

GLOBAL POLICY BRIEFING

LIVING WELL WITH HIV: IMPROVING HEALTH-RELATED QUALITY OF LIFE OUTCOMES

Summary

There have been significant advances in HIV treatment and care which means that, with early diagnosis and stable treatment, people living with HIV (PLHIV) can expect to achieve viral load suppression^a and attain life expectancy comparable to the wider general population.^{1,2} With appropriate treatment and care, HIV is now a manageable chronic disease. Therefore, it is increasingly important to assess and support the health-related quality of life (HRQoL) for PLHIV, including long-term physical, psychological and social health needs.³ HRQoL represents an important public health priority which supports health promotion and resilience.⁴ For society-at-large, enhancing HRQoL has the potential to improve the lives, livelihoods and living standards of PLHIV, which can support economic productivity and performance as well as reduce social exclusion.¹ Securing affordable access to good quality health services (universal health coverage) is critical to improving HIV health outcomes, wellbeing and enhancing HRQoL.⁵ These factors are key to ending AIDS by 2030 and securing UNAIDS 90-90-90 testing, treatment and viral suppression targets^b (progressing to 95-95-95 targets by 2030).¹

Ensuring HRQoL for PLHIV requires coordinated and integrated care and support that directly responds to unmet health needs and lived experiences.⁶ To this end, ViiV Healthcare is advocating for, and committed to, the following policy principles:

	<p>ViiV Healthcare supports a holistic, person-centred approach to addressing HRQoL outcomes through its commitment to researching and delivering innovative HIV medicines. This enables PLHIV to expect and demand greater innovation in treatment and care with the aim of achieving long, healthy and productive lives. Our innovative medicines seek to keep viral loads undetectable, minimise side effects, and support general wellbeing for PLHIV. Beyond the biomedical needs related to suppressing the virus, we also prioritise psychosocial requirements to support drug adherence, non-HIV-related physical and psychological health conditions and overall wellbeing. This also includes freedom from stigma and discrimination.</p>
	<p>ViiV Healthcare is committed to developing and strengthening partnerships to better understand, measure and address a wide range of issues to improve HRQoL for PLHIV. We collaborate to promote evidence-based indicators to assess HIV care which is informed by, and tackles, the real-life experiences of those living with and affected by HIV.</p>
	<p>ViiV Healthcare promotes the inclusion of a 'fourth go' - a living well goal - in the UNAIDS 90-90-90 targets. This urges global health advisors, policy leaders and decision-makers, as well as HIV service providers, to work towards achieving a more comprehensive indicator for health-related quality of life, and to ensure that health systems become more integrated and people-centred to support PLHIV to live well^{7,8}; which has the potential to provide social and economic benefits for wider society. Essentially, viral load suppression merely represents one of several important aspects of living well with HIV.</p>

The challenge

Holistic and person-centred management of HIV as a life-long condition

Significant advances in HIV treatment and care have redefined the challenge of managing HIV as a lifelong condition, and particularly the need to improve its management as a chronic disease alongside co-infections, social issues, and co-morbidities (both HIV and non-HIV related). These include challenges relating to:

- Ensuring HRQoL is routinely assessed and appropriate action is taken for all PLHIV.
- Treatment adherence and tolerability, particularly in PLHIV taking multiple drugs to address comorbidities including increased drug burden (and interaction) due to treatment of age-related comorbidities; health conditions including

^a Viral load suppression to undetectable and untransmittable levels

^b The UN's 90-90-90 Targets seek to achieve (by end of 2020): 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy will have viral suppression.

depression, anxiety, and substance use; the onset of chronic diseases such as diabetes, cancer and cardiac-related conditions; and, opportunistic infections including TB and pneumonia.

- Evolving psychosocial, physical and social care needs to eliminate social- and self-exclusion of PLHIV, including stigma and discrimination.⁹

Healthcare professionals are critical in this process, as having open discussions with clinicians helps PLHIV become more proactively engaged in therapy choices, which leads to better adherence and improved health outcomes.¹⁰

Researching and delivering innovative HIV medicines to improve HRQoL

ViiV Healthcare seeks to drive breakthroughs in HIV science which support a holistic and person-centred approach to managing HIV. Our innovative treatments aim to improve HRQoL by addressing concerns associated with life-long adherence, to minimise side-effects and the inconvenience generated by complex daily regimens. Our research and delivery of innovative HIV medicines seeks to treat PLHIV living with co-morbidities¹¹, co-infections¹² and non-HIV related health issues.

Supporting HRQoL with innovative HIV medicines

ViiV Healthcare has pioneered the development of several new medicines and combination treatments for PLHIV. This includes antiretroviral medicines for naïve, switch (changing medication) and highly treatment experienced populations.^{13,14} Our clinical research collaborations also seek to support a broad spectrum of PLHIV. This includes under-represented and under-served population groups which include women, children and those aged over 50. We continue to innovate with the aim of making improvements in areas such as tolerability and safety; reducing the risks of drug resistance and drug interactions. We also seek to improve dosing schedules and convenience by exploring the development of novel dosing schedules including investigational long acting injectable formulations, implantables and self-administration options.¹⁵ In addition, ViiV Healthcare is committed to developing age-appropriate formulations of our medicines for children.¹⁶

Building global partnerships to improve HRQoL for PLHIV

Evidence indicates that PLHIV have significantly lower HRQoL outcomes compared to the wider general population, even once viral suppression and immunological stability have been achieved.¹⁷ It is vital to first understand how and why HRQoL is affected. Subsequently, it is important to inform decision makers and service providers about how they can best support more appropriate interventions to improve HIV health outcomes.

HRQoL outcomes have many dimensions and are driven by a range of interconnected factors, including depression and other non-communicable diseases, clinical needs, financial and livelihood anxiety as well as experiences and concerns about HIV-related discrimination.^{7,8} Improving access to the health, social, economic and community services that address these wellbeing drivers are vital for PLHIV to live full, active and productive lives. Furthermore, an emphasis on broader wellbeing is instrumental to ensuring PLHIV are motivated to remain on treatment and stay in care. This is an integral part of HIV prevention and ending the AIDS epidemic by 2030.¹⁸

The power of partnership in Europe to address HRQoL outcomes¹⁹

ViiV Healthcare and Gilead Sciences have jointly sponsored HIV Outcomes, a Europe-wide multi-stakeholder initiative bringing together associations and alliances of PLHIV, clinicians, wider healthcare professionals and academics. The initiative seeks to support change that responds to the specific needs and preferences of PLHIV at a country level. This includes supporting better integration and coordination across areas such as mental health, psychosocial service delivery as well as sexual and reproductive health. HIV Outcomes has supported a series of published articles in the 'The Lancet' focused on long term care and wellbeing of PLHIV.²⁰ It has developed recommendations endorsed by the European Commission and undertakes regular engagement with Members of the European Parliament (MEPs). In addition, the initiative has developed informal advocacy platforms in Italy and Sweden. Future ambitions include a focus on implementing its recommendations in Germany, Spain and Romania, as well as contributing to leading multilateral organisation's strategic responses to HIV.

Working with PLHIV, listening, learning and leading to address HRQoL

ViiV Healthcare's Positive Perspectives study (PP2) surveyed 2389 PLHIV across 25 countries. The study is one of the largest of its kind, having developed from an earlier study (PP1), with the objective of understanding the unmet needs and challenges experienced by PLHIV. The study was informed and developed by an international advisory committee of advocacy and medical experts including people living with HIV^{21,22}. The study findings highlight the importance of a holistic approach to care by engaging people living with HIV in open dialogue and joint decision-making with their healthcare providers (HCPs). Just under 75% of those surveyed expressed a willingness to switch to an antiretroviral regimen requiring fewer drugs and less frequent dosages, if viral load suppression could be maintained. Furthermore, the study also provided a greater understanding about the challenges experienced by PLHIV who take multiple drugs, to address various co-morbidities. Another key finding included those who reported active patient-clinician engagement also reported improved HRQoL. These populations had a greater awareness of the 'Undetectable equals Untransmittable' (U=U) ^c public health message. ViiV Healthcare is working with HIV community networks and groups to leverage some of the outcomes generated by PP2 with other evidence to advocate for improvements in services. This reflects the vital role that HRQoL plays in improving the lives of PLHIV to end the AIDS epidemic^{23,24}.

Living well with HIV: the 'fourth 90' - beyond viral load suppression

HRQoL for PLHIV is impacted by far more than just achieving viral suppression. Recent data produced by the UN reported that there are 37.9 million PLHIV globally, and progress towards the UNAIDS 90-90-90 targets was: 79% of PLHIV knew their status, of those, 78% were accessing ART and of those, 86% had suppressed viral loads.²⁵

Despite this significant progress towards the targets, there is growing recognition that wellbeing should become an integral component of the full HIV care continuum.^{18,19} To address this, national HIV policies need to expand the 90-90-90 targets and support inclusive approaches to HIV care that consider diverse factors affecting the overall wellbeing of PLHIV. It is vital that the 'fourth 90' applies to all PLHIV regardless of whether they are on ART and linked to care or have achieved viral suppression. For this reason, the 'fourth 90' should represent an overarching priority, cutting across the existing 90-90-90 targets.²⁶

Furthermore, we are committed to investing in tools to measure and improve the effectiveness of healthcare interventions to better understand the lived experience of PLHIV. These HRQoL indicators support implementing better evidence-informed policy that directly addresses PLHIV's unmet needs; to make progress to achieve the 'fourth 90' on wellbeing.

A person-centred approach to developing HRQoL indicators

Patient-reported outcome measures (PROMs) provide a way for PLHIV to directly share their experiences to improve the quality of HIV care.²⁷ This approach offers an informed and reliable way to assess HRQoL outcomes and in turn, to support better-integrated HIV management. PROMs have demonstrated significant improvements in identifying and managing factors that affect HRQoL.²⁸

Australia and the PozQoL scale: collaborating to improve HRQoL assessments for PLHIV

ViiV Healthcare, in collaboration with a consortium of partners^d, developed a scale to measure HRQoL for PLHIV. The PozQoL tool aims to support the HIV community and healthcare service providers to better evaluate the impact of health interventions for PLHIV, particularly during patient consultations with healthcare professionals.¹⁸ PozQoL focuses on four main areas: psychological (mood, aspirations and sense of self-worth etc.); social (personal life, sense of belonging and social support structures, etc.); health-related; and functional domains (including independence and standard of living). Recommendations generated from the initial PozQoL study have led to implementation and field-testing across a wider range of community and healthcare programmes beyond Australia.²⁹ It has been translated into up to 13 languages and a web-based dissemination plan has been developed. Furthermore, PozQoL also aims to improve programme monitoring and evaluation. This has the potential to inform policy development and implementation that better supports PLHIV. Encouragingly, the Australian National Surveillance system has incorporated the PozQoL indicator as part of its own national HIV strategy monitoring process.³⁰

ViiV Healthcare global policy briefings series: *Making HIV a smaller part of people's lives*

^c Underpinned by robust science, U=U states that maintaining undetectable viral loads through stable treatment adherence means that HIV cannot be sexually transmitted.

^d The Australian Research Centre in Sex, Health and Society (ARCSHS), the National Association of People with HIV Australia (NAPWAHA), Living Positive Victoria, Positive Life NSW and Queensland Positive People.

ViiV Healthcare has developed a series of global policy briefings which outline our commitments through diverse partnerships to tackle key global public health priorities affecting the global, regional, national and community HIV response. We aim to inform public policy and healthcare delivery to ensure no person living with HIV is left behind, by supporting communities affected by HIV.

About ViiV Healthcare

Established in November 2009, we are the only pharmaceutical company solely focused on combating, preventing and ultimately curing HIV & AIDS. ViiV Healthcare is dedicated to researching and delivering innovative HIV medicines and solutions which make HIV a smaller part of people's lives.

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