



OPTIMISING QUALITY OF LIFE FOR ALL PEOPLE LIVING WITH HIV:

Recognising the 4th 90

Findings from the Positive Perspectives 2 study
and policy recommendations for a new era of HIV care

Sponsored by ViiV Healthcare

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ashm



Canada's source for
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information



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

Executive summary

Many people living with HIV can now look forward to near-normal life expectancy, thanks to significant advances in timely diagnosis, antiretroviral treatment and holistic HIV management and care. However, the HIV epidemic is far from being over and many aspects of it have changed.

New challenges have arisen as many people living with HIV live longer and require life-long specialist care for a range of comorbidities (the presence of other health conditions alongside HIV) including gerontological related care as well as primary medical care. People living with HIV have a risk of some/certain chronic health challenges and comorbidities, while many also face stigma and discrimination in health systems, social services and in their public and private lives. Improving and sustaining quality of life influences not only individual wellbeing, but also contributes to global acceptance of the new reality of living well with HIV. Incorporating the views of people living with HIV is essential to developing policies, services and changing attitudes that both meet their needs and reflect this new reality. Positive Perspectives 2¹ is a cross-sectional, international study of 2,389 people living with HIV from 25 countries² currently receiving antiretroviral therapy.

The study highlights a range of challenges that affect the quality of life of people living with HIV.

This policy paper was developed by an international Advisory Committee of advocacy, community and medical experts, including people living with HIV. The Advisory Committee reflected upon the insights gained from this study by applying their understanding and appreciation of the lived experiences of people with HIV, intimate knowledge of the challenges and barriers that continue to impede the lives of people around the globe, and knowledge from evidence-based publications.

This document outlines some of the challenges highlighted in the Positive Perspectives study and which the study team and Advisory Committee consider to be of significant global importance. These challenges reflect the need for a '4th 90' target ensuring that people living with HIV have a quality of life that goes beyond the continuum of treatment paradigm. This builds on the UNAIDS 90-90-90 targets³, which have been instrumental in advancing the current success of HIV care and continue to be the global standard to work to achieve.



However, once reached, viral suppression is simply not enough. There was a time when HIV care focused solely on achieving an undetectable viral load. We must now strive to ensure a quality of life where people living with HIV thrive. To improve wellbeing and quality of life, more holistic models of care will be needed, in order to address the wider psychological, physical and social needs of people living with HIV.

Achieving the 4th 90 should be measured qualitatively, rather than quantitatively, making it much more challenging to measure. This document sets out to consider and propose a policy environment in which the importance of individualisation and fostering patient empowerment is recognised.

Further, we propose a series of policy recommendations designed to improve the quality of life of people living with HIV to be used by policy influencers to advocate for actions that drive improvements in quality of life.

We encourage you to consider how to adapt these recommendations to reflect local context; how they can be used as a reference guide for those shaping policy, strategy and clinical guidelines; and how you can use the findings from this study and recommendations from this policy paper to identify the best practices to address the unmet needs and challenges among people living with HIV.

Quality of life and health outcomes

- Communicating U=U
- Update Action Plans
- Enhanced monitoring
- Holistic approach

Communication, information and shared decision-making

- Patient dialogue
- Public engagement
- Targeted information
- Evidence-informed decision-making

Stigma, discrimination and psychosocial issues

- Health literacy
- Legislative change
- Support networks

Ageing with HIV and treatment over a lifetime

- Life-long care and policy integration
- Develop the evidence base
- Optimise treatment



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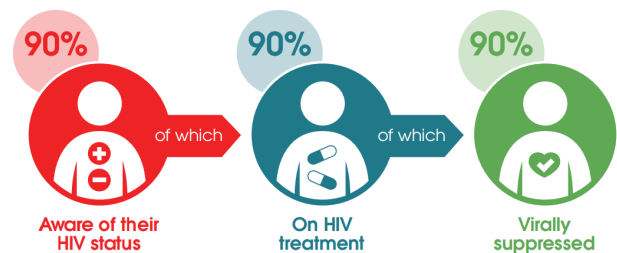
Introduction

The Changing HIV Epidemic

Life expectancy and quality of life for many people living with HIV has increased and improved since the advent of highly active antiretroviral therapy.⁴ Many people living with HIV can have near-normal life expectancy, thanks to advances in diagnosis and treatment. However, far too many people living with HIV are not aware of their status or do not have access to treatment or consistent and high-quality clinical care. For these people living with HIV, an increase in life expectancy and quality of life has yet to be realised.

Current antiretroviral therapy reduces the amount of HIV in the blood (often referred to as someone's 'viral load' – a numerical expression of the quantity of HIV virus in a sample of blood) to a level so low that routine laboratory tests cannot detect it (a reference point commonly referred to as 'undetectable'). This means that HIV cannot be sexually transmitted (Undetectable = Untransmittable). While some countries have made great progress towards the UNAIDS 90-90-90 targets to improve diagnosis, continuous access and adherence to therapy, and viral load suppression by 2020⁵, others still have work to do if they are to reach these goals.

FIGURE 1
The UNAIDS 90-90-90 targets



However, as many people living with HIV live longer, comorbidities (the presence of other health conditions alongside HIV) emerge. A higher prevalence of comorbidities has been demonstrated in people living with HIV compared to those living without HIV⁶. Disease burden, measured by the presence of multiple comorbid conditions, has also been found to be higher in the HIV population⁷. Some conflating conditions or attributes are age-, medication- or risk factor-related while others result from persistent inflammation attributed to HIV itself despite the efficacy of antiretroviral therapy. At a population level, people living with HIV have higher rates of bone disease, some cancers, cardiovascular disease and kidney problems, along with a significant burden of mental health issues⁸.

Mental health conditions left undiagnosed, untreated or poorly managed can degrade overall health, quality of life and, in some cases, the ability to take antiretroviral therapy exactly as directed. Research comparing rates of mental health conditions (also called major mood disorders) between HIV-positive and HIV-negative people found that, overall, rates of diagnosed mental

health conditions were twice as high among HIV-positive people⁹. It also found that HIV-positive people who had milder forms of mental health conditions and/or substance use were likely to subsequently develop more serious mental health problems.

Long-term treatment with antiretroviral therapy can also lead to comorbidities for people living with HIV and increased toxicities as a result of exposure to some antiretroviral therapies over time¹⁰. Finally, there are lifestyle and social factors that exist in every country which intersect and can affect an existing HIV diagnosis.

Health systems must shift to meet the evolving needs of people living with HIV as a chronic and complex long-term health condition. The necessity to rethink how medical and social support services are delivered is increasing alongside the growing numbers of people living with HIV. UNAIDS estimates that the number of people living with HIV globally reached 37.9 million in 2018¹¹ and this number is expected to increase.

A consensus is emerging that health systems must go beyond a solely medical focus which primarily strives only for viral suppression as the endpoint for successful HIV care^{9,12}. To understand the complexity of HIV and AIDS, it is vital to consider and address the entirety of the health needs of people living with HIV – physical, emotional, mental and psychosocial – within the individual's unique and varied social and cultural circumstances, so that quality of life is optimised now and in the long-term. Community involvement is a vital precondition for effective HIV/AIDS management and good quality of life for people living with HIV as it enables health-related behaviours and reduces HIV-transmission and stigma.¹³

An optimal quality of life includes the prevention and treatment of HIV and associated comorbidities as well as self-perceived quality of life which includes the elimination of structural barriers and policies that impede access to good health. However, for people living with HIV, wellbeing and wider social, cultural, legal and economic rights are important components of a good quality of life.¹⁴

Tackling stigma and discrimination in health systems, society and policies - as well as self-stigma - is at the forefront of empowering individuals with HIV and supporting their wellbeing. This, in turn, enables and equips people living with HIV to better manage their long-term health needs, keep their viral load undetectable and reduce the onward transmission of HIV. Tackling HIV related stigma and discrimination also reduces healthcare-associated costs.

Quality of life issues are of significant concern to people living with HIV¹⁵

Living with HIV brings challenges, which can affect the wellness of people with HIV, including issues around stigma, discrimination and marginalisation, personal and sexual relationships, stable work and housing, and both short-term and long-term financial planning including, in the later years, palliative care options.

Incorporating the views of people living with HIV when updating HIV policies, and in the delivery of health and human services, is crucial to healthy ageing and achieving an optimal quality of life among people with HIV.

Ensuring early access to comprehensive HIV testing, treatment and quality mental healthcare as well as basic social support are the basis for long-term health and reduced healthcare costs and impact on health systems.¹⁶

The Voices of People Living with HIV:

The Positive Perspectives Study

Understanding the experiences of people living with HIV is essential to informing policy and services to meet their needs. People living with HIV should be at the centre of the HIV response, taking into consideration not only what services and programmes are available to them, but also the political, legal, socio-economic and cultural environment in which the individual lives¹⁷. In 2017, the Positive Perspectives 1 Survey¹⁸, supported by ViiV Healthcare, was carried out in 9 countries with 1,111 people living with HIV. It aimed to generate insights into the unmet needs of people living with HIV with respect to treatment management, including the impact of both HIV and its treatment on their daily lives. This survey explored the factors driving treatment satisfaction, respondents' views on long-term effects of antiretrovirals, and the burden associated with taking daily medication.

Positive Perspectives Study 2

Positive Perspectives 2 was a cross-sectional international study of 2,389 people living with HIV currently on antiretroviral therapy. It built upon the first Positive Perspectives results (2017) and separate surveys of people living with HIV in Australia, North America, Latin America, Asia Pacific region, Europe, Russia and South Africa.

Positive Perspectives 2 expands the geographical reach from nine countries to 25, including additional countries in the Asia Pacific region, Latin America, Eastern Europe (Russia) and Sub-Saharan Africa (South Africa) and additional countries in Europe. The sample does not capture those who were diagnosed but not yet treated – a subset of people living with HIV who are either likely to be less knowledgeable about their condition and potentially less satisfied with their care and quality of life or may not have access to care.

Fieldwork was conducted from April to August 2019. The initial questionnaire design for the main survey fieldwork was developed by ViiV Healthcare in partnership with an international Advisory Committee that includes advocacy, community and medical experts, including people living with HIV. A key focus of the study was to explore aspects of quality of life for people living with HIV across different countries, regions, epidemics and healthcare systems.

This document draws heavily on the results of the Positive Perspectives 2 study as well as the wider body of scientific knowledge on improving quality of life in people living with HIV.

The Positive Perspectives 2 study was created to generate insights into the unmet needs of people living with HIV with respect to treatment management, including the impact of the disease on their quality of life and the importance of holistic care. While insights are

available only from those diagnosed with HIV, the results offer a global view in an era where HIV has become a non-fatal life-long condition in many – but not all – countries.

Positive Perspective 2 set out to investigate how people living with HIV rate their own health, how living with HIV impacts their lives and affects their outlook for the future, as well as their interactions and relationships with Health Care Providers (HCPs) and their experiences with antiretroviral therapy.

Several key themes emerged from the Positive Perspective 2 data:

Indicators of health-related quality of life are not optimal for a significant proportion of people living with HIV: almost half reporting suboptimal overall health¹⁹.

This perception of reduced mental, physical and overall health impacted their quality of life. This was significantly associated with concerns about HIV treatment, their personal and professional relationships, engagement with their HCP, adherence to treatment, and living with HIV in general. A more holistic approach to care is needed, helping people living with HIV to manage their health conditions and make more informed treatment choices. Holistic care is a complex but cost-effective approach. It goes beyond healthcare support, by including mental health, access to new antiretroviral therapy, support with access to housing and jobs, efforts to reduce stigma and discrimination to zero, and support for peer and community care networks.

The study shines a spotlight on several areas where people living with HIV around the world are facing challenges – such as stigma, mental health, managing comorbidities, shared decision-making and improving their quality of life as they age.

The Positive Perspective study and other research findings²⁰ highlight the need for a comprehensive and holistic approach to HIV and mental health care. Addressing mental health and cognitive challenges in people ageing with HIV should take into consideration biological factors such as HIV's effects on the brain, comorbidities, cognition and mood, and how these drive function in everyday life, as modified by environmental and societal factors including economic marginalisation and stigma.

The prognosis for many people living with HIV has changed; and it is not surprising that their needs have changed alongside it. Although some challenges may remain, it is high time that public, social and healthcare policy be updated to reflect a new reality, one where the broader quality of life of every person living with HIV is valued alongside their quality of healthcare.

Challenges:

Barriers to Better Care

The Positive Perspectives 2 study focused on four key domains:

1. **Self-rated health;**
2. **Living with HIV;**
3. **Interactions with HCPs;**
4. **Attitudes towards, and experiences with, antiretroviral therapies.**

The overarching aim was to assess how these issues interact with quality of life.

The findings identify four major areas of concern to people living with HIV:

Quality of life and health outcomes

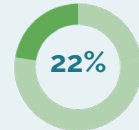
People living with HIV should be empowered to play an active role in their care and equipped to obtain adequate support – for example, taking a friend or loved one to their appointments with their care team and reaching out for peer support.



Respondents who had been living with HIV for a longer period of time prioritised a need for improved dialogue between HCPs and people living with HIV regarding health, social and personal issues, in order to improve their quality of life. Some reported being hesitant to engage with clinicians.

Positive Perspective 2 study findings¹

22% of women living with HIV did not feel confident enough to raise their broad concerns with HCPs.



This speaks to the importance of maintaining open channels of communication on these issues or risk an individual's capacity to optimise their quality of life.

It is a concern to many involved in the oversight of this study that **some people living with HIV report that their HCPs do not inform people living with HIV that undetectable equals untransmittable (U=U)²¹**, one of the most significant scientific developments regarding viral load and infectivity. This means that the virus cannot be sexually transmitted once the viral load is undetectable; not communicating this fact undermines global efforts to challenge the stigma and fear that many people living with HIV have with regard to their concerns of onward transmission. The impact of this omission can dramatically affect couples seeking the most up-to-date information on their reproductive and sexual health choices.

Positive Perspective 2 study findings¹

Two thirds of interviewed women living with HIV said that their provider had told them about U=U while the remainder had not been provided with this critical and crucial information to inform their overall health and wellbeing.



It is clear from the study that there is urgent concern that HCPs should use a common scientific discourse on U=U that is both evidence-based and free from bias and any other prejudices which may be held by the HCP. Despite guidelines from professional organisations, accurate and unambiguous reassurances have not been integrated into routine clinical practice of all HCPs. With the message of U=U not being disseminated to the broader public, there is an invaluable opportunity lost to address many of the fears and risks compounding feelings of stigma and shame that people living with HIV harbour, potentially impacting upon their life-long commitment to treatment²². Knowledge about U=U can reduce anxiety associated with testing and can increase treatment initiation, adherence, and engagement in care.

In addition to personal health benefits, the potential public health benefit of decreasing community viral load is an important rationale for increasing access and removing barriers to optimal treatment, care and services. Reducing community viral load has been linked to a reduction in new HIV incidence. Policymakers and other stakeholders must be made aware that investing in the wellbeing of people living with HIV is not only essential to save lives first and foremost, it is also a key strategy for reaching UNAIDS goals and ending the HIV epidemic.²³

The study also highlighted concerns among people living with HIV about the life-long impact of their medication, particularly about taking additional medications for other comorbidities as they age. **A large number of people living with HIV (67%) said they worried about the long-term impact of HIV medication, while 63% reported concern that the effects of long-term use of antiretroviral therapies are still unclear.**²⁴ These concerns increased in relation to the rising number of comorbidities and medicines that people living with HIV need to take, with 57% being worried about taking more and more medicines as they grow older with HIV²². This data provides the evidence to support continued efforts to evaluate the relationship between polypharmacy and quality of life measures and highlights the imperative to invest in treatment simplification to improve quality of life and cure.

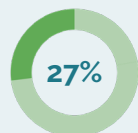
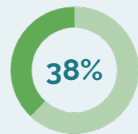
Communication, information and shared decision-making

Creating effective partnerships with people living with HIV to make informed decisions about their own access to healthcare and treatment options, as well as involving them in creating and reviewing policies and programmes that directly impact care, are important cornerstones of the global response to HIV.

People who feel they have contributed to decisions regarding their key care and treatment choices report better health outcomes. Yet the Positive Perspectives 2 study suggests that a majority would like more information, better communication and stronger engagement with their HCPs.

Positive Perspective 2 study findings¹

38% of female respondents did not believe they were given enough information to be involved in making choices about their HIV treatment¹. Some people living with HIV (27%) felt uncomfortable raising their concerns with HCPs for fear of being seen as a 'difficult patient'. This may limit opportunities for a quality dialogue with their provider about their treatment.²⁵



The legacy of HIV's origins as a relatively short-term and fatal illness still shapes the approach taken by some HCPs, policymakers and service providers. For example, institutions such as insurance companies and banks, often restrict or deny access to healthcare, life insurance and mortgage loans for people living with HIV. In contrast, living with a chronic condition often requires the patient to be much more involved in their healthcare. HCPs involved in the treatment of diabetes, cardiovascular disease and lung conditions positively

engage patients in determining treatment pathways and, in some cases, in managing aspects of their own care. This supports greater adherence to therapy which in turn enhances outcomes and wellbeing.²⁶ Involving people living with HIV in their spectrum of care needs is more effective than traditional paternalistic approaches²⁷. Better health outcomes and lower healthcare costs are observed among highly engaged people living with HIV.²⁷ Those in positions to make decisions on behalf of people living with HIV must do so with transparency and accountability.

Stigma, discrimination and psychosocial issues

People living with HIV continue to face significant HIV related stigma and discrimination.

Positive Perspective 2 study findings¹

Stigma (negative attitudes and beliefs about people living with HIV) and discrimination (treating people differently based on their HIV status)²⁸ have a negative impact on testing and treatment adherence, impacting quality of life and health outcomes.²⁹



Criminalising the conduct of sex workers, homosexuals, transgender people, drug users and migrants exacerbates stigma and discrimination and may decrease the use of HIV services, resulting in poorer health and increased HIV transmission³⁰. Addressing stigma and discrimination, including criminalisation of people living with HIV³¹, not only improves the quality of life of people living with HIV but can be linked to helping achieve and sustain viral suppression. This advances the wider public health goal of reducing incidence of HIV^{32,33}.

Significant numbers of study respondents around the world (3 in 5) said they had experienced stigma associated with their HIV status and 58% have hidden or disguised their HIV treatment to avoid disclosure.

Positive Perspective 2 study findings¹

Nearly three in five have hidden or disguised their HIV medicine recently in an attempt to conceal or avoid having to share their status¹.



Those who felt the need to hide their HIV status were more likely to suffer negative mental health outcomes. There is also evidence of discrimination in accessing work (for example, the police and the military) and ill treatment of people living with HIV in the workplace, especially in healthcare services³⁰.

Many people living with HIV now have an unprecedented range of treatment options in a growing number of countries, offering the opportunity to ensure that their HIV can remain undetectable and mitigate side-effects with other treatment options.

Positive Perspective 2 study findings¹

However, daily medication regimens were perceived by some respondents as a burden and a cause of anxiety¹² and simplified treatment regimens need to be further developed.

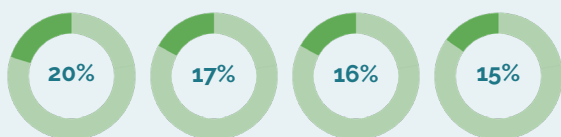


Ageing with HIV and treatment over a lifetime

Alongside an ageing population of people living with HIV, the rates of chronic conditions are on the rise³⁴. For people living with HIV, **the disease burden of comorbidities is higher than the general population**^{6,35} and the Positive Perspectives 2 study suggests that people living with HIV are also coping with a wide range of other long-term illnesses, particularly as they age. Among older respondents (50+ years), the majority reported living with at least one comorbidity. In many cases, these conditions had been diagnosed for more than a decade.

Positive Perspective 2 study findings¹

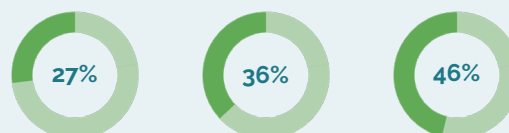
Mental health disorders (20%), high blood pressure (17%), high cholesterol (16%), and sleep disorders (15%) were among the most commonly cited conditions with which participants had been diagnosed¹.



In many cases, people living with HIV were taking medications for other conditions alongside their HIV treatments. Among those who reported having at least one other comorbidity, concern about the long-term effects of HIV medication were higher. People living with HIV with comorbidities also indicated that they would be more likely to adopt HIV treatment regimens composed of fewer medications.

Positive Perspective 2 study findings¹

Overall, **73% of respondents said that they would be open to taking a HIV treatment composed of fewer medicines, provided that their viral load is suppressed.**¹ People reporting polypharmacy³⁶ (those who take 5 or more tablets a day) had significantly poorer health outcomes independent of existing comorbidities: their odds of treatment satisfaction, optimal overall health and virologic control were lower by **27%, 36% and 46% respectively, compared to those without polypharmacy.**



The study also found that those who rate their overall health as 'poor' or 'fair' were less likely to be satisfied with their current HIV treatment. This may be linked to the burden of taking several medicines each day or to side effects of medications which impact on daily life.

Positive Perspective 2 study findings¹

Treatment dissatisfaction was notably higher in women (37%) than men (27%) and is something that should be pursued in future studies.





Recommendations:

4 Steps Forward

The World Health Organisation advocates and promotes a holistic view of health:

“
Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity³⁷
”

Best practice and the findings from the study concur that policymakers and service providers should take a consultative and more rounded approach when crafting responses to the challenges facing people

living with HIV. This requires a shift away from top-down approaches which are not based on the lived experiences of people with HIV. The issues identified through the Positive Perspectives 2 study demand that services designed to meet the needs of the HIV community address quality of life issues, improve communication between HCPs and people living with HIV, continue to tackle the pernicious effects of stigma and discrimination, and develop strategies to manage the complex issues facing those living with comorbidities. These recommendations offer practical, actionable measures to improve quality of life that all health systems should incorporate into modern HIV care.

Quality of life and health outcomes



1

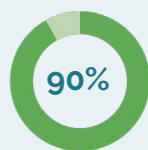
Communicating U=U:

Clinicians, policymakers and community advocates involved in public policy must review patient care guidelines (most notably in the context of those newly diagnosed) to ensure that Undetectable equals Untransmittable (U=U) is a priority message for people living with HIV and their communities. Standards of care and clinical guidelines should encourage clinicians to inform people living with HIV about U=U given its association with reported health outcomes and quality of life. This could be further supported through professional development opportunities for clinicians to better understand the complex and beneficial aspects of how this message challenges stigma and supports mental health³⁸. To further minimise stigma and discrimination and improve quality of life, actions should be taken to inform people living with HIV, policymakers and the broader public about 'U=U'.

2

Update Action Plans:

Policymakers at all levels of government should update any strategic and operational Action Plans to map out their plans to meet the UNAIDS 90-90-90 targets and include a '4th 90' which moves beyond merely suppressing the virus to target quality of life and long-term health. UNAIDS should convene a group of experts, including people living with HIV, to develop and agree on how to define and measure quality of life for people living with HIV, beyond a purely biomedical approach. This should be used cross-culturally and in various regions of the world. UNAIDS should also ask countries to regularly report on their progress in ensuring that people living with HIV enjoy a good quality of life³⁹.



A new '4th 90' UNAIDS target, ensuring that 90% of people living with HIV report a good quality of life⁴², would better address the needs and human rights of all people living with HIV throughout their lives.²⁵

3

Enhanced monitoring:

Authorities at all levels should expand monitoring efforts to reflect the reality of HIV as a life-long condition. This should be guided by the World Health Organisation which, for its part, should collect data about health system responses to long-term challenges faced by people living with HIV. It is no longer sufficient to measure viral load alone; patient wellbeing and quality of life should be consistently monitored. Granular, holistic quality of life indicators, going beyond biomedical indicators to encompass Patient-Reported Outcome Measures, should be developed and incorporated into national guidelines to enable better measurement of quality of life.

4

Holistic approach:

Service providers should tailor care models to provide psychosocial and practical support to help people to prepare to live with HIV in the long-term. This could include individualised advice on pensions, housing security and financial planning; mental health evaluation; sexual health, reproductive support and relationships as well as counselling on lifestyle factors including isolation. Clinical services should ideally be able to either refer or directly provide opportunities for people living with HIV to meet and learn from peers, given that a significant minority had not spoken to anyone other than their HIV HCP about their condition. Peers should act as a link between HCPs, social services, community services and services provided by NGOs. In addition, peer advocates have a better knowledge of what is available and can help people living with HIV find answers to their questions about how to better manage their condition. There is a need to provide high quality education for HCPs including additional training to enable medical services to establish and maintain a non-stigmatising and discrimination-free service setting. As people living with HIV often have several comorbidities, referral systems should be strengthened so that various HCPs have access to information about the healthcare background and ongoing treatment of each person living with HIV.

Case study:

The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) has developed a guide to inform clinicians and other healthcare service providers of the latest scientific developments in antiretroviral treatment.

Undetectable = Untransmittable: A guide for clinicians to discuss²² provides a summary of the evidence, explores important implications of scientific advances, and provides suggestions for legal and psychosocial referrals.

The key message of the guide is that for people who take treatment daily as prescribed and maintain an undetectable viral load, there is no risk of sexually transmitting the virus to an HIV-negative partner. In short, Undetectable = Untransmittable (U=U).

The ASHM guidelines help bridge a crucial gap in guidance for clinicians who need to be better informed but also fully equipped to give accurate and evidence-based information to their patients. Clinicians may find that some patients have encountered this messaging prior to engaging in clinical care, and thus require professional support to understand what it means.

Clinicians are often called upon to 'break the bad news' of a new HIV diagnosis to a patient. However, by integrating the U=U message into their practice, they can provide assurance to the patient about their fear of infecting others. This can allay feelings of stigma and shame, which have a negative impact upon their long-term commitment to care and treatment.

The guide is supported by an ASHM campaign to disseminate accurate and unambiguous information to people with HIV and those at risk. The campaign also challenges HIV-related organisations in government, civil society and the private sector to promote awareness and understanding of U=U. As this message becomes widely known, it has the potential to have a significant positive impact on quality of life and health outcomes for people living with HIV.

Learn more here:

<https://ashm.org.au/HIV/UequalsU/>





Communication, information and shared decision-making

1

Patient dialogue:

All efforts should be made to enable better, more horizontal and open dialogue between people living with HIV and their clinicians. People living with HIV must feel they are in a non-judgmental environment; they must be comfortable sharing with their clinicians all aspects relevant to their quality of life, treatment, care choices as well as information regarding U=U. This open dialogue should become the basis of informed discussions about care and treatment, resulting in better individual and public health outcomes.

2

Patient engagement:

People living with HIV and community groups that wish to engage in policy should become main actors and be fully engaged in all policy and decision-making processes. Drawing on the GIPA (The Greater Involvement of People living with HIV) principles, which advocate for greater involvement of people living with HIV⁴⁰, the voices of the communities most affected by the global epidemic should be crucial to tailor adequate responses to their needs. Patient representatives must be fully engaged members of any international committee or national public health plan on HIV, be present in any local government body with competences on the response to HIV, and engage actively in the design of participative and more horizontal decision-making processes with the different healthcare units, including in the evaluation of the outcomes.

3

Targeted information:

Policymakers, service providers, NGOs and professional bodies should ensure that key subgroups of the HIV community are the focus of tailored communication initiatives. Key subgroups include (but are not limited to) children growing up with HIV, all women, people who use drugs, transgender individuals, people living with disabilities, sex workers, men who have sex with men, Black, Asian and minority ethnic groups, migrants and other marginal groups and sub-populations living with HIV.

4

Evidence-informed decision-making:

Following the World Health Organisation's advice⁴¹ to foster a culture of continuous quality improvement based on the best available evidence, it is time to identify, disseminate and translate the body of knowledge derived from best practices. The community and decision makers should translate this into well designed, evidence-based action plans which serve to accelerate and quantify the gains in health outcomes in an era of chronic diseases. Tools should be developed to enable communities and decision makers to share their expertise to develop programmes to help end discrimination and criminalisation and to safeguard human rights.

Case study:

The relationship between clinicians and those in their care is changing. For people living with HIV, empowerment means playing an active role in making informed treatment choices that best suit their needs.

This approach is underpinned by enhanced dialogue between people living with HIV and their clinicians. It requires care providers to deliver clear and up-to-date information on treatment options, in a non-judgmental environment. This can be further enhanced by targeted information which addresses the needs of key subgroups of the HIV community.

Mothers living with HIV have unique needs. Decisions on infant feeding can be challenging for women with HIV due to contradictory advice. World Health Organisation guidelines advise breastfeeding for up to 24 months – a recommendation geared to countries where formula feeding carries risks arising from low-quality water. At the same time, the World Health Organisation recommends that countries decide for themselves whether to advocate breastfeeding. Formula feeding is recommended for people with HIV in developed regions.

A team of healthcare providers in Toronto has supported four mothers living with HIV who wanted to breastfeed while on effective treatment.⁴² They followed a three-step approach. First, infant feeding was discussed, including the relevant guidelines and support for formula feeding.

Counselling was arranged for those who preferred breastfeeding. This presented opportunities for a deeper discussion of the latest information about breastfeeding and HIV. Women were supported regardless of which path they chose. Those still planning to breastfeed were referred to a paediatric communicable diseases specialist.

After a baby was born, an HIV PCR test was performed, post-exposure prophylaxis treatment was initiated, and the infant was closely monitored. If the baby's HIV tests were negative two to four weeks after breastfeeding had stopped, antiretroviral medications were discontinued.

All care providers are informed of the women's preferences prior to admission, ensuring that mothers do not face discrimination during the busy postpartum period.

Learn more here:

<http://blog.catie.ca/2019/03/11/a-step-by-step-process-on-how-we-can-support-mothers-living-with-hiv/>





Stigma, discrimination and psychosocial issues

1

Health literacy:

Professional bodies, universities and policymakers should work together to provide all HCPs and community care providers with education to help reduce stigma and discrimination in the health system. To achieve the shared public health goal of reducing transmission by addressing stigma and discrimination, HCPs must be equipped with the tools required to address quality of life and psychosocial issues among people living with HIV. In addition, education to deepen understanding of U=U ('cannot pass on the virus') among the general public can play a role in reducing stigma and discrimination at a societal level.

2

Legislative change:

Legislators should address discriminatory practices or laws that contravene human rights by passing legislation that protects access to services, work, education or travel⁴³. Independent structures, if they do not already exist, should be created to oversee government and health system policies/practices to ensure zero discrimination. Complaints procedures should be respectful, confidential and sensitive and should allow citizens to highlight instances of discrimination and include feedback mechanisms which protect confidentiality and whistleblower protection.

3

Support networks:

Transparent, representative and community-led HIV networks need to be established to advocate for and represent people living with HIV and ensure that policymakers and programmes meet their needs. Policymakers should provide HIV community networks with the resources needed to establish programmes, including peer-to-peer networks, to boost the supportive ecosystem that people living with HIV need to not only survive but to thrive. This would equip them with tools to effectively tackle self-stigma and shame. Policymakers should also strengthen health systems to better incorporate learning around mental health, wellbeing and the impact of adherence among people living with HIV.

Case study:

HIV-related stigma and discrimination among HCPs is a barrier to improving services and quality of life for people with HIV. Stigma and discrimination surrounding HIV is particularly prevalent in Russia and has contributed to the local epidemic.

The VERA HIV Med School, Russia, aims to address this through a course for the next generation of doctors, which is designed to equip them with the skills and information they need to deliver optimal care to people living with HIV⁴⁴.

At a week-long educational camp, 20 to 25 young clinicians from Russia, Ukraine, Belarus and Uzbekistan have an opportunity to learn and discuss HIV in an academic environment. There is a strong focus on the impact of stigma and discrimination, and their role in addressing this in a healthcare setting.

The curriculum is delivered through interactive lectures and workshops with leading doctors and scientists working in HIV-related fields in Russia. Crucially, aspiring clinicians meet with people living with HIV. In addition, they engage with lawyers, social workers, psychologists, HIV activists, and representatives of NGOs to learn from their unique stories. Every camp is an opportunity for participants to develop skills specific to the HIV context and to understand the key social and legal aspects of their patients' diagnosis.

The project reflects ongoing efforts by the Russian AIDS.CENTER Foundation to enhance HIV care in the region. Since 2018, approximately 150 doctors participated in seven training sessions. Most participants (82%) noted a change in their attitude towards HIV transmission, which is confirmed by questionnaires showing a decrease in perceived discrimination among participants.

By fostering a network of young doctors with training in discrimination and stigma, the VERA HIV Med School is helping to reshape attitudes among health professionals.

Learn more here:

<https://www.unaids.org/ru/resources/presscentre/featurestories/2018/october/educating-next-generation-of-russian-doctors>



Ageing with HIV and treatment over a lifetime



1

Life-long care and policy integration:

Policies should reflect the needs of people living with or at greater risk of HIV at all ages and stages of life (for example, in nursing homes), including the prevention and management of comorbidities. Policymakers should integrate HIV into policies that tackle the long-term care of the population in general based on multi-disciplinary, mainstream care models. HCPs should work with people living with HIV to create personalised, integrated and outcomes-focused care plans, tailored to each individual.

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2**Develop the evidence base:**

Research funding agencies should fund community research studies on the long-term health of people living with HIV with a view to informing person-centred, long-term care for people as they live and age with HIV.

3**Optimise treatment:**

Service providers and clinicians should facilitate opportunities for people who prefer to take fewer treatments, offering greater flexibility, fewer interactions with other medicines and substances, and better quality of life. Clinicians should have the flexibility to provide people living with HIV with information about available treatment options, based on their needs, empowering them to make informed treatment choices. Policymakers must also foster a pro-innovation environment to enable the development of better treatments with fewer side-effects and a positive impact on quality of life, in line with patients' preferences. Research opportunities and access to new medicines for patients with multi-resistant viruses should be prioritised.

Case study:

The first case of HIV/AIDS was diagnosed in Romania in 1985. Today, half of the 16,000 people living with HIV in Romania were infected while in state-run orphanages and hospitals between 1985 and 1995.⁴⁵

This large subgroup of the HIV community is known as the Romanian Cohort – part of the wider population of 'Ceausescu's children' that spent part of their childhood in orphanages and survived the turbulence that followed the collapse of communism in 1989. Despite these severe challenges, in 2001, Romania became one of the first countries in the world to introduce legislation reducing barriers to care for people with HIV.

Current legislation ensures a wide range of rights to social and health benefits for people affected. However, the concept of quality of life for adults living with HIV is not well established.

Romania offers a distinct opportunity to advance an outcomes-focused and patient-centred approach to long-term HIV care in a unique setting. Experts in Romania, supported by peers across Europe, are applying the HIV Outcomes recommendations¹⁰. HIV Outcomes⁴⁶, a multi-stakeholder European initiative, was created in 2016 to advance the quality of life of people with HIV – beyond viral suppression.

Through meetings with key stakeholders, and the establishment of a HIV Outcomes Steering Committee in Romania, a series of tailored recommendations were developed. The process highlighted the need for a study on quality of life among people with HIV in Romania, helping to build an evidence base on which to build effective policies.

The Steering Committee also recommended education programmes for clinicians and advocacy campaigns to modernise public attitudes to HIV. Romania is one of several European countries which have road-tested the HIV Outcomes recommendations. This initiative offers direct benefits to people in Romania while providing an example to peer countries of the steps required to improve the care of people with HIV.

Learn more here:

<https://hivoutcomes.eu/national-level/>



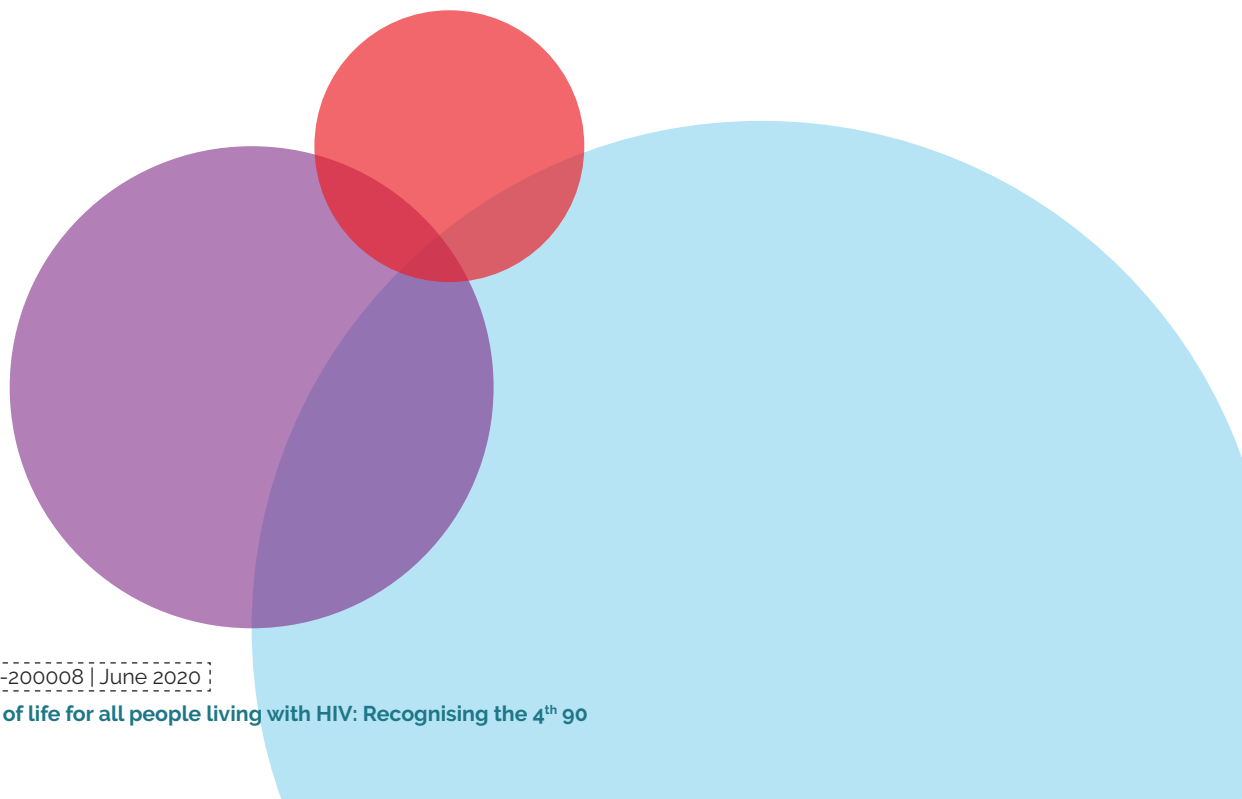
Conclusions:

Towards Optimal Healthcare for All People living with HIV

The above recommendations were developed in response to the findings from the Positive Perspectives 2 study. They were further elaborated by the study team and the international Advisory Committee based on their insights on the data and their understanding of the unmet needs facing people living with HIV around the world. Some of the recommendations require investment to reduce the long-term burden of HIV on individuals, communities and health systems; while others are less resource-intensive but require sustained commitment and policy changes. There remains no doubt that there is an urgent need to instigate the required shifts in behaviours and practices across health systems, and in society more broadly, that continue to hamper real progress on halting transmission and increasing the quality of life of those with HIV.

The challenges facing people living with HIV in 2020 are very different to those observed in the 1980s and 1990s. Greater longevity is cause for celebration. However, optimising the quality of life of people living with HIV is essential to completing the HIV success story – turning a once-fatal disease into a manageable chronic condition that no longer prevents citizens from living full, productive, meaningful and happy lives.

As indicated by UNAIDS⁴⁷, funding for HIV has already fallen dramatically and this represents a fundamental challenge that needs to be addressed for the benefit of people living with HIV and in order to achieve the goals outlined above. The COVID-19 pandemic has highlighted the value of robust healthcare systems. Resilient services that are equipped to manage transmissible diseases and related challenges are essential to public health and personal wellbeing. More than that, the pandemic has taught us that health systems are interconnected and that patients with chronic conditions can face higher risks from respiratory illnesses such as SARS-CoV2. The value of evidence-based policymaking, investing in research, and developing mature person-centred services is seen in the capacity of health systems to cope with shock. This report offers a pathway to improving how health systems – and societies – handle the next phase of the HIV pandemic. As economies and health systems rebuild, it is our strong belief that redesigning HIV care should be a priority.



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