

## FACTSHEET HIV and quality of life



Quality of life (QoL) is an essential issue for all people, regardless of whether they are living with HIV or not. This factsheet is intended to be used as a good practice guide for STOPAIDS members and the wider international development sector.

The paper takes a whole-life-course approach and highlights best-practice case studies from across the STOPAIDS membership. The paper explores what QoL is and what it means for people living with HIV; provides a summary of key components of initiatives and considerations for their design; highlights gaps in QoL initiatives; and concludes with recommendations for all stakeholders in the HIV response.

### WHAT DO WE MEAN BY QUALITY OF LIFE?

QoL is a broad ranging concept that is affected in a complex way by various factors. This can include a person's physical health, mental state, economic opportunities, personal beliefs and social relationships. Societal well-being (for the most part influenced by government choices in areas including education and health) can play an important part in determining someone's overall quality of life.

#### Quality of life and health related quality of life – what is the difference?

QoL is broader than Health Related Quality of Life (HRQoL) because it includes assessments of non-health related features of life. HRQoL is connected to an individual's health or disease status.<sup>3</sup> QoL helps us understand aspects of life that extend beyond health, for example education and the social environment. In comparison, HRQoL only considers aspects of life related to health.

QoL and HRQoL are interconnected and influence each other. HRQoL should be seen as both a result and a cause of having good / poor QoL in other aspects of life. For example, employment, housing, social relationships and economic opportunities. This factsheet will consider both QoL and HRQoL.

#### DEFINITION

The World Health Organization (WHO) defines QoL “as 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”.<sup>1</sup>

Frontline AIDS defines QoL as something that is:<sup>2</sup>

- **Multi-dimensional:** it is not about one single thing, but made up of multiple, varying factors.
- **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).

### QUALITY OF LIFE IN THE CONTEXT OF GLOBAL HEALTH POLICIES

#### Sustainable Development Goals

In 2015 governments agreed to the 2030 Agenda for Sustainable Development. This included Sustainable Development Goal (SDG) 3 on 'Good Health and Well-being' that seeks to promote well-being for all at all ages.

The SDGs are interdependent. There is interconnectedness between QoL and targets across the SDGs. Efforts to achieve goals such as reducing poverty are needed to promote better health. While in turn, improving health outcomes is key to the success of SDGs.<sup>4</sup> Therefore, improved QoL should be seen as both an essential contribution to, and result of, achieving the SDGs.

#### Person-centred approaches

Governments and healthcare providers are increasingly seeking to deliver healthcare in person-centred, integrated ways. There is international high-level support for this shift. For example it is highlighted by the World Health Organization's *Framework on Integrated Person-Centred Health Systems*,<sup>5</sup> the *Consolidated Guideline on Sexual and Reproductive Health and Rights of Women living with HIV*,<sup>6</sup> and the *Consolidated Guidelines on Self-Care Interventions for Health*.<sup>7</sup>

## DEFINITIONS

**Person-centred:** People using health and social services are positioned as equal partners in planning, developing, monitoring and evaluating their care. This means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome.<sup>8</sup> This approach helps make sure someone's care meets their needs. Person-centred services are co-created by the service provider and the patient. Mutual trust, respect and empathy are the foundations of the carer-patient relationship.

**Programme integration:** Joining together different kinds of services in order to optimise outcomes. This could be organising referrals from one service to another, or offering one-stop comprehensive and integrated services.

In the context of HIV, integrated programmes may include sexual and reproductive health, primary care, maternal and child health, screening and referral for intimate partner violence,<sup>9</sup> mental health services<sup>10</sup> as well as integration of HIV testing and counselling with the diagnosis, prophylaxis, and treatment of tuberculosis (TB), and other comorbidities, including non-communicable diseases<sup>11</sup>.

A person-centered approach is critical to understand the needs of a person and the environment and behaviour that puts them at risk.<sup>12</sup> Person-centered and trauma-informed care<sup>13,14</sup> has been shown to significantly improve well-being and QoL for people with long-term or chronic health conditions. This includes dementia,<sup>15</sup> HIV,<sup>16</sup> malaria and cancer;<sup>17</sup> non-communicable diseases and harm-reduction services. A person-centered approach also helps ensure more effective service delivery for diverse and key populations.

With the increasing calls for person-centred approaches and Universal Health Coverage, it raises the significance of QoL initiatives. This underscores the need to generate more evidence to support the scale up of community-led leadership in developing and delivering services.

## ADVANCING THE QUALITY OF LIFE OF PEOPLE LIVING WITH HIV

People living with HIV desire the same quality of life as any other person. They have the same needs, desires and aspirations.<sup>18</sup> But QoL is especially pertinent for people living with HIV. It affects their ability to enter and stay within the continuum of care. This affects their ability to become and remain virally suppressed. While viral suppression is important both for individuals living with HIV and responses to the epidemic, it is not the end point of action on HIV.<sup>19</sup>

Rather than simply prolonging the lives of people living with HIV, initiatives should be taken to ensure they are healthy, happy and fulfilled.

## QoL initiatives

Given that QoL is person-dependent, QoL initiatives involve a package of personalised support and services.

QoL services have focused mostly on person-centred clinical initiatives from the health system. However, the Quality of Life Partnership has highlighted that greater attention needs to be given to the other critical domains. This includes integrated, person-centred community-led initiatives; and, empowered, engaged and resilient people living with HIV.

QoL initiatives should look to address the needs and desires of the whole person. This includes but extends beyond their HIV status. QoL initiatives should also be comprehensive in that they should not only be about treatment but also prevention, care and support.

Frontline AIDS proposes that to experience quality of life, a person living with HIV needs access to high quality, appropriate, and comprehensive support and services for their whole-person.<sup>20</sup> This requires attention to three core components:

- Prevention, care, support and treatment for HIV and co-infections including TB and hepatitis C.
- Prevention, care, support and treatment for non-HIV-specific physical and mental health issues.
- Well-being and wider social, cultural and economic rights.

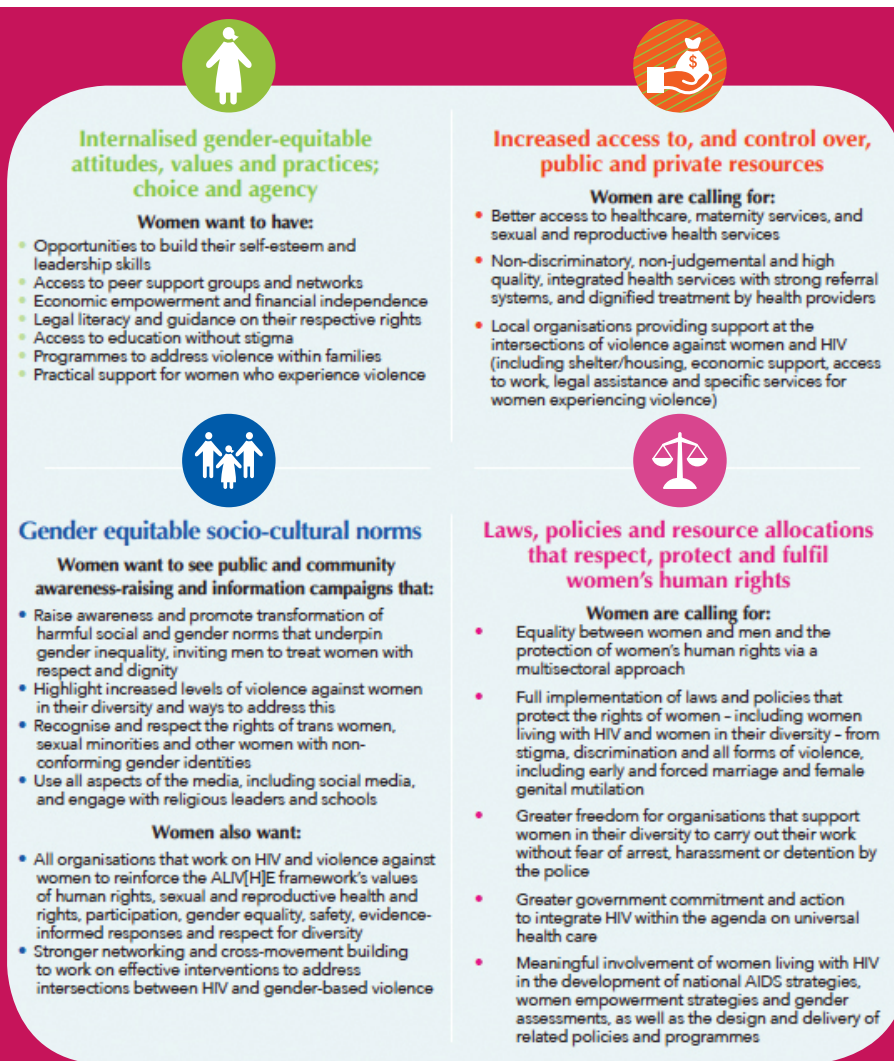
For QoL initiatives, it is important to consider the wider social and cultural rights that have a strong impact on people living with HIV. In respect to violence against women, it is important to consider the *Action Linking Initiatives on Violence Against Women and HIV Everywhere (ALIV[H]E) Framework*.<sup>21</sup> It was developed to strengthen responses and widen the evidence base on 'what works' to reduce violence against women. The ALIV[H]E Framework – based on the Gender Change Matrix – is used to analyse the priorities of women living with HIV (see Figure 1).

## 'The fourth 90'

QoL has become increasingly important in policy discussions about the future of HIV prevention, care, support and treatment.

UNAIDS' 90-90-90 HIV treatment strategy published in 2014 recommended expanding access to HIV testing, treatment and retention in care services.<sup>23</sup> The strategy with its three targets has brought clear benefits to the HIV global treatment response. However, it failed to explicitly include a target that spoke to the quality of life of people living with HIV.

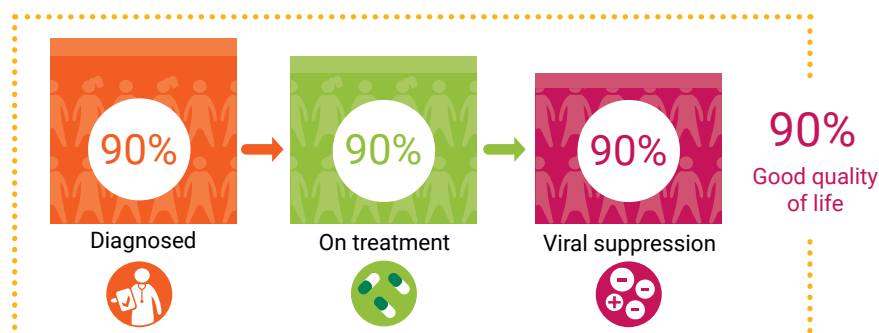
**Figure 1: The ALIV[H]E Framework used by women living with HIV in the Middle East and North Africa region to identify their priorities.<sup>22</sup>**



Similarly the WHO's *Global Health Sector Strategy on HIV for 2016–2021*, includes the 90-90-90 targets, which call on health systems to reduce under-diagnosis of HIV, treat a greater number of those diagnosed, and ensure that those being treated achieve viral suppression.<sup>24</sup> Within this strategy, it advocates for person-centered care of people living with HIV and implicitly acknowledges that viral suppression is not the ultimate goal of treatment. However, it does not include an explicit target for health-related quality of life.

The 'fourth 90' was proposed as an additional target to the 90-90-90 targets to ensure that 90% of people with viral load suppression have a good health-related quality of life. The initiative was originally called for the 'fourth 90' to be positioned after viral suppression, but it now frames quality of life as a wrap-around goal that applies to all stages in the HIV prevention, care, support and treatment cascade.<sup>25</sup> This approach envisions QoL as an essential component to facilitate people entering into the continuum and then achieving and maintaining viral suppression.

**Figure 2: Integrating quality of life into the 90-90-90 target for HIV treatment<sup>26</sup>**



## THE DIFFERENT COMPONENTS TO ACHIEVING QUALITY OF LIFE OF PEOPLE LIVING WITH HIV

Whilst QoL of people living with HIV is person-dependent, the following components are key to delivering comprehensive support and services for a whole person and improving QoL and HIV outcomes.

### Prevention, care, support and treatment for HIV

If a person living with HIV has a good quality of life, they are more likely to be able to access and adhere to antiretroviral therapy. In turn, they are more likely to achieve viral suppression. Without QoL initiatives that seek to enhance the QoL of people living with HIV – such as peer support, economic opportunities and stigma-free health services – people living with HIV may be less able to adhere to treatment and achieve viral suppression. HRQoL dimensions such as cognitive functioning, financial status and medical care, are closely associated with antiretroviral therapy adherence.<sup>27</sup>

Women and other inadequately served populations that are disproportionately affected by HIV face significant challenges to treatment access, including violence in healthcare settings.<sup>28,29</sup> These factors can result in mental health issues and limited ability to access or adhere to treatment.<sup>30,31</sup>

### Prevention, care support and treatment of non-HIV-specific physical and mental health issues

#### Sexual and reproductive health and rights

People living with HIV can face significant barriers from realising their sexual and reproductive health and rights. For example a review found women living with HIV in Latin America and the Caribbean are more likely to have fewer contraceptive choices, more unplanned pregnancies, are at an increased risk of post-partum sterilisation and exposure to sexual and institutional violence.<sup>32</sup> In order to meet the health needs and rights of women living with HIV, interventions need to be put into place to overcome barriers to service uptake and continued engagement.<sup>33</sup> It is essential to address barriers such as social exclusion and marginalisation, criminalisation, stigma, gender-based violence and gender inequality.<sup>34</sup>

#### Comorbidities

People living with HIV may be at increased risk of additional chronic conditions and diseases. This includes TB, hepatitis B, hepatitis C and some forms of cancers, such as cervical cancer. Research suggests that additional chronic conditions increase as people living with HIV age. Sometimes these problems also occur at younger ages compared to the

general population.<sup>35,36</sup> Research in England and Wales suggests two-thirds of people living with HIV have at least one long-term health condition other than HIV.<sup>37</sup>

#### Mental health

In order to treat HIV effectively, it is necessary to address people's mental health conditions. These can affect QoL and overall health outcomes. People living with HIV are disproportionately affected by mental health conditions, with those living in the UK being twice as likely to experience mental health conditions compared to the general population.<sup>38,39</sup>

Mental health conditions may include emotional distress, anxiety, depression, treatment for depression, addiction, post-traumatic stress disorder (including PTSD from receiving an HIV positive diagnosis), cognitive impairment and mania. There can also be mental health side effects in some HIV treatment. Sometimes mental health challenges are not directly linked to having HIV but other factors and life events. Depression is the most common mental disorder affecting people living with HIV and/or TB, with the risk for depression being two and three times higher for people with HIV and TB.<sup>40</sup> The increased risk of depression is influenced by factors including HIV-related stigma, internalised stigma, intimate partner violence and/or violence in healthcare settings and treatment side effects.

Many people living with HIV experience internalised stigma as a result of their HIV diagnosis. For many, taking an HIV test is still associated with shame and they feel very much to blame as a result of all the global taboos around the main routes of adult transmission, and inferences they and others make about their reputations, which many decades now of public health education have still failed to dismantle. In addition, people with HIV can already be marginalised by society through their identity as women, as people of colour, as people who use drugs, who do sex work, or who are gay, lesbian or trans, experience additional layers of internalised stigma. This internalised stigma, often compounded by PTSD, can have a significant effect on QoL with highly detrimental consequences for on-going self-care.

A growing body of research shows that the groups most affected by HIV (such as people who inject drugs, sex workers, men who have sex with men, transgender people) are more likely to experience mental health conditions.<sup>41</sup> Intersectional stigma can amplify these conditions.<sup>42</sup> For example, research from the Sophia Forum in the UK revealed high levels of unmet need and poor mental health among women, including trans women, living with HIV.<sup>43</sup> Adolescents and young people living with HIV globally have higher rates of depression and mental health problems than others of their age.<sup>44,45</sup> Despite young people living with HIV being more likely to have mental health conditions, of the

young people living with HIV who responded to Youth Stop AIDS' global research survey, only 28% were aware of the mental health support services that are available to them.<sup>46</sup>

Individuals with unsupported mental health conditions are less likely to seek HIV testing and follow advice given in response to their test result.<sup>47</sup> By contrast, women who become pregnant face routine ante-natal testing and often learn that they have HIV with no psycho-social support, yet are then blamed by health staff for not returning to the clinic, and by family members for having 'brought' HIV into the home.<sup>48,49</sup> To increase testing, adherence and QoL, there needs to be improved access to high-quality mental-health treatment that is delivered in a person-centered way.<sup>50</sup>

### COVID-19 pandemic

The COVID-19 pandemic has been shown to disproportionately affect people's mental health.<sup>51</sup> Levels of depression, harmful substance use, and suicidal behaviour have risen.<sup>52</sup> There is also widespread evidence of increased levels of intimate partner violence.<sup>53,54</sup> For long-term survivors of HIV, the COVID-19 pandemic has also been noted to be triggering and having the potential to bring back trauma.<sup>55</sup>

The discrimination and marginalisation experienced by key populations and young people living with HIV places them at heightened risk of experiencing mental health challenges during the COVID-19 pandemic. Research from UNICEF highlights that the pandemic may aggravate feelings of loneliness, depression and anxiety in key populations and young people living with HIV.<sup>56</sup>

During the pandemic in affected regions, it has been harder for people living with HIV to access services that support their QoL and HIV management. For example, collecting medication and accessing mental health initiatives like peer support.

### The pregnancy journey for women living with HIV and their children

The perinatal period presents various challenges for women living with HIV. This includes the mental health challenges that pregnancy alone can contribute to, with the added impacts of being diagnosed in pregnancy. The impact of being diagnosed in pregnancy have been shown to include feelings of loss, thoughts of suicide or self-harm.<sup>57</sup> Over a third of domestic violence starts or gets worse when a woman is pregnant. Women living with HIV are already more likely to experience intimate partner violence compared to the general population. This presents further challenges for women to improve QoL for themselves and their newborn.<sup>58,59</sup> It has also been shown that women living with HIV can face barriers to bonding with their newborn and suffer from anxiety from waiting for the last HIV test result for their newborn.<sup>60</sup>

### Palliative care to relieve pain, whether from HIV-related or broader health issues

The continued importance and need for palliative care in HIV management is underlined by factors including the high prevalence of pain and symptoms; the toxicity, side effects, and virological failure associated with antiretroviral therapy; emergence of comorbidities; and the comparatively higher death rates among people living with HIV.<sup>61</sup>

STOPAIDS has proposed that effective palliative care to improve the QoL for people living with HIV should include aspects of:<sup>62</sup>

- Psychosocial care and support – counselling, emotional support, spiritual support, bereavement support.
- Clinical care – pain management, treatment of AIDS-related illnesses and opportunistic infections, particularly TB and sexually transmitted infections.
- Psychosocial and medical care and support for families, friends, care-providers and children affected by HIV.

### Well-being and wider social, cultural, civil / political and economic rights

An enabling environment is a mandatory prerequisite for quality of life. Yet, non-health related domains (such as criminalisation and unfavourable laws, poverty, gender inequality and other legal, structural and societal barriers) frequently prevent people living with HIV to realise their social and economic rights. This ultimately impacts on someone's QoL.

HIV-related stigma and discrimination deeply impact self-assessments of overall quality of life. Key factors include stigma (in families, communities and healthcare settings), discrimination, isolation and human rights violations.<sup>63,64</sup> When this occurs, it has been linked to medication non-adherence and other negative health outcomes for people living with HIV.

People living with HIV in general can often experience HIV-related discrimination in healthcare settings worldwide.<sup>65</sup> For example, in Algeria 53.5% of people living with HIV reported being denied health-care services because of their HIV status.<sup>66</sup>

Improving the QoL of people living with HIV requires paying particular attention to factors such as happiness, social connectedness, poverty, fatigue reduction and freedom from violence.

The Quality of Life Partnership argues that a supportive foundation are essential for people living with HIV to enter into and remain in the continuum of care.<sup>67</sup> This foundation would look to address people's basic needs and desires, and support the most marginalised. Basic needs (including secure income, education, social protection, personal safety

and food and water security) must be met before people can consider addressing higher level needs. For the most marginalised, support for people to be able to act without fear of punitive consequences or stigma and discrimination needs to be addressed alongside basic needs. This calls for an urgent need to train staff across the health and social care sectors, police and criminal justice system in trauma-informed care.<sup>68</sup>

Projects funded by the Robert Carr Fund provide strong examples of the type of initiatives being delivered that seek to create a supportive foundation for marginalised populations affected by HIV. Robert Carr Fund funds networks and supports advocacy in every region of the world, wherever inadequately served populations face a disproportionate burden of HIV and serious human rights violations.

However, lack of funding for women's rights organisations in general has also added to the huge and chronic QoL challenges for many women living with HIV activists.<sup>69</sup> The Organisation for Economic Co-operation and Development (OECD) reports that only 0.5% of funds that target gender equality as a principle objective actually reach women's rights organisations.<sup>70</sup>

The widespread fear and uncertainty about COVID-19 may create further challenges for marginalised communities from being able to realise their basic rights. Stigma, discrimination, undue or un-evidenced restrictions and harmful criminal sanctions and policy environments threaten the ability of communities being able to realise their rights. STOPAIDS have advocated for a human rights based approach to COVID-19, with meaningful community and civil society engagement.<sup>71</sup>

## THE QUALITY OF LIFE INITIATIVES OF PEOPLE LIVING WITH HIV

Frontline AIDS propose that QoL initiatives should be designed and implemented in a way that is:<sup>72</sup>

- **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 and evaluation.
- **Integrated**, so that quality of life initiatives are embedded into existing HIV programmes (rather than delivered in isolation) and linked to other relevant services, such as for tuberculosis (TB), harm-reduction services and 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 services.
- **Ethical and based on good practice**, such as meaningful engagement, confidentiality and a human rights-based approach.

Through providing base practice case studies from across the STOPAIDS membership, this factsheet considers three critical types of QoL initiatives in more detail:

- person-centred clinical initiatives from the health system
- integrated, person-centred community-led initiatives, and
- empowered, engaged and resilient people living with HIV.

These initiatives must be seen as equally important domains to achieving improved QoL for people living with HIV.

### Person-centred clinical initiatives from the health system

There is an increasing number of QoL initiatives being delivered as part of existing health systems. This is partly as a result of countries seeking to deliver person-centered care that is integrated within the health system. These services could look to support people living with HIV to achieve and maintain undetectable status; and prevent, care and treat non-HIV-specific physical and mental health issues.

The growth in the QoL services delivered by facility-based services reflects the broader HIV care agenda that is emerging. The shift calls for health systems to focus on health-system integration, HIV-related discrimination, new measures of progress, and new roles for civil society.<sup>73</sup> QoL services need to be implemented as an intrinsic right of all people. In addition, due to people living with HIV living longer and, therefore, taking treatment for longer periods of time, there is a growing instrumental need to have good on-going QoL services in place. Aging increases the risk of developing additional morbidities and so screening, care and treatment protocols are required to ensure that people living with HIV remain healthy and feel motivated enough to manage to stay on treatment.

There are several examples of facility-based services (including the HIV Clinic, Kristiansand, Norway) that seek to take a user-driven approach in the delivery of QoL initiatives.<sup>74</sup> This approach involves engaging each individual. For example, asking them questions and providing information and support relating to their physical and mental health, financial situation and faith. Healthcare providers often take this approach in combination with adopting a case management system. This involves having a representative (such as a nurse, social worker or peer) being allocated responsibility for managing and coordinating whole-person support for each patient.<sup>75</sup>

Eliminating stigma and discrimination in healthcare settings has also been project spearheaded by UNAIDS' *Agenda for Zero Discrimination in Health-Care Settings*.<sup>76</sup> Governments are also taking national action to respond. For example, the Thai Government established a national network to monitor HIV-related stigma and discrimination in healthcare settings, and findings are informing ongoing efforts to counter this problem.<sup>77</sup> The People Living With HIV Stigma Index also provides an effective tool that measures and detects changing trends in stigma and discrimination experienced by people living with HIV, including in healthcare settings.

Some argue healthcare systems have been too focused on achieving the UNAIDS 90-90-90 targets at the expense

of ensuring quality of life. Within health systems in sub-Saharan Africa, it has been suggested that integration of care to improve access to a variety of health services for people living with HIV is often confined to reproductive health.<sup>78</sup> In addition, people living with HIV are often treated in rural health centres with limited resources to manage comorbidities. This can create further challenges to providing integrated health services.<sup>79</sup> By contrast, Women Fighting AIDS in Kenya (WOFAK), with support from UNAIDS, has rolled out the *Implementation Guide for the WHO Consolidated Guideline on SRHR of women living with HIV* as a pilot in three counties, with a very positive response from healthcare workers.<sup>80</sup>



### Mildmay Uganda

Mildmay Uganda is a multi-disciplinary General Hospital, with its core programmes being concentrated across 16 districts of Central Uganda. They

specialise in delivery of comprehensive and integrated healthcare in areas including treatment services; complementary social services; and health training and education.



Their family-centered holistic, integrated approach focuses on the holistic needs and well-being of a client living with HIV – physical, social, spiritual and emotional. Their multi-disciplinary approach brings together a range of professionals including medical doctors, nutritionists, social workers, and physiotherapists.

Mildmay Uganda is one of the implementers of the PEPFAR-funded *Determined Resilient Empowered Aids free, Mentored & Safe (DREAMS)* programme. The programme focuses on HIV prevention among girls and young women aged 15-24 years through evidence-based interventions to address HIV risk behaviours, HIV transmission, and gender-based violence.

One of the young women that Mildmay Uganda has supported through the DREAMS project is Janet. Born into a family of eight siblings, Janet's mum separated from her dad due to intimate partner violence when she was 12 years old. With her mother not being able to afford looking after all her children, Janet's friend introduced her to transactional sex.

Janet narrates, "It was a terrible experience. At 13 years, I lost my virginity to a stranger in a painful experience. I didn't mind that I could have contracted HIV". None of the men that Janet had sex with used a condom and she was advised that she was too young to contract HIV. Janet adds that "for one year, my life was defined by transactional sex. 'Enjoying life' was defined by selling sex to men, between 7-8 times daily" Janet recounts that she contemplated suicide as she "lost value in society and became tired of transactional sex".

"Namukwaya Rose (a DREAMS Coordinator) came to me during her routine home visits in search of girls like me and gave me hope to live," Janet recalls. Janet was tested for HIV at the Mildmay Uganda supported DREAMS safe space in Mityana district. After receiving a HIV negative

diagnosis, Janet became committed to being at the safe space and was enrolled into the DREAMS programme.

While at the Center, Janet was equipped with knowledge and skills in knitting, tailoring, marketing and financial literacy. Through the vocational and agricultural skills gained from DREAMS, Janet has set up a home vegetable garden and is hopeful that this will improve her income and the home. Through DREAMS, Janet now mentors other girls and young women in her community.

Janet is one of the 61,708 young women and girls (aged 10 to 24) that has been enrolled on the DREAMS

programme. In 2019 alone, over 24,934 young women received vocational skills training.

This case study highlights how person-centred, clinical initiatives from the health system can effectively support the holistic needs of people living with HIV, including those from inadequately served populations. With Mildmay Uganda actively exploring new roles for civil society, tackling discrimination and integrating services; they are effectively helping people to achieve and maintain undetectable status whilst treating non-HIV specific issues.

### **Integrated, person-centred community-led initiatives**

Since the start of the HIV response, the leadership of affected communities and civil society organisations has been critical. This is from peer support to fighting for access to HIV treatments. Community-led initiatives have been shown to be an effective way to improve someone's QoL. For example, linking people to services where they live and preventing disease progression.

These initiatives have often proven to be more accessible, more relevant and ultimately more cost-effective than those provided by the health system.<sup>81,82</sup> Community-led initiatives, (such as peer navigation, lifestyle change support, nutritional support, adherence support, mental health support) have the potential to identify individuals who are vulnerable to comorbidities. It can then support them to make changes that will help prevent progression to clinical stages, while maintaining an undetectable viral load.

In particular, community-led groups have proven successful in delivering peer support. Peer support is argued to be a prominent element of well-being. This is particularly pertinent given people living with HIV are living longer and therefore encounter new challenges with their health and other aspects of their lives.<sup>83</sup>

Although community-led initiatives have been shown to be effective and cost-effective, they are often under-funded. In addition, they are often not integrated with facility-based services or seen as an essential component to support the QoL people living with HIV.

### **Empowered, engaged and resilient people living with HIV**

In order to optimise HIV outcomes and improve QoL, it is important to ensure that people living with HIV can meaningfully engage in their HIV disease management.

For other chronic diseases, such as diabetes, the best clinical outcomes can be achieved by supporting people to become the primary manager of their own care.<sup>84</sup> Research shows that people living with HIV who perceived themselves to be involved in their HIV therapy decisions are more convinced and satisfied with their treatment.<sup>85</sup> It is therefore important that people living with HIV have the knowledge, will and power to become agents of their own disease management. This can be supported by health literacy, legal literacy and self-care.

However, there are challenges in some contexts around the world. For example in sub-Saharan Africa, there is often minimal involvement of patients in the planning and implementation of health services.<sup>86</sup> This can often be due to the traditional belief where patients tend to defer to the healthcare worker's judgement and decisions, accepting whatever care is offered.<sup>87</sup>

When a person does not have the capacity or does not want to fulfil this role, it is important for them to have the chance to either learn how to do so or to be offered services that support them in this role. This could be from non-healthcare workers, such as family members or peers.



### IPPF's Integration for Sustainability – Policy to Practice project

Increasing bi-directional linkages between HIV and wider sexual, reproductive, maternal, new-born, child and adolescent health, can have multiple far-reaching benefits, increasing the uptake of services and improving quality of care – especially of the most marginalised including people living with HIV.

A longstanding project, being implemented by International Planned Parenthood Federation and GIZ BACKUP Health, has been gathering evidence to improve integration between HIV and SRH services – currently in four countries, Cameroon, Guinea Conakry, Malawi and Togo.

In its current phase, the project is working alongside national ministries of health and civil society organisations to understand current service delivery models – focusing on the experiences of key populations and at-risk groups, including sex workers, men who have sex with men, and adolescents. The project aims to provide viable pathways towards more integrated and person-centred approaches, by identifying bottlenecks to effective integration – as well as examples of good practice and opportunities for additional investment.

During the initial stakeholder analysis, multiple barriers to client's quality of care were uncovered, including:

- Poor training: current training is delivered in silos, leading to the disruption of key services.
- Infrastructure challenges: the design and layout of the healthcare facilities are based on vertical service delivery models, which creates challenges around client flows/referrals.
- Weak coordination: although there is a high-level commitment to integration, facilities lack guidelines on how to implement this vision. This leads to duplications in service delivery.
- Discriminatory and/or stigmatising services: youth and key-population friendly services are patchy or non-existent. This deters people from utilising services, and communities lack the platforms to hold the health system to account.

The project worked to address these challenges across the 13 pilot sites. Part of this work focused on improving integration of services at the institutional level. In 2019, 13 subnational and three national technical-working groups (TWGs) on HIV/SRH integration were established or revitalised, with representation from ministries of health, UNFPA, Global Fund CCMs and IPPF affiliates, and increasingly community-based organisations. These TWGs supported the development of new guidelines and toolkits, to help strengthen the coordination and delivery of integrated HIV/SRH services, at the clinical level.



The second part of the project focused on supporting new service delivery models. This included promoting a one-stop shop approach (where clients receive all services on one site) or supermarket-type approach (where existing referral mechanisms are strengthened). To achieve this, clinics implemented a new mentoring scheme, to promote the importance of integration and human rights-based and youth-friendly services – and to provide training to address skills gaps. In three months, 75 mentors and 170 mentees were trained. This led to significant improvements in the quality of care. Client flows between different departments increased substantially. Across the 13 pilot sites, 95% of clients received at least three integrated services per visit, and over 80% of clients reported reduced waiting times. In Cameroon, Guinea and Malawi, key populations also reported feeling more comfortable when attending facilities.

Civil society and key population-led organisations were heavily involved in the development of this project – identifying pilot sites, undertaking stakeholder analyses and contributing to the development of each tailored mentorship programme. The creation of community dialogues and a community scorecard also gave clients an opportunity to express their concerns directly to their healthcare providers. The project gave civil society the opportunity to push for community-based service delivery modes, including peer-education and peer-led service delivery. This has led to improvements in the quality of care. For example, in Cameroon, youth and adolescent services have now been adapted following communities recommendations.

This case study provides an example of how to operationalise the integration of services, both at a policy and programmatic level. It shows how, with little investment, through on-site training and the re-organisation of services, facilities can bring about positive changes relatively quickly.



### Terrence Higgins Trust – At Home service



The coronavirus emergency, social distancing and isolation measures have had a vast impact on our services. Our clinics are closed. Face-to-face support groups and counselling are not able to function. But the needs of people living with HIV remain, and in many ways are more acute than ever, with social isolation, fear and uncertainty directly affecting the quality of life of people living with HIV.

We have seen an increase in enquiries from people living with HIV concerned about coronavirus. Amidst confusion and inconsistent messaging from the government, we worked with the British HIV Association to provide accurate advice and guidance based on the latest medical evidence.

Within a short space of time we also re-deployed resources to bolster a suite of digital living-well services to support people living with HIV – THT At Home.

Our counselling and emotional support service is now available digitally. Online counselling and emotional

support can help with the same range of personal and interpersonal problems as face to face counselling, but with the convenience of accessing the service from home via video call, phone or web chat.

The THT myHIV forum is a safe online space, moderated by trained peers, where members can meet other people living with HIV and ask questions, or just be there for a chat. The peer-to-peer offering of the forum has proved to be essential support for many people living with HIV.

We have also adapted our peer support groups to be available digitally – including groups for our older clients. A new weekly ‘living well in lockdown’ peer learning and support webinar helps people living with HIV to look after themselves, manage uncertainty and anxiety and build resilience for the future.

In a short space of time we have been able to mobilise a modern digital offer, based on identified need, which we will learn from and continue to adapt in the future.

## CASE STUDY

## Frontline AIDS and partners – READY+

For nearly a decade, the world has stepped up effort to reach the 90-90-90 targets to find, test and treat people living with HIV in order to achieve viral suppression. Yet adolescents and young people, particularly in sub-Saharan Africa, are still dying from AIDS-related illnesses. For many young people achieving the second and third 90s are goals that can often mask a complex story of intersecting mental health issues. These issues impact on their QoL as societal and self-stigma, late disclosure, isolation and fear and can lead to stopping treatment, suicidal thoughts and sometimes death.

In 2006, Tendai from Zimbabwe became ill and developed sores all over his body. He was diagnosed with HIV and started taking medication but his health did not immediately improve. He was frustrated because he didn't get a clear explanation of why he had to take medication every day. Tendai then stopped taking his medication for more than a year and a half, because of the bitterness and sadness he felt towards those who lied to him about his health over the years.

Some young people who have been on treatment since childhood are grappling with treatment fatigue whilst also going through puberty, which comes with its own fair share of challenges, and navigating friendships and intimate relationships. "Pill fatigue is the main challenge for young people. If someone is born with HIV, they take medication from maybe the age of six. So, they might say that these pills are becoming a problem and they no longer want to take them," Tendai says. "Also, people might have suicidal thoughts and the fastest way to suicide might just be defaulting on their medication." He adds: "I had no friends because of my sickness and my skin was so horrible. The community elders and the caregivers of my friends actually disowned me as friends to their children. It was a tough situation, a heart-breaking situation."

Through the READY+ programme, Frontline AIDS and its partners are working with and for adolescents and young people living with HIV in eSwatini, Mozambique, Tanzania



and Zimbabwe to feel empowered and take control of their well-being.

Tendai received support from a Community Adolescent Treatment Supporter (CATS) from Africaid (a young person who provides clinical and social support to their peers). This improved his mental health so that crippling self-stigma was replaced with hope and opportunities. "He came to my house every day trying to be a friend to me, but by then I was a closed book," says Tendai. "I didn't want to be anyone's friend. I thought 'can't he see that I've got sores all over my body and everyone in this community is disowning me to play with?' But he was so persistent." After attending peer support groups at Africaid for a number of years, Tendai was selected to become a peer supporter through the READY+ programme.

More work needs to be done to address the impact of poor mental health on short- and long-term quality of life. With support, training and advice, adolescents and young people living with HIV, their families, healthcare providers and the wider community can address mental health issues to minimise their detrimental effects, particularly for those who are marginalised and vulnerable.

The support Tendai received has been life changing. He was a CATS for five years and helped hundreds of young people, and now he continues to be an advocate for adolescents and young people living well with HIV.



### Salamander Trust – *Stepping Stones*

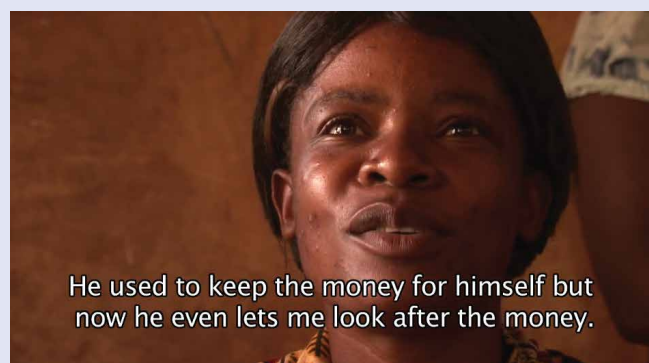
The *Stepping Stones* training programme was first published in 1995, and was wholly revised and updated in 2016. It focuses on gender, HIV, communication and relationship skills, and enables female and male participants to develop critical literacy skills in order to understand why we behave in the ways we do: how gender, generation, resulting power imbalances and other issues such as poverty, alcohol use, access to education, health resources and services, and other factors, influence our choices – or lack of them. The programme then supports participants to propose and agree on ways in which all involved can collectively make appropriate gendered and rights-based changes in our lives. As such, it supports participants to review and change social norms.



COWLHA (Coalition of Women Living with HIV and AIDS) was funded by the UN Trust Fund for Women to use *Stepping Stones* in 144 communities across 12 districts of Malawi during 2011-14. Their project, which also provided access to paralegals, aimed to reduce intimate partner violence against women living with HIV by involving COWLHA's members and their partners and other couples in *Stepping Stones* workshops.

The baseline research outlined how secrecy, disharmony and violence within relationships relating to the women's HIV status undermines management of living with HIV, including mental health issues, reduced adherence to antiretroviral therapy, and poorer physical health outcomes. Working with the women alone would not be sufficient, as their ability to manage HIV was tied to their partners' attitudes and behaviour. At endline,

the reported incidence of physical violence had been halved compared to the baseline (from 20% to 9% of respondents), while reported experience of sexual violence over the past 12 months had reduced from 41% to 11% (80% of the respondents were women). The changes were said to have come from improved communication and understanding between couples, reduced use of alcohol, and fewer extra-marital partners, enabling couples to escape from negative cycles of behaviour and to rebuild their relationships. There was also an increase in partners attending HIV testing together, and in individuals telling their partner they were going for HIV testing, thus creating more honesty and ability to manage HIV within their relationships. In a film subsequently made about the programme, these findings were echoed. Men and women reported how the programme had helped men to understand that their actions had been intimate partner violence. The men gained courage to go for testing and, if positive, to start on treatment. This improved the men's health, reduced the burden of care on women, making both men and women happier and healthier, which in turn enabled them to continue and/or start antiretroviral therapy. They also reported how this had a positive knock-on effect on the children in the communities.<sup>90</sup> A similar story of links between intimate partner violence, mental health, and low adherence to antiretroviral therapy, with a post-workshop move to reduced intimate partner violence, improved male testing, better mental health, better adherence and happier, safer adults and children is echoed in a film made by caregivers of children living with and/or affected by HIV in Tanzania, after a *Stepping Stones with Children* programme there.<sup>88,89,91,92</sup>





### 4M Mentor Mothers Network

The 4M Mentor Mothers Network (4M Net) programme run by and with women living with HIV, has been running since 2016 as a Salamander Trust project; in 2019 is registered as an independent Community Interest Company CIC. 4M Net was established to provide peer mentoring and support for other women living with HIV going through the perinatal journey. It seeks to ensure the sexual and reproductive health and rights of women living with HIV as they go through the pregnancy journey, in line with the WHO 2017 Guideline on this issue.<sup>93</sup>

4M Net provides easily accessible virtual peer support through WhatsApp and has influenced UK policy guidelines around peer involvement of Mentor Mothers. Each Mentor Mother works alongside health and social care professionals as part of a multi-disciplinary team, making it easier for them to support a woman through her pregnancy. 4M Net focuses on addressing stigma and other intersectional issues such as mental health and violence through Mentor Mother peer support, mentoring and supervision, webinars and training workshops.

Catherine\* is a black African woman who migrated to the UK aged 27 with her five-year old son in the mid-90s to join her husband who was studying there at the time. The couple were diagnosed with HIV a year later. They felt their hopes for more children were completely shattered. With better treatment options, things looked brighter and through accessing local peer support Catherine met Rose, who had been through the pregnancy journey herself whilst living with HIV. Rose encouraged and supported Catherine to consider her pregnancy options and, together with the help of a midwife, Catherine became pregnant and delivered a healthy HIV-negative son.

Catherine was so grateful for the support and mentoring she received she trained as a mentor mother herself. After completing basic training she attended the 4M Net three-day residential course with 13 other women from across the UK.



The training covers many key aspects to support other women living with HIV through their own perinatal journey. Catherine continues to support other women through face-to-face and phone interactions and receives ongoing supervision from the 4M Net core team. Catherine has developed many personal and professional skills through the process. With practical mentoring and support of the core team she delivers talks, presents at national and international engagements, co-facilitates trainings and is involved in peer research. Catherine has also returned to paid work. She says;

*"It has been like an emotional roller coaster; my personal development has increased. From minimal confidence to such a high level of confidence in pregnancy and HIV issues. I'm confident to support women. Seeing women empowered through my support has been so fulfilling. Long live 4M Network."*

This case study demonstrates the effectiveness of peer support and highlights the relevance of grassroots programmes such as 4M Net, and why funding is important for sustainability.<sup>94</sup>

### Response to COVID-19

4M Net's response to COVID-19 is to enhance the way we deliver the majority of our support through increased telephone support, supervision and webinars and circulating up to date alerts on COVID-19. We have recently produced a policy brief on the multiple harmful effects of COVID-19 lockdown on pregnant women living with HIV across the UK. 4M Net has also contributed to policy statements, including 'Women Working Virtually' – a protocol guide to working digitally with safety.<sup>95</sup>

You can read more about the 4M Net here: <https://4mmm.org/>

\* All names and details have been changed. Any resemblance to real life characters is purely coincidental and non-intentional.



### Sophia Forum – WISE UP+

WISE UP+ (Women Inspire Support and Empower to Unleash Positive Potential) is a structured series of workshops designed and led by women living with HIV with the aim of building a dynamic community of female HIV advocates. The objectives of the WISE UP+ programme are:

- To alleviate isolation – where there is no/low access to services, addressing unmet needs in service design and delivery;
- To increase knowledge and power – so that women are involved in healthcare decision making, dialogue with health professionals, becoming activists;
- To meet the needs of ALL HIV-positive women – exploring health disparities specific to culture, age, marginalised groups and intersectionality;
- To provide a safe space where women can share experiences, be creative and develop advocacy messages to inform policy and commissioning decisions;
- To endorse positive sex messages so that women can work towards the lives and relationships they want.



WISE UP+ methodology importantly centres on the leadership of women living with HIV. For this workshop six women living with HIV were recruited as co-facilitators for the weekend as a pilot initiative, providing a platform for them to grow and to develop facilitation skills.

The WISE UP+ methodology aims to create a safe space of community and connection, through which shared aims and expectations are defined to shape the workshop experience. Through this, the experiences, priorities and stories of all participants are centred and explored.

All areas of knowledge, skill and confidence showed improvement after the workshop, with particularly marked improvement in knowledge about menopause and about ageing with HIV, skills in setting objectives and planning advocacy activities, and confidence in speaking up on important issues

Quote from one participant: *“What you created enabled some emotional beautiful moments of support and connectedness and it was a privilege to be part of it. If I am honest I have felt like an outsider in terms of the HIV sector for a very, very long time and I did not think I would ever feel connected again, but I really did!”*

ADVOCACY  
TRAINING FOR  
WOMEN LIVING  
WITH HIV

WOMEN INSPIRE SUPPORT AND EMPOWER TO UNLEASH POSITIVE POTENTIAL

WISE  
UP+

## QUALITY OF LIFE INITIATIVES – WHERE ARE THE GAPS?

Community-led initiatives are both efficient and cost-effective for improving HIV outcomes and QoL for people living with HIV. The case studies in this paper highlight that they work across different identities and contexts. However these types of initiatives are often under-funded, not integrated with facility-based services and not seen as an essential component to support the health and well-being of people living with HIV.

It is critical that we can measure the impact of initiatives seeking to improve quality of life for programme planning, resource allocation, building investment cases and ultimately for achieving better health outcomes. Currently, funding flows mostly to clinical initiatives and research where the evidence generated is more quantitative and rigorous. Qualitative data generated by community-led and person-based initiatives are often seen as less objective and of less value. To respond to this, it is essential to advocate for greater investment in community-led initiatives and to strengthen the quality of data and the monitoring and evaluation models that can demonstrate their impact.

However, monitoring HRQoL can be difficult as the concept of wellbeing is subjective. Data collection can be burdensome and costly, particularly for civil society in resource limited settings. The UNAIDS-commissioned ALIV[H]E Framework supports communities to monitor, evaluate and document work; strengthen the evidence base on violence against women and HIV linkages; and collect evidence on what works to reduce this violence.

This approach has been successfully implemented in several regions. For example in Botswana, it has accelerated the participation of women and girls with disabilities in programmes that address violence and influenced the development of a government disability policy.<sup>96</sup>


Attempts to measure HRQoL for people living with HIV could take the form of a single global question (such as a self-rated health status). It could also be a multidimensional index that can be used to generate an overall HRQoL score from several questions. The latter approach has additional benefits in that it can allow comparisons with the general population.<sup>97</sup> An example of a multidimensional index is the PozQoL study that developed, tested and validated a short and freely available scale assessing QoL among people living with HIV in Australia.<sup>98</sup>

With the increasing calls to incorporate a stronger focus on QoL in HIV programming, there remains a need to develop a practical way to evaluate QoL of people living with HIV and related initiatives. Due to the increasing importance of HIV quality of life, GNP+ led the formation of the HIV Quality of Life Partnership comprising GNP+, Frontline AIDS, the International Planned Parenthood Federation (IPPF), NCD Alliance, STOPAIDS, UNAIDS, the World Health Organization and the Global Network of Young People Living with HIV (Y+).


This partnership aims to develop a comprehensive model of measuring quality of life of people living with HIV. This includes measuring the impact of community-led initiatives in order to make a strong investment case for these services.<sup>99</sup>

## RECOMMENDATIONS


### Donors and domestic governments

 Donors and domestic governments should allocate resources to quality of life initiatives, especially person-centred community-led initiatives, as part of essential support and services for people living with HIV. This will also help sustain support networks and initiatives for marginalised populations.

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 Donor countries should fully support social enablers targets in the new 2021-2030 Global AIDS response targets and resource allocation to be endorsed at the UNAIDS 47th Programme Coordinating Board meeting in December 2020.

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 QoL, social enabler and mental health targets should be fully integrated into the next Global Fund and UNAIDS strategies.

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### Health providers


 Health providers should develop packages of integrated, person-centred facility-based services to meet the differentiated quality of life needs of individuals living with HIV. This will also help support people living with HIV to become engaged in their disease management.

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 Health providers and programme managers should support people living with HIV to become engaged in their disease management.

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### All stakeholders

 Stakeholders should work to create an enabling environment for quality of life for all people living with HIV by reducing stigma and criminalisation and other structural barriers. This includes increasing funding to support an effective civil society that both delivers services and conducts advocacy.

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 Donors, healthcare providers and civil society should agree on the robustness of data generated for community-led and person-centred HIV initiatives. Stakeholders should jointly establish clear and commonly agreed M&E systems for qualitative data from community-led initiatives and develop agreed indicators for measuring QoL; incorporating QoL in all normative models of what good quality HIV care looks like.

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 Stakeholders in the HIV response need to work together to address the socio-economic environment that can impact on the QoL of people living with HIV. UNAIDS and UNDP should conduct further research and establish a country-comparative database on the socio-economic well-being of people living with HIV. This database could be used to support QoL initiatives and related policy development.

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