHIV to feel empowered, educated and informed about their therapy choices. This is further supported by data from Positive Perspectives 2 which demonstrate that self-reported higher HCP-PLHIV engagement was associated with significantly better self-reported health outcomes and improving the quality of communication between PLHIV and HCPs may better support HRQoL.



Self-reported HCP-PLHIV engagement was associated with better self-reported:11

Significant numbers of PLHIV in the study reported not feeling comfortable discussing important HIV-related issues with their HCPs:







The top issues considered treatment priorities among those who had been living with $HIV \ge 2$ years (1,841) were:

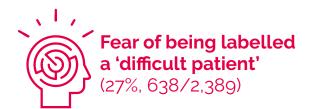
- \rightarrow concerns regarding ART side-effects (67%, 1,234/1,841)
- \rightarrow long-term impacts of HIV medicines (60%, 1,114/1,841)

Yet among those rating these issues as a priority, approximately 1/3 were uncomfortable discussing them with their HCPs (32%, [400/1,234] and 38% [426/1,114] respectively)²

The Positive Perspectives study data indicated that many participants did not report high engagement with their HCPs¹¹

(1,576/2,389) 66%

Among participants, the most reported barriers to communication with HCPs were:2

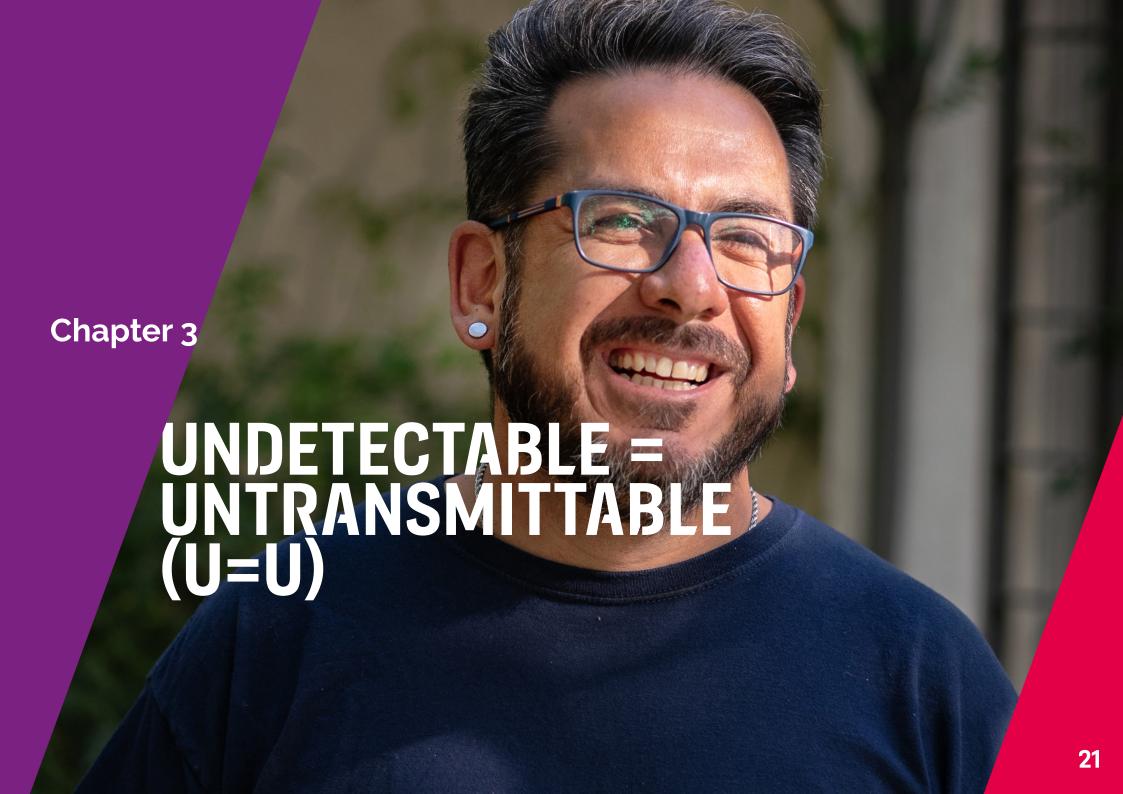






Study participants who reported low or moderate engagement with their HCPs were more likely to report **treatment dissatisfaction** and **suboptimal overall health** than those reporting high HCP engagement.²





UNDETECTABLE = UNTRANSMITTABLE (U=U)

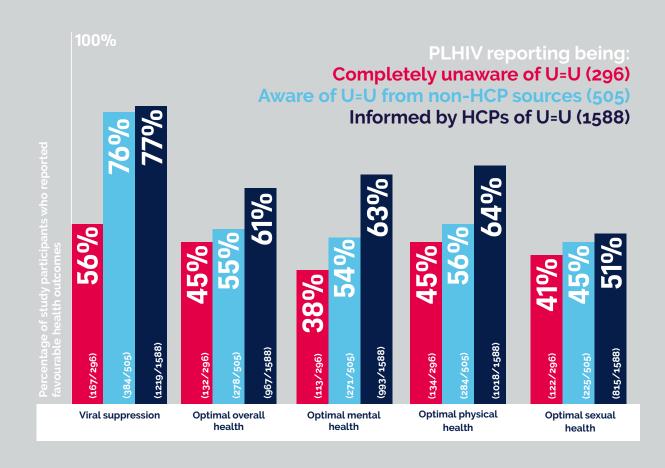
If PLHIV are on treatment and maintain undetectable levels of the virus (i.e. viral load < 200 copies/ml)¹², they cannot transmit the virus to their sexual partners. The landmark PARTNER, PARTNER 2 and Opposites Attract studies looked at over 120,000 instances of sex without a condom, where one partner was HIV positive and one was HIV negative. Results found that where the HIV positive partner was on an effective treatment – reducing the amount of the virus to 'undetectable' levels – there were zero cases of HIV transmission i.e.

Undetectable = Untransmittable. 13,14,15



HCPs now have further incentive to inform PLHIV about U=U; Positive Perspectives 2 data show a direct correlation to improved self-reported health outcomes among those reporting to have been made aware of U=U by their HCPs:

Those that reported being informed of U=U by their HCPs (66%, 1,588/2,389) reported more favourable outcomes than those who reported not being informed. Compared with those not informed of U=U, they were also significantly more likely to report:³



U=U is a powerful tool for HCPs to use, and should be included as standard-of-care in clinical guidelines.



Just over one-third (801/2,389) of PLHIV who participated in the study reported they were not told about U=U by their HCPs:3

- → 21% (505/2,389) reported they became aware from non-HCP sources
- →12% (296/2,389) reported they were completely unaware of U=U



Significant differences in levels of awareness of U=U were seen between men who have sex with men (71% aware, 718/1,018) versus men who have sex with women (58% aware, 276/479)³



(1,048/1,588) of participants informed of U=U by their HCP reported feeling comfortable discussing concerns relating to the safety of others and prevention of transmission, compared to 36% (107/296) of those completely unaware of U=U³



The results showed **stronger associations** with favourable self-reported health outcomes among people living with HIV who reported being informed of U=U by their HCP compared with those who learned from non-HCP sources or were unaware of it³



KEY TAKEAWAYS

As part of open and active dialogue between HCPs and PLHIV, an opportunity for HCPs exists to share the empowering message of U=U with all PLHIV to help improve health outcomes and QoL.³

Being informed of U=U by HCPs specifically can be beneficial to health outcomes, illustrating that U=U should be included as standard-of-care in clinical guidelines.

HCPs can actively communicate U=U to under-informed populations such as women and men who have sex with women, to ensure that all people living with HIV and their partners can benefit from knowing about U=U.

Please visit www.viivhealthcare.com for more information about the Positive Perspectives 2 study



TREATMENT CHALLENGES

Modern ART has improved the lives of millions of PLHIV who have access to treatment, with medications for the treatment of HIV continuing to progress and meet specific needs. However, data from the Positive Perspectives study indicate that many PLHIV face challenges with their ART, which they may not be raising with their HCPs.

These challenges were reported to be due to a range of factors including the physical effects of medication, psychological impacts, or fears of social repercussion. Many participants also struggled to remain adherent, which may influence disease progression, transmission and the development of drug resistance. Through delving deeper into how PLHIV feel about their treatment, the Positive Perspectives study identified the unmet needs concerning HIV treatment that exist, and the desire for innovative treatments that may ease the burden of daily ART and support QoL.



Even among study participants who were fully satisfied with their medication, three in five (61%, 639/1,056) still reported gaps in their HIV management and aspired for new treatment choices.⁴

Improvements to HIV medicine ranked as either first or second most important were:4



77% (1,842/2,389) of participants believed that future advances in HIV will improve their overall health and wellbeing⁴



Positive Perspectives results identified challenges associated with daily treatment that some PLHIV face, with many also reporting low treatment satisfaction, virologic failure and suboptimal overall health.

Treatment-related challenges included:19



Physical: 72% (745/1,041) of participants who reported experiencing side effects from their HIV medication indicated that they impact their daily life



Emotional: 58% (1,394/2,389) said that taking pills for HIV every day is a link to some bad memories from their past



Psychosocial: 58% (1,383/2,389) reported disguising/hiding their HIV medication to avoid sharing their HIV status

Study participants who reported stress or anxiety caused by daily HIV medication were over three times more likely to report a poorer outlook in relation to their HIV-related mortality compared to those who did not report this stress or anxiety.¹⁹



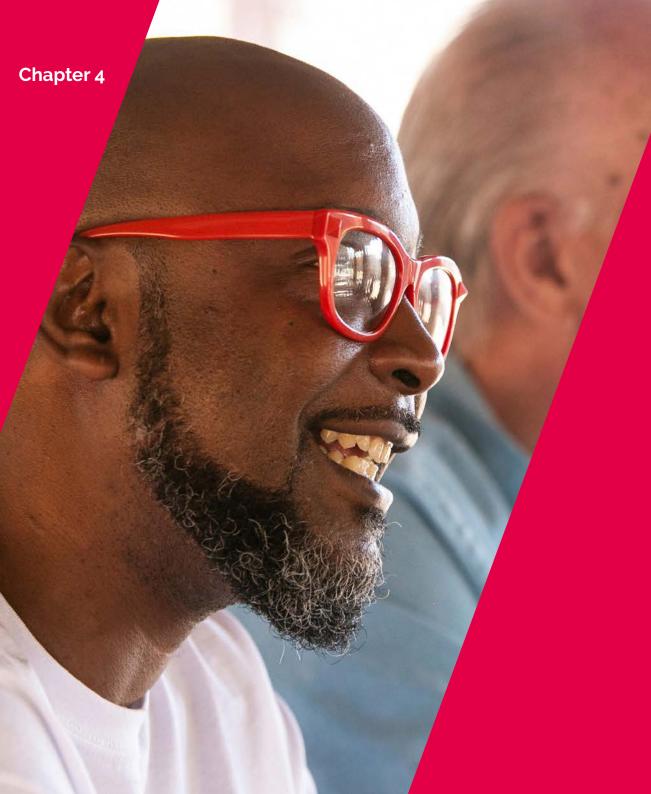
adherence.20

Nearly 1 in 4 (25%, 575/2,389) study participants reported suboptimal adherence – those that reported suboptimal adherence were less likely to report optimal self-reported health than those who reported optimal

Top reasons for missing ART ≥5 times were:20

- → Feelings of depression/being overwhelmed (7%, 176/2,389)
- → A desire to forget about having HIV (7%, 168/2,389)
- → **Work** (6%, 145/2,389)

Almost a third (29%, 639/2,389) of PLHIV of PLHIV reported missing ≥1 dose within the past 30 days because they "were not in a situation where they felt comfortable taking their pills." ¹9



KEY TAKEAWAYS

Simplified and less conspicuous treatment regimens may help PLHIV improve their adherence and benefit overall health outcomes.

HCPs can proactively discuss treatment challenges and aspirations with their patients to identify regimens that best suit their lifestyles and health goals.

Please visit www.viivhealthcare.com for more information about the Positive Perspectives study



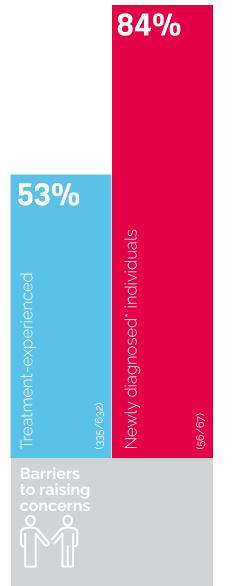
HIV IN SPECIFIC GROUPS

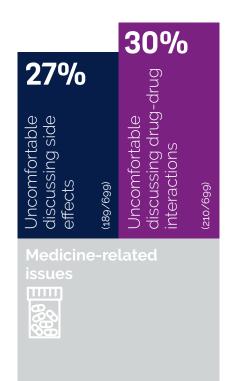
Thanks to advances in ART, people living with HIV with access to treatment can look forward to near normal life expectancies. However, to leave no one living with HIV behind, addressing the unmet needs of all groups of PLHIV, including key populations covered in this report and those who may be underrepresented or not prioritised, is crucial. Some in these underrepresented groups reported divergent unmet needs in the Positive Perspectives study, highlighting the importance of shining the spotlight on the experiences of specific groups.

The Positive Perspectives study evaluated the experiences of specific groups of participants defined by age, gender, or sexual orientation, and explore tailored solutions to better support these underserved communities.



The number of PLHIV aged ≥50 years is currently estimated to be almost 9 million and is increasing.²³ Communication issues can hinder optimisation of care, with over half of PLHIV aged ≥50 years reporting barriers to raising concerns, including medicine-related concerns, with their HCPs:²⁴





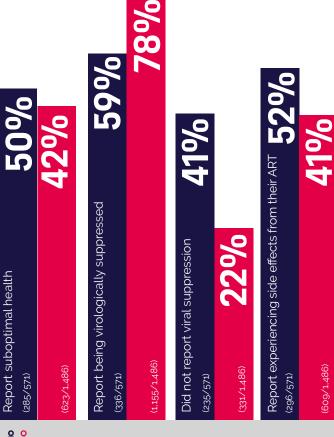
For medicine-related issues,
more than a quarter of PLHIV aged
≥50 years (27%, 189/699) self-reported
as being uncomfortable discussing
side effects of HIV medications
with their HCPs, while approximately
one-third (30%, 210/699) reported being
uncomfortable discussing concerns
about drug-drug interactions²⁴

It isn't always possible for PLHIV to make planning for the future a top priority. As the majority of PLHIV are now living longer, engaging in open dialogue with their HCPs may help address their evolving treatment needs over a lifetime.

Today, women make up more than half (52%) of all people living with HIV worldwide²⁵, and HIV and AIDS is now the leading cause of death globally for women aged 15-44.²⁶

Positive Perspectives 2 data shine a light on some of the gender-based differences in the experience of HIV care between women living with HIV (WLHIV) compared to men living with HIV (MLHIV) and emphasise some of the specific challenges faced by WLHIV.

Overall, WLHIV
in the study
reported significantly
poorer health outcomes
compared with MLHIV,
and reported less viral
suppression and more
treatment-related
side effects:6



Despite over two thirds (69%, 393/571) desiring greater involvement in their care, a significantly higher proportion of WLHIV were uncomfortable discussing treatment issues with HCPs due to:6



Positive Perspectives 2 data show that those who reported being informed of U=U by their HCPs had more favourable health outcomes, yet many WLHIV reported they were not informed:6



1 in 3 (34%, 196/571)
WLHIV reported their
HCPs had not told them
about U=U and did not
believe maintaining
effective treatment
prevents transmission⁶





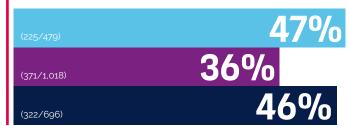
The majority of study participants (43%, 1,018/2,389) were men who have sex with men (MSM), but one-fifth (20%, 479/2,389) of the study population was made up of men who have sex with women (MSW).

While both women and MSM are at greater risk of infection from an HIV-positive male partner and face a range of associated challenges, MSW who are living with HIV also experience considerable unmet needs and face challenges with their overall health, treatment and adherence.

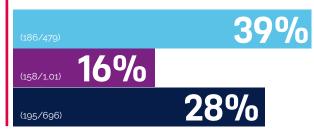
MSW who participated in the Positive Perspectives study were found to have the greatest unmet needs compared with MSM and WLHIV.

Negative health outcomes that were most prevalent in MSW in comparison with MSM and WLHIV included self-reported:7

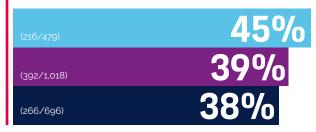
Suboptimal overall health



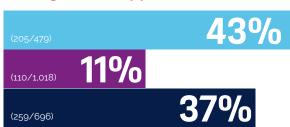
Suboptimal adherence



Polypharmacy



Virologic non-suppression



MSW MSM WLHIV

Compared with MSM and WLHIV, MSW were more likely to report perceived barriers to discussing concerns with HCPs.⁷



(n=421/479) 88% (n=601/1081) 59% (n=506/696) 73%

Compared with MSM and WLHIV, MSW also reported the highest incidence of experiencing side effects from ART:7



Among study participants who reported experiencing side effects, MSW were also more likely than MSM and WLHIV to report skipping at least one dose of ART in the past month due to side effects (56% [138/247] vs 24% [86/360] & 33% [113/341]) and feeling uncomfortable discussing these side effects with their HCP (55% [135/247] vs 34% [122/360] & 43% [147/341]).



KEY TAKEAWAYS

Significant unmet needs persist in subpopulations of PLHIV, and can differ depending on age, gender or sexual orientation.

- → As PLHIV grow older, priorities evolve, highlighting the importance of HCPs and PLHIV having ongoing open discussions to address changing needs
- → Engaging with HCPs regarding treatment, mental health, pregnancy and sexual intimacy can help WLHIV live well with HIV
- → MSW reported the greatest unmet need, so it is crucial that targeted approaches are implemented to address specific concerns and help improve health outcomes

Acknowledging these differences when planning and administering care can help narrow disparities.

Please visit www.viivhealthcare.com for more information about the Positive Perspectives study

CALLS TO ACTION

COMMUNITY-BASED ORGANISATIONS

→ Community-based organisations and peer groups can support PLHIV to build confidence to discuss their individual needs with their HCPs beyond being undetectable to help improve QoL

HCPS

- → HCPs can advocate for and implement more holistic approaches to HIV care, including measures of QoL for PLHIV
- → HCPs can continue regularly evaluating PLHIV concerns about treatment, comorbidities and polypharmacy to help alleviate anxieties and worry experienced by PLHIV
- → HCPs can continuously stress the advantages of viral suppression, including U=U
- → HCPs can place special emphasis on communicating with underserved populations such as MSW, WLHIV and PLHIV aged ≥ 50 years

PLHIV

→ PLHIV should feel empowered to play active roles in their HIV care; they should engage in open dialogue with their HCPs, discussing future plans and long-term health concerns, including polypharmacy

PUBLIC HEALTH

- → Public health officials can develop standards of care that enable HCPs to effectively measure and optimise QoL
- Associations of clinicians can advocate for and provide care beyond viral suppression, developing initiatives that maintain and optimise QoL over the long-term
- → Public health campaigns can support informing the public about U=U to help minimise stigma and discrimination



ABOUT VIIV HEALTHCARE

ViiV Healthcare is a global specialist HIV company established in November 2009 by GlaxoSmithKline (LSE: GSK) and Pfizer (NYSE: PFE) dedicated to delivering advances in treatment and care for people living with HIV and for people who are at risk of becoming infected with HIV. Shionogi joined in October 2012. The company's aim is to take a deeper and broader interest in HIV/AIDS than any company has done before and take a new approach to deliver effective and innovative medicines for HIV treatment and prevention, as well as support communities affected by HIV.

For more information on the company, its management, portfolio, pipeline and commitment, please visit www.viivhealthcare.com.

We would like to thank all those involved in the Positive Perspectives 2 study, including PLHIV, community organisations, activists and HCPs. With their support, we are working to elevate the voices of PLHIV worldwide.

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