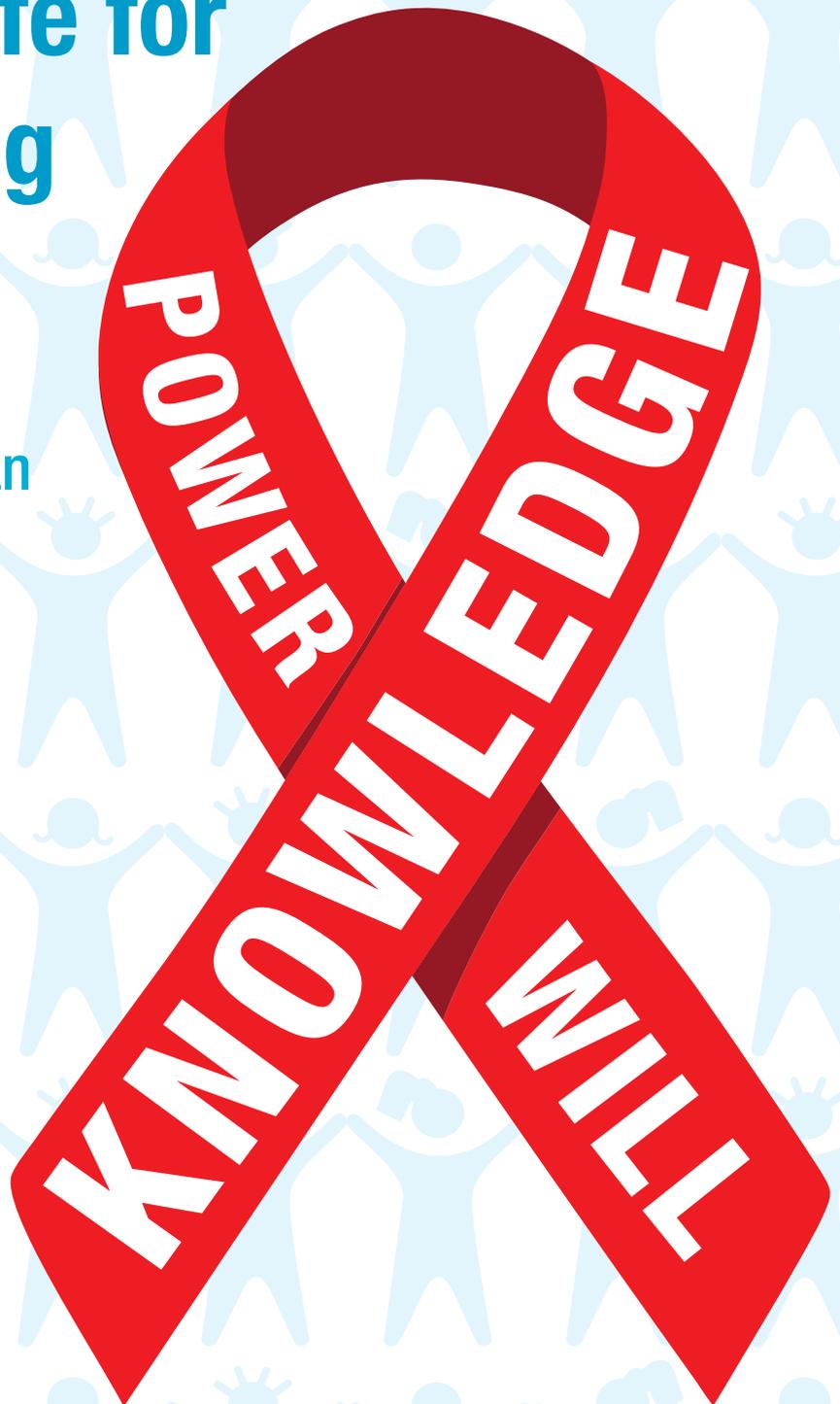




Quality of life for people living with HIV:

what is it, why does
it matter and how can
we make it happen?



About the International HIV/AIDS Alliance

We are an innovative alliance of nationally based, independent, civil society organisations united by our vision of a world without AIDS.

We are committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

Our actions are guided by our values: the lives of all human beings are of equal value, and everyone has the right to access the HIV information and services they need for a healthy life.

International HIV/AIDS Alliance

91-101 Davigdor Road

Hove, East Sussex

BN3 1RE

United Kingdom

Tel: +44 1273 718 900

Fax: +44 1273 718 901

Email: mail@aidsalliance.org

Registered charity number
1038860

www.aidsalliance.org

Acknowledgements

This briefing has been written by the International HIV/AIDS Alliance in collaboration with its international partners (Linking Organisations) and with independent consultants. In addition, it has the support of STOPAIDS and the United Kingdom's All Party Parliamentary Group on HIV/AIDS.

Editor: Hester Phillips

Design: Garry Robson

Additional illustration (p12): Jane Shepherd

© International HIV/AIDS Alliance, 2018

Information contained in this publication may be freely reproduced, published or otherwise used for non-profit purposes without permission from the International HIV/AIDS Alliance. However, the International HIV/AIDS Alliance requests that it be cited as the source of the information.

Unless otherwise stated, the appearance of individuals in this publication gives no indication of either sexuality or HIV status.

Introduction

Throughout four decades of the epidemic, people living with HIV's quality of life has been a fundamental issue. It has shaped many of the good practices and principles that have guided the global response, including the greater involvement of people living with HIV (GIPA) and Positive Health, Dignity and Prevention (PHDP).

Now, within a rapidly changing and increasingly complex environment for HIV, there is a need to rethink and refocus on quality of life.

Access to antiretroviral therapy (ART) has revolutionised both HIV treatment and prevention. It has enabled many people living with HIV to maintain or regain their physical health. It has also enabled many HIV positive people to achieve viral suppression, when the level of HIV in the blood is so low it is undetectable and untransmissible to others². This fundamental shift has transformed the medical understanding of HIV from a 'fatal' and 'emergency' disease to one that is 'chronic' and 'manageable'³. In turn, the experience of living with HIV has the potential to go from one of survival to one of living well and living long. Today, people living with HIV who adhere to ART and achieve viral suppression have almost the same life expectancy as anyone else⁴.

However, viral suppression should not be seen as the 'end goal' of responses to HIV, nor as the end of people's experience of living with the virus. It does not, in isolation, constitute quality of life. As described in this briefing, multiple and varied challenges associated with being HIV positive remain, especially in the long term, including mental health issues, social stigma, violations of human rights, living with co-morbidities, discrimination in healthcare settings and isolation. Many of these have a detrimental impact on people's quality of life, particularly for those who are marginalised and vulnerable.

In addition, among the world's 36.9 million people living with HIV, one in four remain unaware of their HIV status⁵. Among those who have tested HIV positive, 21% do not have access to treatment and, of those who have access to ART, 19% have not achieved viral suppression.

These tensions occur against the backdrop of the Sustainable Development Goals (SDGs) which – while mandating for no one to be left behind, an 'end to AIDS' and access to universal health coverage – risk a move towards large-scale, biomedical responses to health that neglect the specific and diverse needs of individuals and specific diseases.

"Doctors, governments don't understand. They think because medication is available, all is sorted. But our health is on a rollercoaster! Just because you are undetectable does not mean you are always well."

A woman living with HIV in the United Kingdom¹

1. Sophia Forum and Terrence Higgins Trust (2018) *Women and HIV Invisible No Longer: A National Study of Women's Experiences of HIV*
2. UNAIDS (2017) *Public Health and HIV Viral Load Suppression*
3. HIV: The Long View Coalition Europe, Gilead, Future Foundation (2016) *A Healthier Future Starts Today: Key Trends Shaping The Future Of Healthcare In Western Europe*
4. Nakagawa F, Lodwick RK, Smith CJ, et al (2012) 'Projected Life Expectancy Of People With HIV According To Timing Of Diagnosis', *AIDS*, 26 (3) 335-43.
5. UNAIDS (2018) *Miles to Go: Closing Gaps, Breaking Barriers, Righting Injustices*



Quality of life for people living with HIV is essential to achieving the SDGs, rather than being a distraction or an optional extra. This briefing describes what quality of life is, why it matters, what interventions look like, and where the concept fits within global frameworks. It is informed by the practical experiences and technical expertise of a wide range of stakeholders and institutions⁶, including networks of people living with HIV and other civil society organisations in the United Kingdom (UK) and the global South.

What is quality of life for people living with HIV?

Building on definitions by institutions such as the World Health Organisation (WHO)⁷, quality of life can be understood as something that is:

- **Multi-dimensional:** it is not about one single thing, but made up of multiple, varying factors⁸.
- **Specific to each person:** the multiple factors vary according to each individual's unique identity, status and interpretation, as influenced by things such as their gender, culture and socio-economic status.
- **About both the negative and the positive:** it is shaped by both the *absence* of negative factors (e.g. ill health and poverty) and the *presence* of positive ones (e.g. social relationships and contentment)⁹.

For people living with HIV, whether with viral suppression or not, quality of life is based on the same sort of needs, desires and aspirations as any other person. However, it is also affected by the (often negative) issues that continue to be associated with HIV, compared to other health or social statuses. Examples include stigma (in families, communities and healthcare settings), discrimination, isolation and human rights violations¹⁰. As a result, achieving quality of life for people living with HIV requires particular attention to factors such as happiness¹¹, social connectedness¹², fatigue reduction¹³ and freedom from violence¹⁴.

“An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept, affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.”

World Health Organisation⁷

6. The methodology for this briefing involved: (1) A desk review of resources, including journal articles, web pages and policy briefs produced by a organisations involved in this area of work such as Centres for Disease Control, European AIDS Treatment Group, the Global Network of People Living With HIV (GNP+), HIV Outcomes, Positively UK, Sophia Forum, UNAIDS, and WHO (2) Sessions at the International AIDS Conference 2018, Amsterdam, including those documented in Moody K (2018) *Report of the Workshop: In Search of the 4th '90': Exploring and Defining What Quality of Life Means for Communities and Strategising How We Get There, AIDS 2018* (3) Interviews with selected stakeholders (4) Workshops involving representatives of the International HIV/AIDS Alliance and other civil society organisations, held in November 2017 and May 2018. The external stakeholders at the first workshop were Juno Roche, Clini-Q; Alice Welbourn, Salamander Trust; Bakita Kasadha, Development Trainer and HIV Activist; Flavian Rhode, Positive Vibes Namibia; and Nikos Dedes, Positive Voice. The external stakeholders at the second workshop were Nikos Dedes, European AIDS Treatment Group; Angelina Namiba, Salamander Trust; Bakita Kasadha, Consultant: HIV, Young People and Women and Y+ Board West & Central European representative, Y+ Board; Kevin Moody, Freelance Consultant: HIV Quality of Life; Rita Wahab, Mena Rosa; Rosenara Huidrom, Alliance India, and Nadine Ferris France, International Public Health Consultant.

7. WHO 'WHOQOL: Measuring Quality of Life' (accessed November 2018) <http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>

8. Referenced from multiple sources including IESE Business School (2013) *Quality Of Life: Everyone Wants It, But What Is It?* and Centres for Disease Control 'Health Related Quality Of Life (HRQOL)' <https://www.cdc.gov/hrqol/concept.htm> (accessed November 2018)

9. IESE Business School (2013) *Quality Of Life: Everyone Wants It, But What Is It?*

10. Erdbeer G, Sabranski M, Sonntag I, Stoehr A, Horst HA, Plettenberg A, et al. (2014) 'Everything Fine So Far? Physical and Mental Health in HIV-Infected Patients With Virological Success and Long-Term Exposure to Antiretroviral Therapy', *Journal of International AIDS Society*, 4 (3) and TheBody.com: Fawcett, D (4 January, 2018) 'Social Connectedness and HIV: Strategies for Better Health'

11. Northwestern University (17 April, 2017) 'Teaching happiness to men with HIV boosts their health'

12. TheBody.com: Fawcett, D (4 January, 2018) 'Social Connectedness and HIV: Strategies for Better Health'

13. Erdbeer G, Sabranski M, Sonntag I, Stoehr A, Horst HA, Plettenberg A, et al. (2014) 'Everything Fine So Far? Physical and Mental Health in HIV-Infected Patients With Virological Success and Long-Term Exposure to Antiretroviral Therapy', *Journal of International AIDS Society*, 4 (3).

14. International HIV AIDS Alliance quality of life meeting, November 2017.

To have quality of life, a person living with HIV needs access to high quality, appropriate, and comprehensive support and services for their *whole-person*. This requires attention to three core components:

- 1. Prevention, care, support and treatment for HIV**, which addresses a person's biomedical needs (e.g. for viral load testing and ART) and psychosocial needs (e.g. for peer mentoring and adherence counselling).
- 2. Prevention, care, support and treatment for non HIV-specific physical and mental health conditions**, including in relation to co-morbidities (e.g. diabetes, cardiovascular disease and cancer).
- 3. Well-being and wider social, cultural and economic rights**, such as those relating to gender equality, human rights, economic empowerment, access to education and political inclusion.

Quality of life requires an understanding that, while viral suppression is important for both individuals living with HIV and responses to the epidemic, it is not the *end point* of action on HIV. It is not enough to simply prolong the lives of people living with or at risk of HIV. Those lives also need to be healthy, happy and fulfilled.

Why does quality of life for people living with HIV matter?

Quality of life matters to all people living with or at risk of HIV – whether or not they know their status, are accessing ART or have achieved viral suppression.

However, the importance of quality of life has gained renewed traction following the increase in ART access and evidence of 'treatment as prevention'. In simple terms, the relationship between quality of life and viral suppression is a 'virtuous circle' [see Figure 1]. If a person living with HIV has a good quality of life, they are more likely to maintain ART, in turn, achieving viral suppression. Meanwhile, being virally suppressed can significantly boost a person's quality of life, and vice versa. Without factors that enhance quality of life, such as peer support, economic opportunities and stigma-free health services, people living with HIV may be less able to adhere to treatment. This risks a rise in their viral load and deterioration in their health status. It also risks new HIV infections among others.

In practice, the relationship between quality of life and viral suppression is more complex, and there are many potential interruptions to the 'virtuous circle'. This partly reflects that HIV, as a disease, continues to bring clinical challenges, such as treatment failure or drug side effects, which impact on a person's physical health and emotional well-being. For example, a study in Germany found that, despite achieving viral suppression, people living with HIV on ART for at least five years still suffered high levels of distress due to the symptoms of their condition¹⁵.

15. Erdbeer G, Sabranski M, Sonntag I, Stoehr A, Horst HA, Plettenberg A, et al. (2014) 'Everything Fine So Far? Physical and Mental Health in HIV-Infected Patients With Virological Success and Long-Term Exposure to Antiretroviral Therapy', *Journal of International AIDS Society*, 4 (3).



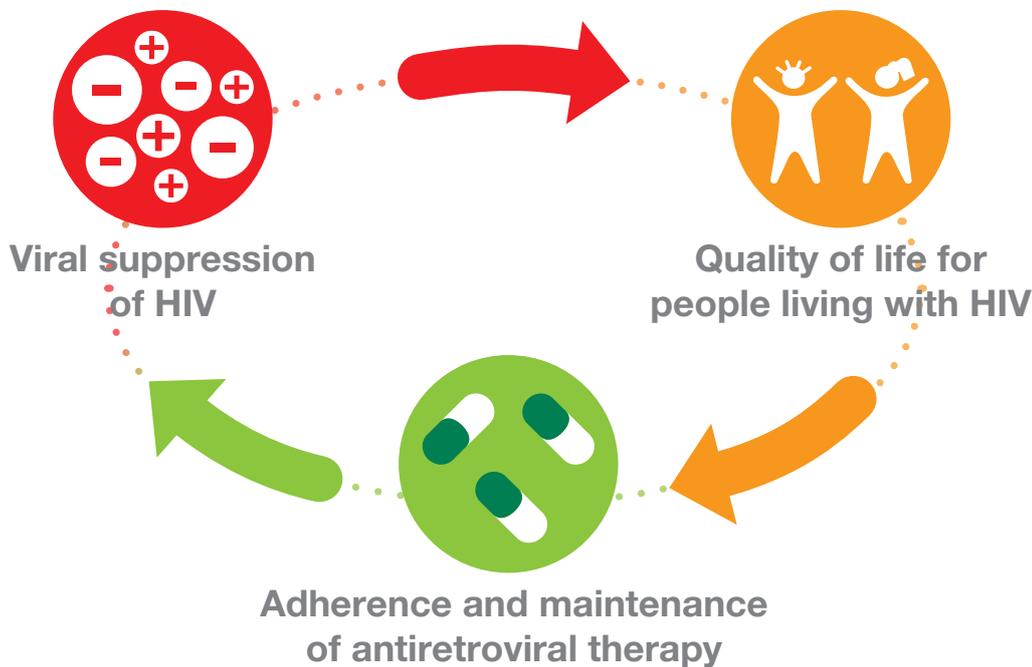


Figure 1: The relationship between quality of life and viral suppression of HIV

People living with HIV may also be at increased risk of additional chronic conditions and diseases such as cardiovascular disease and cancer¹⁶. Some of these conditions reflect the biological impact of immunodeficiency, particularly over the long term. Research in England and Wales suggests two-thirds of people living with HIV have at least one long-term health condition other than HIV, with the proportion especially high among people over 50¹⁷.

Other risks reflect the unique challenges faced by key populations who are most affected by HIV. For example, an HIV-positive person who uses drugs – who is criminalised and lacks access to harm reduction services – may experience additional health impacts, such as co-infection with hepatitis C. Additionally, within stigmatising societies and punitive legal environments, key populations – including men who have sex with men, transgender people and sex workers – may be more likely to smoke tobacco or use alcohol (further indicators for poor health)¹⁸, and less likely to access support and services.

The complexity of quality of life for people living with HIV reflects the lived reality of a disease that, despite medical advances, is wrought by decades of fear, stigma and uncertainty. A study in the UK found people living with HIV (including those with viral suppression) have significantly lower health-related quality of life than the general population due to higher levels of anxiety and depression¹⁹.

As indicated, age is an increasingly important subject for discussions and strategies on quality of life. People living with HIV are now living beyond previous predictions, and are experiencing age-related health and social challenges alongside their HIV status. Likewise, gender can strongly

16. Lazarus JV, Safreed-Harmon K, Barton SE, Costagliola D, Dedes N, del Amo Valero J, Gatell JM, Baptista-Leite R, Mendão L, Porter K, Vella S and Rockstroh JK (2016) 'Beyond Viral Suppression of HIV – The New Quality of Life Frontier' *BMC Medicine*, 14 (94) and HIV Outcomes Beyond Viral Suppression (29 November, 2017) 'People Living with HIV Can Live Longer, But Urgently Need Improved Care to Achieve Better Health Outcomes and Quality of Life'

17. National AIDS Trust, Terrence Higgins Trust, Positively UK, British Association for Sexual Health and HIV, NAZ, British HIV Association and MSD (2017) *A Declaration on 'Whole Person Care' in HIV Care and Support*

18. Olojede OO, Sekoni A, Olawunmi AS, Odeyemi KA (2017) 'Tobacco and Alcohol Use Among a Sample of Men who have Sex with Men in Lagos State, Nigeria', *Annals of Medical and Health Sciences Research*, 7, 30-36.

19. Miners A, Phillips A, Kreif N, Rodger A, Speakman A, Fisher M, Anderson J, Collins S, Hart G, Sherr L, Lampe FC (2014) 'Health-Related Quality-Of-Life of People With HIV in the Era of Combination Antiretroviral Treatment: A Cross-Sectional Comparison with the General Population', *The Lancet HIV*, 1 (1).

affect a person's quality of life. For example, a national study in the UK conducted by the Sophia Forum and Terrence Higgins Trust found 58% of women living with HIV, including those with viral suppression, had experienced some form of violence due to their HIV status and 42% had received a mental health diagnosis since becoming HIV positive²⁰. A global survey of people living with HIV identified respondents' top concern about growing older with HIV as the onset of other health conditions and diseases associated with ageing²¹.

Another reason why quality of life for people living with HIV matters is its potential for cost effectiveness. There are growing indications that addressing quality of life is not only better for individuals, but for countries' budgets and economies in the long term as it reduces demands on health systems and social care services²². For example, Positively UK has demonstrated how peer support among people living with HIV encourages self-management and frees up clinical staff, saving local health authorities and clinical commissioning groups in the UK £5 million per year²³. By enhancing someone's quality of life, while also making them less likely to need additional health services in the future, such interventions can help to ensure a country's financial investment in HIV treatment results in concrete health outcomes that are felt, not only in the short term, but throughout a person's life²⁴. In economic terms, what is good for the individual is also good for the country.

Examples of the economic benefits of addressing quality of life are seen in case studies from diverse countries. For example, the HIV Clinic in Kristiansand, Norway [see Figure 7] found a holistic approach to quality of life, based on a user-driven model and case management system, not only brought better and broader health outcomes for clients but also improved the cost-efficiency of its services²⁵. Similarly, 56 Dean Street in London, UK [see Figure 7], found that, by integrating a wide range of quality of life-related services (such as for HIV treatment, drug use and mental health) in one location, it could reduce the number of separate appointments for clients and, in turn, the expense of services²⁶.

Where does quality of life for people living with HIV fit within the global response to HIV?

Much of the current thinking around quality of life is based on existing frameworks that have guided and progressed comprehensive prevention, care, support and treatment for people living with HIV. A key example is Positive Health, Dignity and Prevention (PHDP), developed by the Global Network of People Living with HIV (GNP+) and UNAIDS in 2011²⁷. This expanded on earlier concepts of 'positive living' and 'positive prevention' to encompass a full range of health and social justice issues, grouped under eight components [see Figure 2].

20. Sophia Forum and Terrence Higgins Trust (2018) *Women and HIV Invisible No Longer: A National Study of Women's Experiences of HIV*

21. Survey conducted by the International Association of Providers of AIDS Care in collaboration with UNAIDS, GNP+ and the International Community of Women Living With HIV (ICW), cited in Moody K (2018) *Report of the Workshop: In Search of the 4th '90': Exploring and Defining What Quality of Life Means for Communities and Strategising How We Get There, AIDS 2018*

22. HIV Outcomes A Call To Action By The HIV Outcomes Initiative: *Improving Outcomes For People Living With HIV*

23. Positively UK (2017) *Now What? The Effectiveness Of Peer Support In HIV And The Need For Action*

24. Positively UK (2018) *Gay and Bisexual Men's Project: Evaluation Report*

25. For further information see <https://www.gnpplus.net/blog-user-driven-care-norway/>

26. For further information see <http://dean.st/>

27. GNP+ and UNAIDS (2011) *Positive Health, Dignity And Prevention: A Policy Framework and GNP+ and UNAIDS (2013) Positive Health, Dignity and Prevention – Operational Guidelines*





Figure 2: Positive Health, Dignity and Prevention

The PHDP framework promotes a set of principles²⁸, including the notion that policies and programmes for people living with HIV should be designed and implemented with the greater involvement of people living with HIV, known as the GIPA principle. It also highlights the importance of placing the person living with HIV at the centre of managing their own well-being.

More recently, quality of life has been framed by the latest international commitments that guide prioritisation and investment for the global response to HIV. These include the 90-90-90 targets that, by 2020, not only call for 90% of all people living with HIV to know their status and 90% of those diagnosed to receive sustained ART, but for 90% of all people receiving ART to have viral suppression²⁹. Another key commitment is the WHO's Global Health Sector Strategy on HIV (2016-21)³⁰, which aims to achieve zero new HIV infections, zero HIV-related deaths and zero HIV-related discrimination in “a world where people living with HIV are able to live long and healthy lives”.

28. The guiding principles are: (1) We are more than patients (2) We will not be treated as vectors of transmission (3) We are all responsible for HIV prevention (4) We have needs and desires to be fulfilled

29. UNAIDS (2017) 90-90-90: An Ambitious Treatment Target To Help End The AIDS Epidemic

30. WHO (2016) Global Health Sector Strategy on HIV for 2016-2021

1. Adopt an integrated, outcomes-focused and patient-centred approach to long-term HIV care:
 - Put comorbidity prevention, treatment and management at the centre of long-term HIV care.
 - Coordinate outcomes-focused care delivery using a personalised care plan.
 - Integrate services for mental health and neurocognitive impairment.
 - Ensure an ongoing focus on sexual and reproductive health.
 - Increase systematic participation of people living with HIV in decisions about their care.
2. Expand national monitoring of long-term HIV care and outcomes.
3. Fund cohort studies to provide information on the long-term health of people living with HIV.
4. Combat stigma and discrimination within health systems.
5. Upscale involvement of the HIV community in priority setting at country level.

Figure 3:
Recommendations to Member States by HIV Outcomes Beyond Viral Suppression Coalition

There is a growing recognition that quality of life needs to be situated and recognised within current international commitments. A number of key stakeholders have made quality of life a specific advocacy focus. Of note, the HIV Outcomes Beyond Viral Suppression initiative (HIV Outcomes), which brings together leading advocates, civil society and academia³¹, has progressed the subject in Europe. The initiative aims to make the long-term health, well-being and chronic care of people living with HIV central to the HIV response, through the mobilisation of policy and decision makers³². In November 2017 at the European Parliament, HIV Outcomes launched a set of policy recommendations on quality of life³³ [see Figure 3]. These were subsequently road tested in Italy (which promotes a chronic care model for HIV) and Sweden (the first country to achieve the 90-90-90 targets).

In November 2018, HIV Outcomes is revisiting the European Parliament to share the lessons learnt from these road tests, and to advocate for greater national, European and international cooperation on the long-term well-being of people living with HIV³⁴. It will also launch a virtual good practice clinic; an online resource, sharing good practice examples from health authorities, medical professionals, civil society organisations and patient representatives³⁵.

The advocacy 'asks' of HIV Outcomes have evolved over time. While the initiative originally called for quality of life to be seen as a separate 'fourth 90' (positioned after viral suppression)³⁶, it now frames quality of life as a wrap-around goal that applies to all stages in the HIV prevention, care, support and treatment cascade³⁷ [see Figure 4].

31. HIV Outcomes' partners include AIDS Action Europe, AFEW, East Europe and Central Asia Union of PLWH, European AIDS Treatment Group, Gilead and Viiv Healthcare.

32. HIV Outcomes (29 November, 2017) 'People Living with HIV Can Live Longer, But Urgently Need Improved Care to Achieve Better Health Outcomes and Quality of Life'

33. HIV Outcomes 'Recommendations launched at the European Parliament November 2017' and HIV Outcomes Beyond Viral Suppression (29 November, 2017) 'People Living with HIV Can Live Longer, But Urgently Need Improved Care to Achieve Better Health Outcomes and Quality of Life'

34. HIV Outcomes Initiative (27 November, 2018) 'Improving Long-Term Health and Well-Being of People Living with HIV: Learning from Country Experiences in Chronic Care' <http://hivoutcomes.eu/event/compendium-of-good-practices-on-the-long-term-health-chronic-care-and-well-being-of-people-living-with-hiv/>

35. HIV Outcomes (11 October, 2018) 'Call for Submissions: Good Practices on the Long-Term Health, Well-Being and Chronic Care of People Living with HIV' <http://hivoutcomes.eu/update/call-for-submissions-good-practices-on-the-long-term-health-well-being-and-chronic-care-of-people-living-with-hiv/>

36. Lazarus JV, Safreed-Harmon K, Barton SE, Costagliola D, Dedes N, del Amo Valero J, Gatell JM, Baptista-Leite R, Mendão L, Porter K, Vella S and Rockstroh JK (2016) 'Beyond Viral Suppression of HIV – The New Quality of Life Frontier' *BMC Medicine*, 14 (94).

37. Health is Global: Lazarus VJ and Safreed-Harmon K (3 October, 2018) 'Depicting a New Target For the HIV Response: How Do You See the "Fourth 90"?' <https://www.isglobal.org/en/healthisglobal/-/custom-blog-portlet/visually-depicting-a-new-target-for-the-hiv-response-how-do-you-see-the-fourth-90-/5511380/0>

Many stakeholders warmly support such ‘asks’. However, others warn that linking quality of life for people living with HIV to treatment-specific targets risks an overly medicalised and HIV-specific approach, when approaches should be more holistic and comprehensive³⁸. They also note that any targets, including for quality of life, should be 100%, in that they should include the ‘missing 10%’ of people living with HIV, who are often the most vulnerable and marginalised.

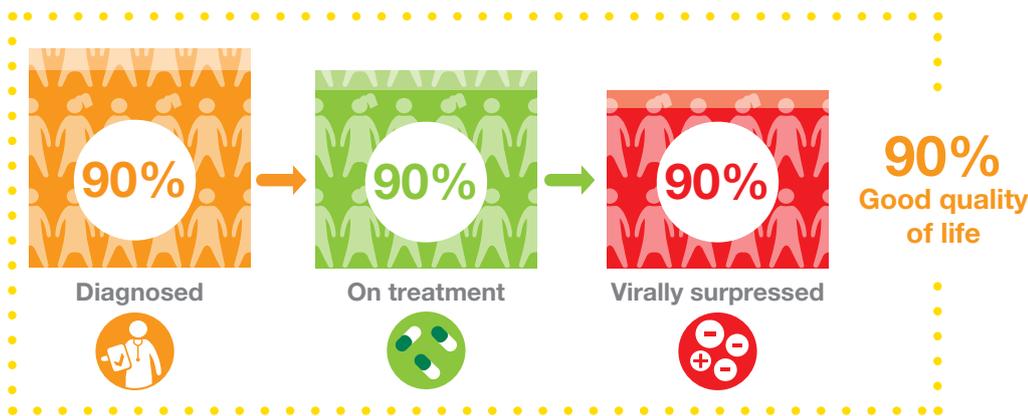


Figure 4: Integrating quality of life into the 90-90-90 targets for HIV treatment

What do interventions to improve quality of life for people living with HIV look like?

Enhancing quality of life for people living with HIV requires paying attention to what interventions are provided, how the interventions are implemented, and when the interventions are delivered.

What quality of life interventions should be provided?

As summarised in Figure 5, interventions to enhance quality of life for people living with HIV involve a package of support and services. These should address the diverse and life-long needs of the whole person, including, but extending beyond, their HIV status. Furthermore, measures that do address HIV should be comprehensive in that they should not only be about treatment but prevention, care and support – the latter described by STOPAIDS as the ‘forgotten pillar’ of the HIV response³⁹.

Interventions should respect that quality of life for people living with HIV is highly personalised. One person’s quality of life might be improved by addressing the side effects of ART and going back to work; another’s might be boosted by being accepted back into their family and getting support to control their diabetes.

38. International HIV AIDS Alliance quality of life meeting, November 2017.

39. UK Consortium on AIDS and International Development (2011) *Care and Support: The Forgotten Pillar of the HIV Response* <https://stopaids.org.uk/wp/wp-content/uploads/2017/06/CareSupportAdvocacyDoc2011.pdf>

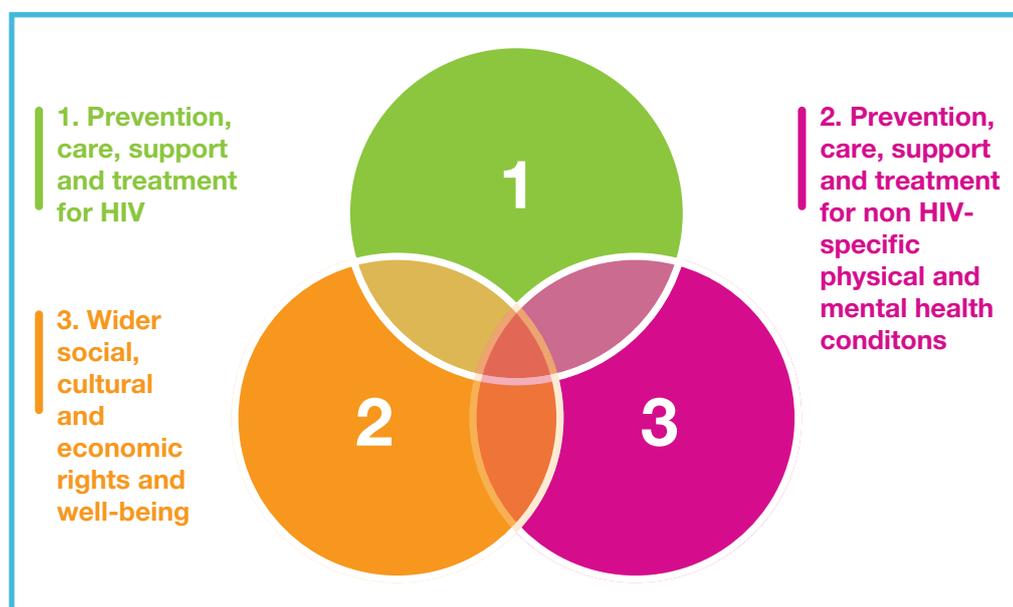


Figure 5: Package of support and services to enhance quality of life for people living with HIV

How should quality of life interventions be implemented?

To achieve quality of life for people living with HIV it is also important to look at how interventions work⁴⁰. This involves packages being designed and implemented in a way that is:

- **Person-centred**, with programmes and services focused on the specific needs of each individual and delivered through a case management approach.
- **Person-involved**, so that decisions are taken with, and not for, people living with HIV, and people living with HIV are involved in all stages of an initiative's design and implementation.
- **Integrated**, so that quality of life interventions are embedded into existing HIV programmes (rather than delivered in isolation) and linked to other relevant services, such as for tuberculosis (TB) or sexual and reproductive health and rights.
- **Within a continuum**, with multi-disciplinary teams and different organisations and sectors working together in order to minimise the number of different delivery points at which people living with HIV have to access services⁴¹.
- **Ethical and based on good practice**, such as of meaningful engagement, confidentiality and a human rights-based approach.

The first characteristic listed – that of person-centred approach – is especially important for quality of life interventions⁴². The International HIV/AIDS Alliance suggests the aim of such an approach is to “understand the needs of a person, their capacity to make responsible decisions, and the environment and behaviour that puts them at risk”. The approach also “consciously adopts the perspectives of individuals, families and communities and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways”⁴³.

40. Lazarus JV, Safreed-Harmon K, Barton SE, Costagliola D, Dedes N, del Amo Valero J, Gatell JM, Baptista-Leite R, Mendão L, Porter K, Vella S and Rockstroh JK (2016) 'Beyond Viral Suppression of HIV – The New Quality of Life Frontier' *BMC Medicine*, 14 (94).

41. Beta Blog: Land E (3 October, 2017) 'For People With HIV, What's Next After Viral Suppression?' <http://betablog.org/people-hiv-whats-next-viral-suppression/>

42. Sheikh K, Kent Ranson M, Gilson L (2014) 'Explorations on People Centeredness In Health Systems' *Health Policy and Planning*, 29 (2).

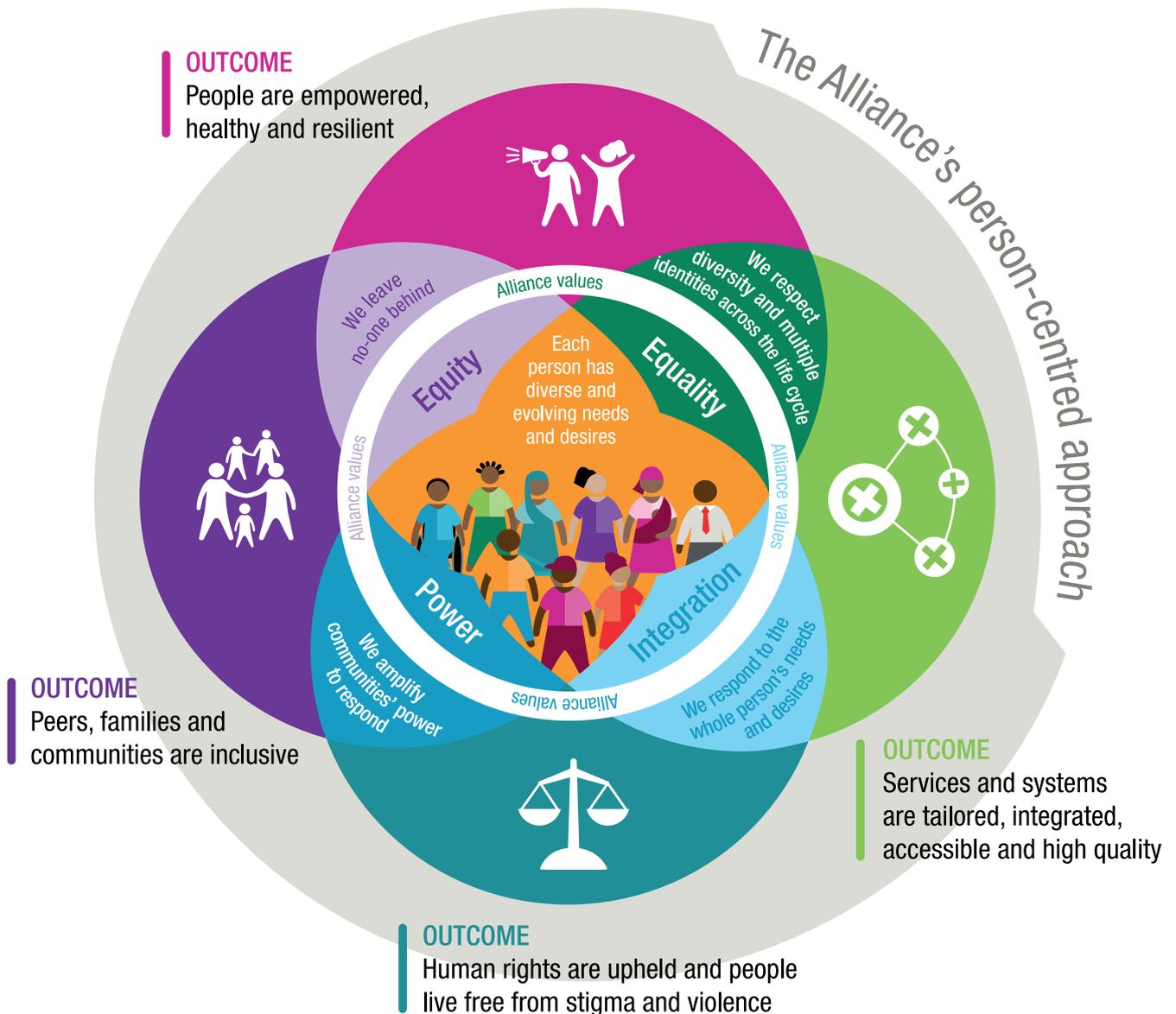
43. International HIV/AIDS Alliance (2016) *HIV, Health and Rights: Sustaining Community Action, updated 2016-20 strategy*



As shown in Figure 6, a person-centred approach is based on appreciating that each individual has diverse and evolving needs, hopes and desires. Understanding and addressing this brings multiple, positive outcomes at different levels, not only for individuals but also for services and systems.

The WHO advocates for HIV services that are “organised around the health needs and expectations of people rather than diseases”⁴⁴. This requires a range of strategies and actions such as building the communication skills of healthcare providers, giving patients adequate information to make informed decisions, and coordinating care for people who need multiple types of services. Figure 7 provides examples of what person-centred approaches within interventions to support quality of life for people living with HIV look like in practice.

Figure 6: The International HIV/AIDS Alliance’s person-centred approach



44. WHO (2016) Consolidated Guidelines on the Use of Antiretroviral Drugs For Treating and Preventing HIV Infection Recommendations for a Public Health Approach: Second Edition

When should quality of life interventions be delivered?

It is also important to consider when interventions for quality of life should be provided. Such support should be incorporated from the earliest possible stages of the HIV prevention, care, support and treatment cascade. This includes specifically targeting people newly diagnosed with HIV to establish positive practices from the start, prevent them from feeling isolated, and help them to maintain or increase their quality of life⁴⁵.

Figure 7: Examples of person-centred approaches to support quality of life for people living with HIV

HIV Clinic, Kristiansand, Norway⁴⁶

In 2012, the clients of the HIV Clinic at Sørlandet Hospital in Kristiansand, Norway were asked how they would run the clinic if they had the chance. This consultation led the management to undertake a dramatic redesign of services to provide more holistic and higher-quality support and promote quality of life. The clinic's model changed from being institution-driven, to one based on:

- **a user-driven approach**, which involves engaging each individual, for example by asking them questions and providing information and support relating to their physical and mental health, financial situation and faith
- **a case management system**, which involves someone such as a nurse, social worker or peer being allocated responsibility for managing and coordinating whole-person support for each individual patient.

Key steps taken by the clinic included the appointment of an HIV coordinator: a nurse responsible for setting up and monitoring individual care plans for clients and coordinating follow-up with internal and external services, both health and non-health related. Other important steps included the development of comprehensive checklists that addressed a core set of issues during appointments in order to standardise the approach to individual care, and provision of a mandatory 'HIV master class' for people living with HIV, designed to improve people's understanding of well-being and empower them to engage in the management of their own disease. The work was supported by a user forum, and people living with HIV were given a formal decision-making role at all levels of the clinic.

The new model was based on the hospital's long-term experience working with other chronic diseases. Its results included increased user engagement in services, better and broader health outcomes for clients, reduced physician time, and improved cost-efficiency of services.

45. Positively UK (2018) *Gay and Bisexual Men's Project: Evaluation Report*

46. Moody K (2018) *Report of the Workshop: In Search of the 4th '90': Exploring and Defining What Quality of Life Means for Communities and Strategising How We Get There, AIDS 2018*

Figure 7 (continued): Examples of person-centred approaches to support quality of life for people living with HIV

Vihaan, Alliance India

Named after the Sanskrit word for ‘dawn’s first light,’ Vihaan is a national initiative to establish and manage 350 Care and Support Centres across India. It aims to expand access to essential services, increase treatment adherence, reduce stigma and discrimination, and improve quality of life for people living with HIV. Its comprehensive support and services include counselling, TB screening, partner testing, home-based care, follow-up with people who discontinue treatment, and referrals to other organisations. To support its work, Vihaan uses an innovative, tablet-based tool to facilitate case management. The tool helps programme staff track improvements in the quality of life of individual clients and link them to additional (health and non-health) services, both within the programme and external to it. It also enables Vihaan to better collect evidence, improve data accuracy, and plan and prioritise its services. The programme has distributed 2,000 tablets across 30 states, accompanied by training. The tool has enabled Vihaan to provide 1.2 million referrals for people living with HIV, around 593,700 linkages to forms of social protection (such as nutritional or pension schemes), and report around 6,100 cases of discrimination (experienced within family and health service contexts).

56 Dean Street, London, UK⁴⁷

56 Dean Street is an award-winning, government-run HIV and sexual health clinic in London, UK. Its services are available to anyone but it particularly caters for gay men and other men who have sex with men and it is staffed by a combination of peers and trained health professionals. The clinic integrates a wide range of services, such as for HIV treatment, mental health and drug use, all in one location. It offers both bookable appointments (such as for safer sex counselling) and walk-in services (such as for post-exposure prophylaxis). It also offers extensive telephone, email and online services. 56 Dean Street complements its clinical services with counselling support, and has a number of health advisors who are trained to address issues such as depression, sexual relationships and disclosure of HIV status. It also provides linkages to other services such as CliniQ, a sexual health and well-being service for transgender people. In addition, the clinic runs a programme of entertaining and educational community engagement events, such as exhibitions and films.

Conclusions and recommendations

As the global response to HIV continues through its fourth decade, a good quality of life for people living with HIV is a fundamental right and a critical challenge. It is something that is multi-dimensional and specific to each individual person. However, quality of life is also affected by the communities, societies, political contexts and legal environments in which people live, and the frameworks that guide global health and development.

Quality of life is vital for all people living with HIV, including those from key populations, whether virally suppressed or not. Action to address it should be based on established good practice, including GIPA and person-centred approaches.

As donors and other key stakeholders develop their work on quality of life for people living with HIV, the following actions are recommended within relevant policies, strategies and resource allocations:



Recognise and profile the on-going importance of quality of life for all people living with HIV, whether they have achieved viral suppression or not. This should be based on an understanding of quality of life as something that is a right, holistic and multi-dimensional.



Develop packages of long-term, chronic care interventions to meet the differentiated quality of life needs of individuals living with HIV. This should be based on the notion of quality of life being specific to each person, affected by factors such as their age, gender, culture, economic situation, period of living with HIV, level of viral suppression, and whether they are from a key population most vulnerable to, and affected by, HIV.



Allocate resources to quality of life interventions as part of essential support and services for people living with HIV, not as an optional extra. This should involve the costing of quality of life interventions, provision to include quality of life interventions in programme proposals and funding requests, and recognition of quality of life interventions as an important strategy for cost effectiveness.

