POSITIVE PERSPECTIVES STUDY, WAVE 2 RESULTS REPORT

A view into the lives of people living with HIV

ViiV Healthcare

CONTENTS

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
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. Thanks to innovations in antiretroviral treatment (ART), HIV is now a long-term, treatable health condition and most PLHIV are living longer, healthier lives.

While there is still more work to be done to ensure universal access to ART, significant progress has been made in reaching the UNAIDS 90–90–90 targets set for 2020:

- 90% of all PLHIV will know their HIV status
- 90% of all people with diagnosed HIV infection will be in medical care and receive sustained ART
- 90% of all people receiving ART will have viral suppression

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 target that has become known as the 'fourth 90.'

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 most PLHIV now live longer, a collaborative and holistic approach to HIV care that facilitates ongoing communication between PLHIV and HCPs can help improve health outcomes and quality of life.

Garry Brough

Lead for Peer Learning, Partnerships & Policy, Positively UK; Co-Founder Bloomsbury Patients Network; Community Representative for NHIVNA, London HIV Clinical Forum and London Fast Track City Leadership Group

ABOUT THIS REPORT

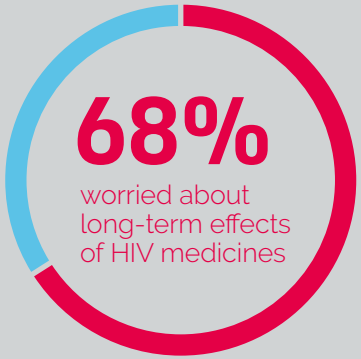
Building on the unique knowledge gained from the initial Positive Perspectives survey, Wave 1 (Positive Perspectives 1) undertaken in 2017, this report focusses on results from the Positive Perspectives study, Wave 2 (Positive Perspectives 2). It investigates how PLHIV rate their own health, how living 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.

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.

POLYPHARMACY

multiple treatments and HIV

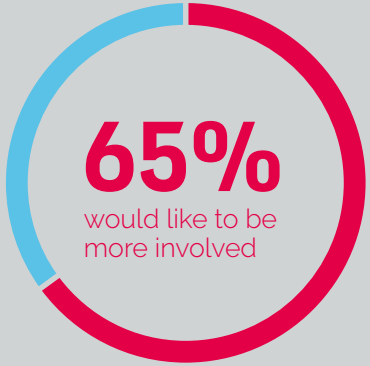


(1,425/2,112*) of PLHIV in the study were worried about the long-term effects of HIV medicines[1]

57%
concerned about
multiple medicines

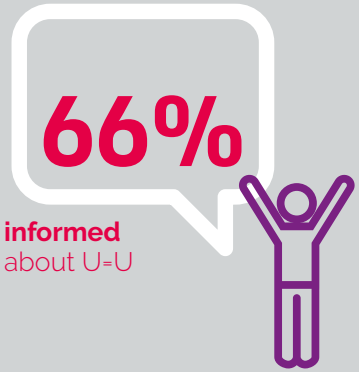
(1,195/2,112*) of PLHIV were concerned about taking more medicines as they grow older[1]

OPEN & ACTIVE DIALOGUE



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

UNDETECTABLE = UNTRANSMITTABLE (U=U)

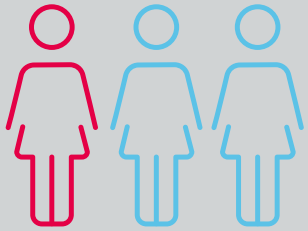


Those who reported being informed of U=U by their HCPs (1,588/2,389) had more favourable health outcomes than those who reported not being informed[3]

*Total number of participants is 2,112 as the figures were calculated before the inclusion of additional data from Russia and South Africa

KEY INSIGHTS

HIV & WOMEN



66% (375/571) of WLHIV in the study reported that their HCPs told them about U=U, **however this leaves 1 in 3 (34%, 196/571) WLHIV who reported they were not told about U=U by their HCPs**[4]

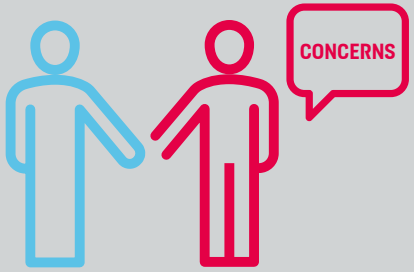
(491/571) of WLHIV reported that they believe maintaining effective treatment prevents transmission,[4] however 14% (80/571) reported that they do not believe maintaining effective treatment prevents transmission[4]

(285/571) of WLHIV were more likely to report suboptimal health compared to 42% (609/1,486) of MLHIV[4]

AGEING WELL WITH HIV

1/4

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



Barriers to raising concerns with HCPs, including medicine-related concerns, were reported by 53% (336/632) of treatment-experienced and 84% (56/67) of newly diagnosed* PLHIV aged ≥50 years[6]

*Newly diagnosed in the study was defined as PLHIV who have been diagnosed from January 2017

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:

Eurasia
Russia (n=150)

North America:
USA (n=400), Canada (n=120)

Europe:
UK (n=123), France (n=120), Germany (n=120), Italy (n=120), Spain (n=120), Portugal (n=60), Switzerland (n=55), The Netherlands (n=51), Republic of Ireland (n=50), Austria (n=50), Belgium (n=50), Poland (n=50)

Africa
South Africa (n= 179)

Asia Pacific:
Australia (n=120), Japan (n=75), Taiwan (n=55), China (n=50), South Korea (n=50)

Central and South America
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.

Chapter 1

POLYPHARMACY

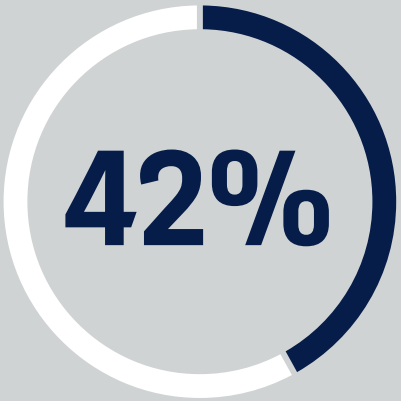
multiple treatments and HIV

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.[7]

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:



Overall prevalence of polypharmacy amongst PLHIV in the study[1] (887/2,112*)

82%

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

Taking multiple medications shouldn't compromise QoL. Positive Perspectives 2 data show that PLHIV worry about aspects of their HIV care related to polypharmacy:

68%

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

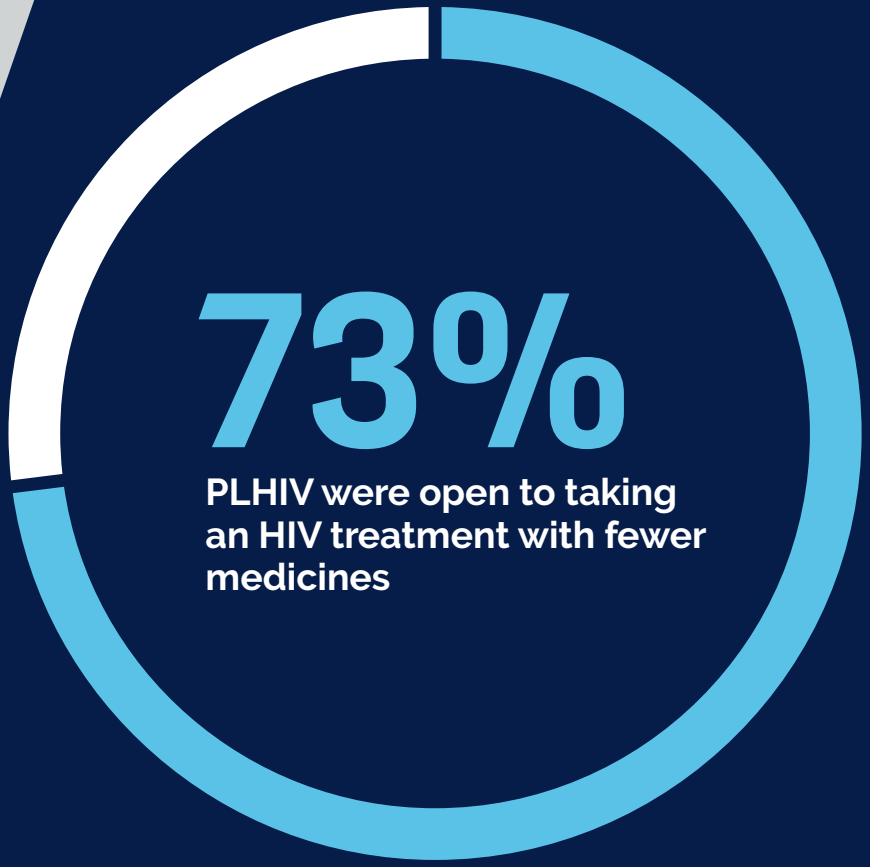
(1,195/2,112*) of PLHIV were **concerned about taking more medicines** as they grow older[1]

*Total number of participants is 2,112 as the figures were calculated before the inclusion of additional data from Russia and South Africa

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]

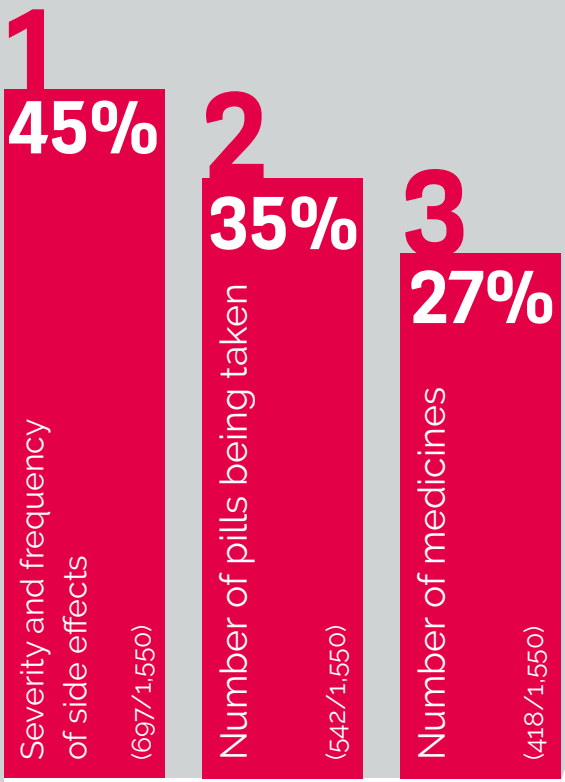
Conversely, after controlling for the presence of comorbidities, optimal overall health is almost 20% higher among those without polypharmacy - 63% (1,322/2,112*) vs 47% (984/2,112*), regardless of reported virologic control[1]



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]

*Total number of participants is 2,112 as the figures were calculated before the inclusion of additional data from Russia and South Africa

The top three reasons citied for switching treatment were to reduce:[1]



This question was answered by people in the study who had ever switched treatment (1,550)

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 (35% vs 50%)**[1]

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

*Total number of participants is 2,112 as the figures were calculated before the inclusion of additional data from Russia and South Africa

KEY TAKEAWAYS

It is important for PLHIV to plan ahead with their HCPs to ensure their evolving treatment needs are met and any other health conditions are taken into consideration.

PLHIV should be encouraged to discuss any concerns about their QoL, as well as current and future treatment needs, with their HCPs.

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

Chapter 2

OPEN AND ACTIVE DIALOGUE

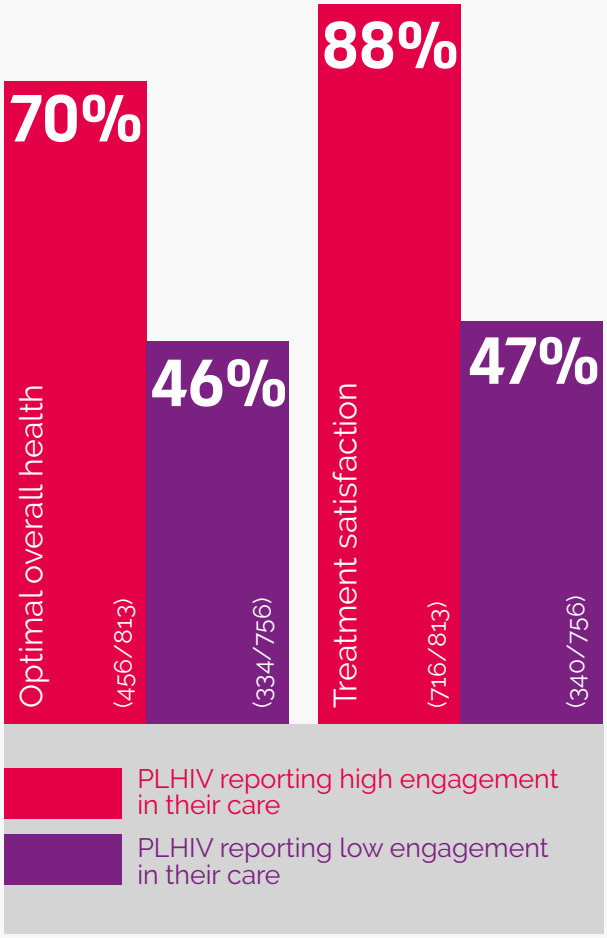
OPEN AND ACTIVE DIALOGUE

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.

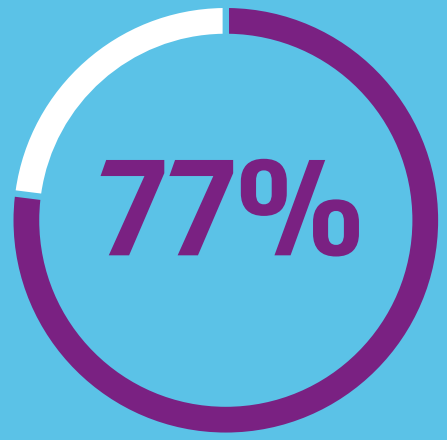
This all-encompassing approach, which also includes peer support, is known as 'holistic care'. Open and active dialogue between HCPs and PLHIV, coupled with support from peers and community organisations, enables PLHIV to feel comfortable discussing their treatment desires and concerns as well as their lifestyles and to collaborate with their HCPs to effectively manage their HIV.[8,9]

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.[8] This is further supported by data from Positive Perspectives 2 that demonstrate that HCP-PLHIV engagement was associated with significantly better health outcomes, and improving the quality of communication between PLHIV and HCPs may better support the fourth 90 goal of improving QoL.[2]

HCP-PLHIV engagement was associated with better health outcomes:[2]



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



(1,847/2,389) **reported ≥one issue they felt uncomfortable discussing** with their HCPs[2]

(1,556/2,389) **reported that they would like to be more involved in decisions** about their HIV treatment[2]

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

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

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

KEY TAKEAWAYS

PLHIV and HCPs should be encouraged to have open conversations to make sure they understand all the options available to help manage their HIV care.

Support from peers and community organisations can help PLHIV to build their confidence in talking openly to their HCPs about how to best manage their HIV care.

Attentive listening as part of active dialogue can help people feel comfortable discussing their treatment goals.

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

Chapter 3

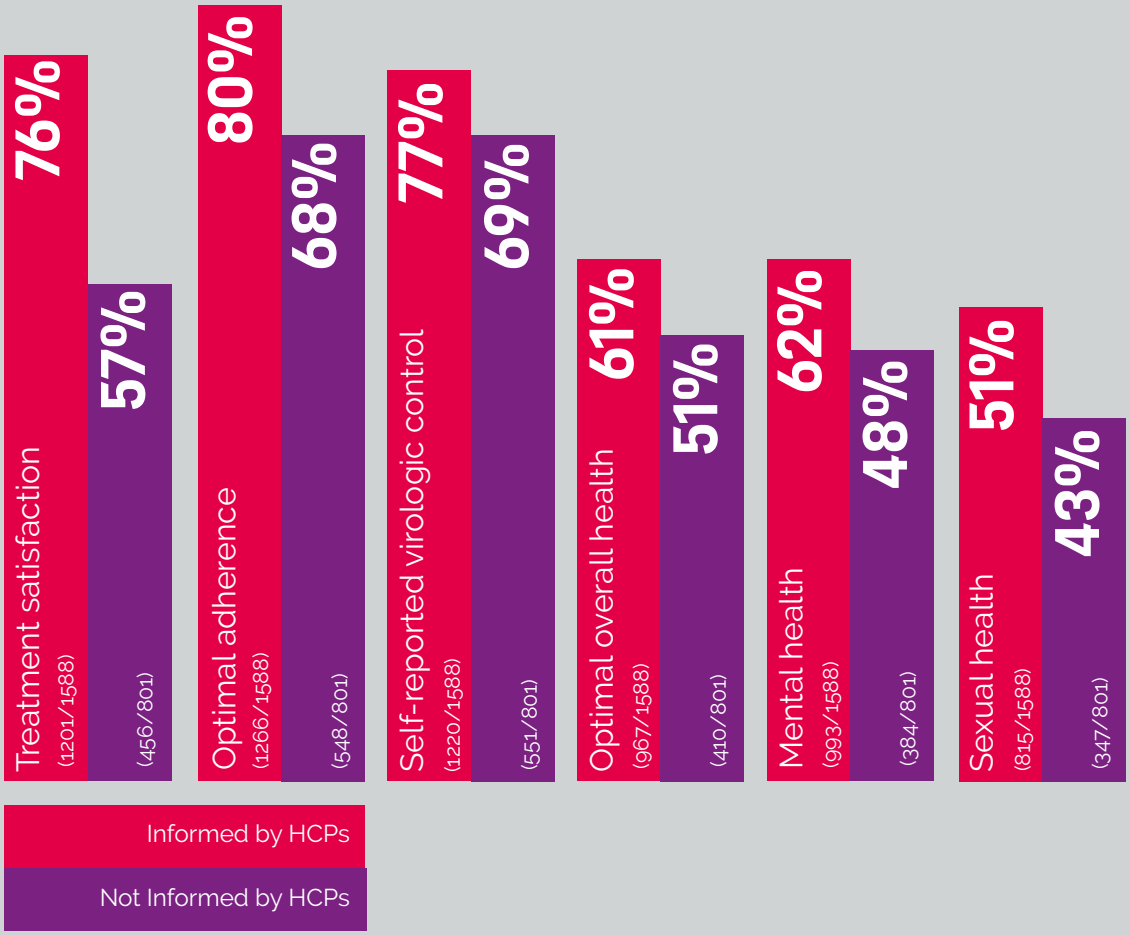
UNDETECTABLE = UNTRANSMITTABLE (U=U)

UNDETECTABLE = UNTRANSMITTABLE (U=U)

If PLHIV are on treatment and maintain undetectable levels of the virus (i.e. viral load < 200 copies/ml)[10], they cannot transmit the virus to their sexual partners. The landmark PARTNER study looked at over 58,000 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.[11]

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

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



Just over one-third (34%, 801/2,389) of PLHIV in the study reported they were not told about U=U by their HCPs, and men who have sex with women are the least likely group to report having been given this information[3]

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]

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

Chapter 4

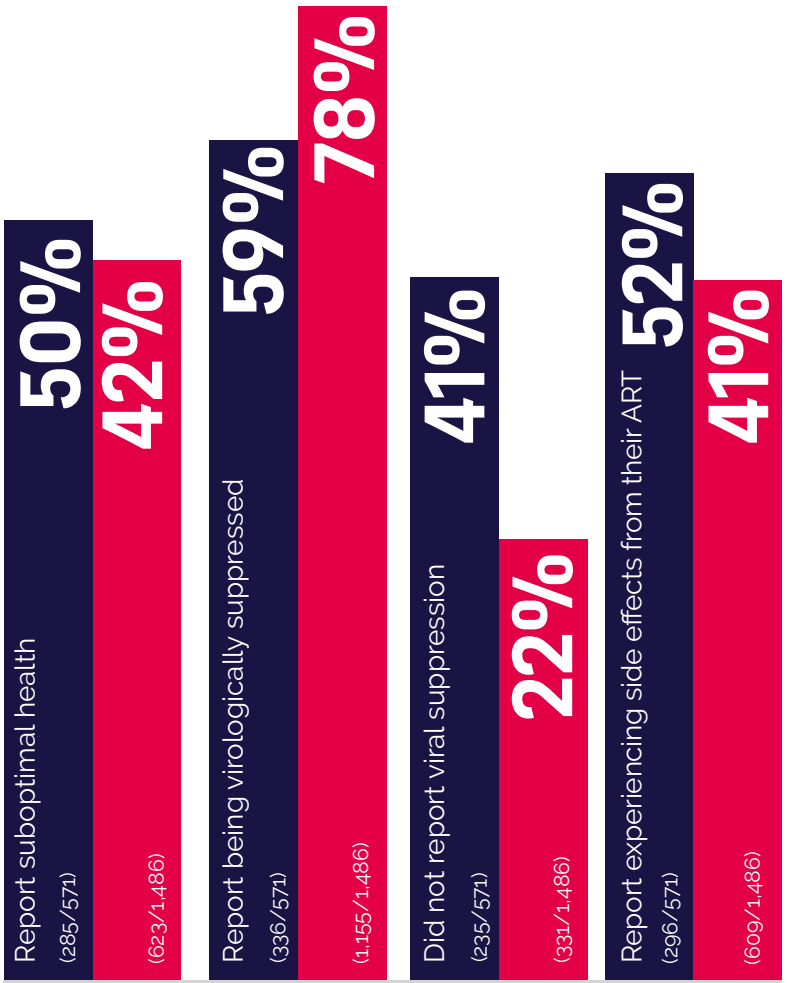
HIV AND WOMEN

HIV AND WOMEN

Today, women make up more than half (52%) of all people living with HIV worldwide,[12] and HIV and AIDS is now the leading cause of death globally for women aged 15-44.[13]

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.

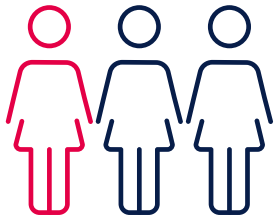
Overall, WLHIV in the study reported significantly poorer health outcomes compared with MLHIV, and reported less viral suppression and more treatment-related side effects:[4]



*Total number of participants is 2,112 as the figures were calculated before the inclusion of additional data from Russia and South Africa

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:[4]

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:[4]



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 transmission[4]

KEY TAKEAWAYS

WLHIV face different challenges to MLHIV and it is important that these are addressed to help improve health outcomes.

Open discussions with HCPs regarding treatment, mental health, pregnancy and sexual intimacy can help WLHIV to feel empowered and get the answers they need to help them live well with HIV.

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

Chapter 5

AGEING WELL WITH HIV

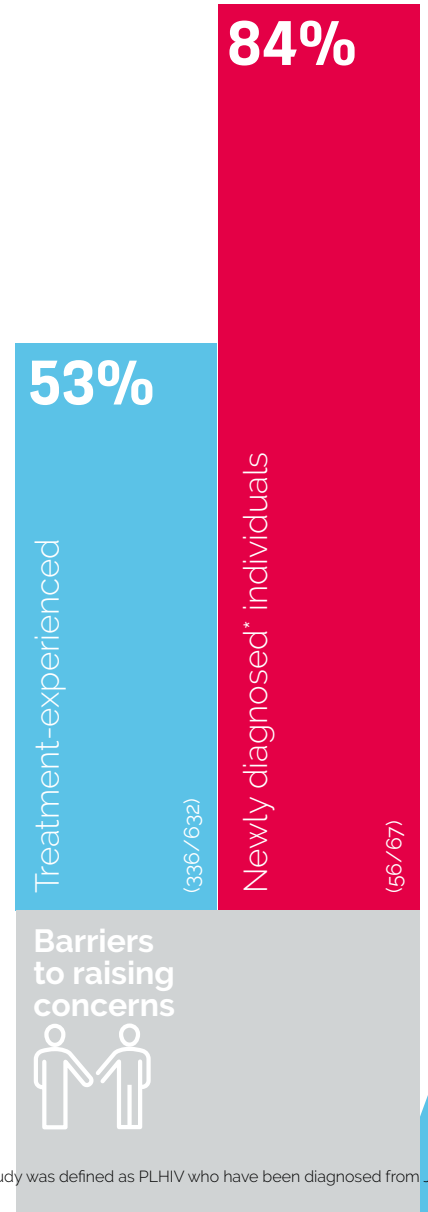
AGEING WELL WITH HIV

The number of PLHIV aged ≥50 years is currently estimated to be almost 9 million and is increasing.[14]

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, it is important they are engaged in open dialogue with their HCPs to help address their evolving treatment needs over a lifetime and to understand how identifying and planning for these with their HCPs can improve health outcomes. This is particularly important as PLHIV are often more vulnerable to age-related health conditions such as cardiovascular disease, type 2 diabetes, kidney disease, liver disease, osteoporosis and several cancers as they age, compared to those not living with HIV.[15]

In the study almost one-quarter (23%, 161/699) of PLHIV aged ≥50 years reported suboptimal health on all domains (physical/mental/sexual/overall). Groups most at risk were those reporting two or more comorbidities, poor adherence, treatment dissatisfaction or gastrointestinal side effects from ART.[5]

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:[6]



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 interactions[6]

*Newly diagnosed in the study was defined as PLHIV who have been diagnosed from January 2017

KEY TAKEAWAYS

The priorities of PLHIV evolve as they grow older, highlighting the importance of HCPs and PLHIV having ongoing open discussions to address changing needs.

Addressing treatment concerns, such as the effects of other medicines, can help improve QoL and help PLHIV be prepared for healthy ageing with HIV.

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

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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The artistic photography used in this report features people living with HIV

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