



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.



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ABOUT THIS REPORT

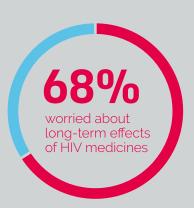
Building on the unique knowledge gained from the initial Positive Perspectives survey, Wave 1 (Positive Perspectives 1) undertaken in 2017, this report focusses on results from the Positive Perspectives study, Wave 2 (Positive Perspectives 2). It investigates how PLHIV rate their own health, how living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

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 medicines¹



57% concerned about multiple medicines

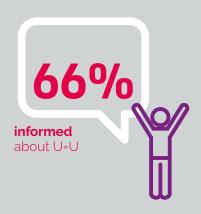
(1,195/2,112*) of PLHIV were concerned about taking more medicines as they grow older¹

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

HIV & WOMEN



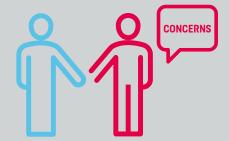
66% (375/571) of WLHIV in the study reported that their HCPs told them about U=U, however this leaves 1 in 3 (34%, 196/571) WLHIV who reported they were not told about U=U by their HCPs⁴

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



(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 transmission⁴



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 years⁶



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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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)

Existing panels of PLHIV

size of 2,389 participants.

were recruited through:

- 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

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: 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 satisfaction¹

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 control¹

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 citied for switching treatment were to reduce:

Severity and frequency of side effects

(697/1.550)

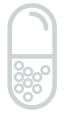
Number of pills being taken (542/1.550)

Number of medicines (542/1.550)

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:



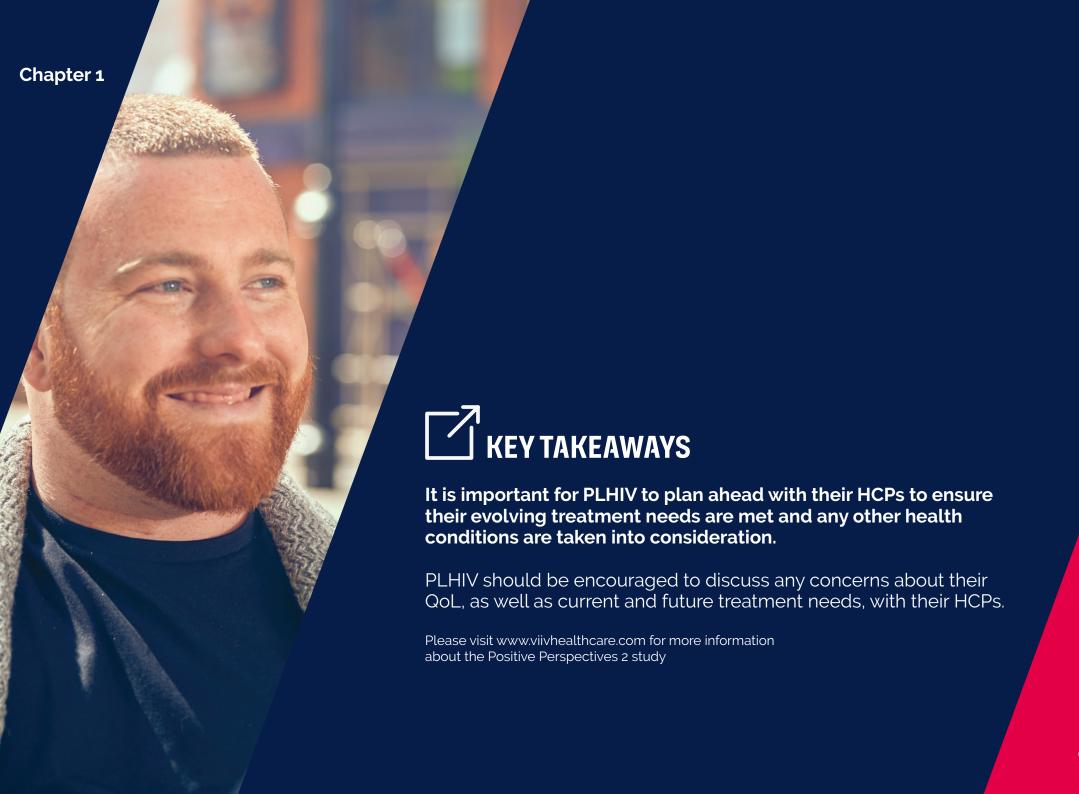
Minimizing the long-term impact of HIV treatment - 16 percentage points difference (44% vs 60%)¹



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





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.

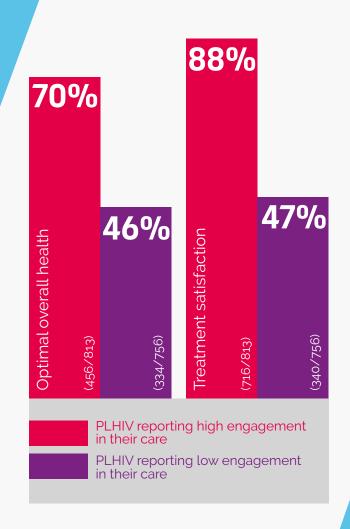
This all-encompassing approach, which also includes peer support, is known as 'holistic care'. Open and active dialogue between HCPs and PLHIV, coupled with support from peers and community organisations, enables PLHIV to feel comfortable discussing their treatment desires and concerns as well as their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

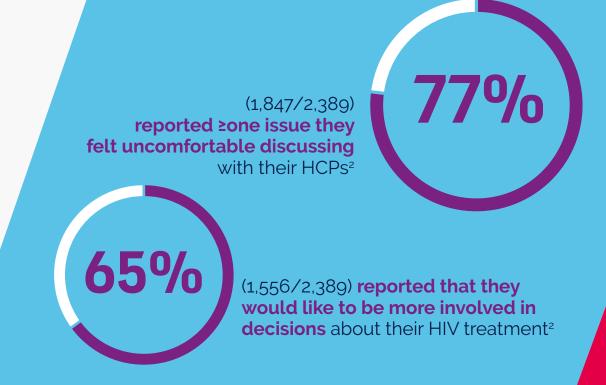
Data from the initial Positive Perspectives 1 survey showed that having open discussions with their HCPs helps PLHIV to feel empowered, educated and informed about their therapy choices.⁸ This is further supported by data from Positive Perspectives 2 that demonstrate that HCP-PLHIV engagement was associated 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:





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)

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





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



Not Informed by HCPs



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 information³





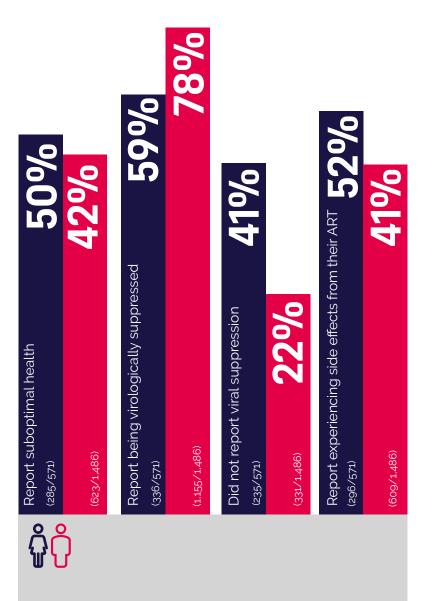
HIV AND WOMEN

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



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 transmission⁴



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

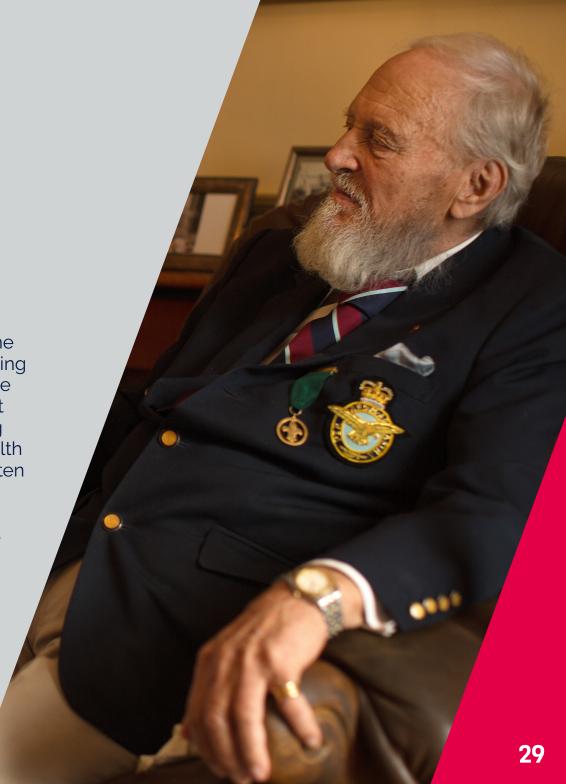


AGEING WELL WITH HIV

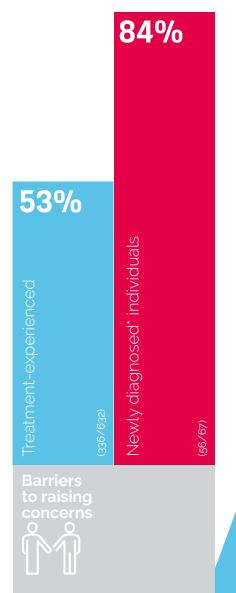
The number of PLHIV aged ≥50 years is currently estimated to be almost 9 million and is increasing.¹⁴

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

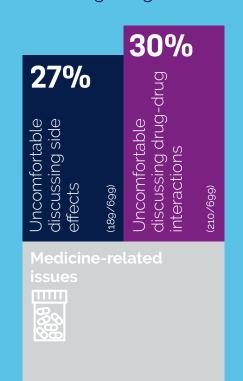
In the study almost one-quarter (23%, 161/699) of PLHIV aged ≥50 years reported suboptimal health on all domains (physical/mental/sexual/overall). Groups most at risk were those reporting two or more comorbidities, poor adherence, treatment dissatisfaction or gastrointestinal side effects from ART.⁵



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 interactions⁶



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.

REFERENCES

- 1. Okoli C, de los Rios P, Eremin A, Brough G, Young B, Short D. Relationship Between Polypharmacy and Quality of Life Among People in 24 Countries Living With HIV. Prev Chronic Dis 2020;17:190359. DOI: http://dx.doi.org/10.5888/pcd17.190359
- 2. Okoli C, Brough G, Allan B, Castellanos E, Young B, Eremin A, Corbelli GM, Mc Britton M, Muchenje M, Van de Velde N, de los Rios P. Putting the heart back into HAART: greater HCP-patient engagement is associated with better health outcomes among persons living with HIV (PLHIV) on treatment; Poster PED 0808 Presented at the 23rd International AIDS Conference, July 6–10, 2020.
- 3. Okoli C, Richman B, Allan B, Brough G, Castellanos E, Young B, Eremin A, Corbelli GM, McBritton M, Hardy D, Muchenje M, Van de Velde N, de los Rios P. A tale of two 'U's and their use by healthcare providers: a cross country analysis of information sharing about undetectable = untransmittable (U=U); Poster PED 0773 Presented at the 23rd International AIDS Conference, July 6–10, 2020.
- **4.** Okoli C, de los Rios P, Muchenje M, Young B. Treatment experiences, perceptions towards sexual intimacy and child-bearing, and empowered decision making in care among women living with HIV; Positive Perspectives; Presented at the 10th International Workshop on HIV & Women, Boston, MA, March 6–7, 2020.
- 5. Short D, Spinelli F, Okoli C, de los Rios P. Clinical and sociodemographic characteristics associated with poor self-rated health across multiple domains among older adults living with HIV; Oral OAD 0903 Presented at the 23rd International AIDS Conference, July 6–10, 2020.
- **6.** Short D, Spinelli F, Okoli C, de los Rios P. Understanding the changing treatment concerns of older people living with HIV and difficulties with patient-provider communication; Poster PED 0787 Presented at the 23rd International AIDS Conference, July 6–10, 2020.
- **7.** Edelman EJ, Gordon KS, Glover J, McNicholl IR, Fiellin DA, Justice AC. The next therapeutic challenge in HIV: polypharmacy. Drugs & Aging 2013;30(8):613–28.https://link.springer.com/article/10.1007/s40266-013-0093-9
- **8.** ViiV Healthcare. Data on File Positive Perspectives Survey 2017. www.viivhealthcare.com/en-gb/hiv-treatment-and-care/the-positive-perspectives-survey/
- 9. Chen, W. et al. Engagement with Health Care Providers Affects Self- Efficacy, Self-Esteem, Medication Adherence and Quality of Life in People Living with HIV. Journal of AIDS & Clinical Research 2013, 04(11).
- **10.** NAM AIDSMAP. What does undetectable = untransmittable (U=U) mean? www.aidsmap.com/about-hiv/what-does-undetectable-untransmittable-uu-mean
- **11.** Rodger AJ, Cambiano V, Bruun T et al. Sexual Activity Without Condoms and Risk of HIV Transmission in Serodifferent Couples When the HIV-Positive Partner Is Using Suppressive Antiretroviral Therapy. JAMA 2016, 316(2)
- **12.** UNAIDS. Core Epidemiology Slides. Available at: https://www.unaids.org/sites/default/files/media_asset/UNAIDS_2017_core-epidemiology-slides_en.pdf . Last accessed June 2020.
- 13. Global health estimates 2016: deaths by cause, age, sex, by country and by region, 2000–2016. Geneva: World Health Organization; 2018. https://www.who.int/healthinfo/global_burden_disease/estimates/en/index1.html Last accessed June 2020.
- **14.** UNAIDS. Get on the fast-track, the life-cycle approach to HIV 2016. www.unaids.org/sites/default/files/media_asset/Get-on-the-Fast-Track_en.pdf
- **15.** Burki T. People ageing with HIV face an uncertain future. The Lancet HIV. Feature, Volume 6, PE816-E817, December 01, 2019. DOI: https://doi.org/10.1016/S2352-3018(19)30381-9.

