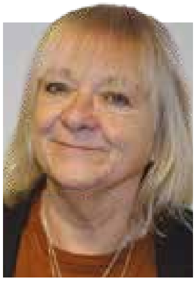
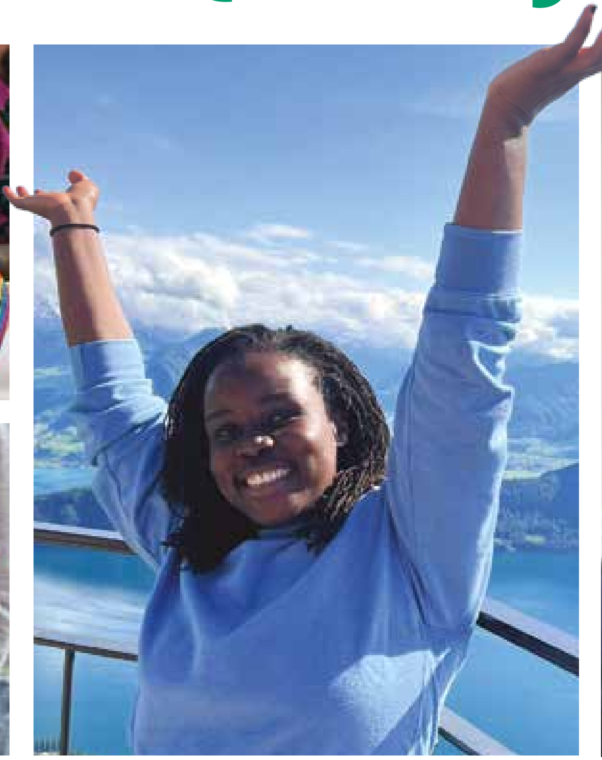
appg THE ALL-PARTY PARLIAMENTARY GROUP on HIV & AIDS



HIV and Quality of Life



What do we mean?
How do we achieve it?

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All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues.
The views expressed in this report are those of the group.

Contents

Definitions

AIDS - AIDS (acquired immune deficiency syndrome) is the name used to describe a number of potentially life-threatening infections and illnesses that happen when your immune system has been severely damaged by the HIV virus. While AIDS cannot be transmitted from 1 person to another, the HIV virus can.

BAME - Black, Asian and Minority Ethnic (BAME) communities

Discrimination – When you do negative things to me because I am at-risk or living with HIV.

HIV-related stigma – When you think negative things about me because I am at-risk or living with HIV.

HIV - HIV (human immunodeficiency virus) is a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome). There is currently no effective cure. Once people get HIV, they have it for life. But with proper medical care, HIV can be controlled.

HIV-1 & HIV-2 - HIV-1 and HIV-2 are two distinct viruses. Worldwide, the predominant virus is HIV-1. HIV-1 accounts for around 95% of all infections worldwide. HIV-2 is estimated to be more than 55% genetically distinct from HIV-1.

Intersectional discrimination – Acknowledges that discrimination is complex and there are many experiences and identities that combine and interact to determine how discrimination affects different people. People at-risk or living with HIV also experience discrimination because of groups they belong to and/or ways they self-identify. Racism, sexism, homophobia, and transphobia interact and combine in how the HIV response is experienced by different people.

Internalised (Self)-Stigma – When I think or say negative things about myself, or do negative things to myself, because I am at-risk or living with HIV. Internalised stigma is when the negative beliefs and views you witness, and experience, are internalised and become how you see yourself.

PEP - PEP (sometimes called PEPSE) is a combination of HIV drugs that can stop the virus taking hold. It can be used after the event if you believe you may be at risk of HIV transmission.

PrEP - PrEP (pre-exposure prophylaxis) is a pill people can take regularly to prevent them getting HIV from sex or injection drug use. When taken as prescribed, PrEP is highly effective for preventing HIV.

U=U - Undetectable = Untransmittable' (U=U) is a campaign explaining how the sexual transmission of HIV can be stopped. When a person is living with HIV and is on effective treatment, it lowers the level of HIV (the viral load) in the blood. When the levels are extremely low (below 200 copies/ml of blood measured) it is referred to as an undetectable viral load. This is also medically known as virally suppressed. At this stage, HIV cannot be passed on sexually.

List of Abbreviations

APPG	All Party Parliamentary Group
ART	Antiretroviral therapy
BAME	Black Asian and Minority Ethnic
BHIVA	British HIV Association
BASHH	British Association for Sexual Health and HIV
CBOs	Community-based organizations
CHIVA	Children's HIV Association
EJAF	Elton John AIDS Foundation
HRQoL	Health Related Quality of life
LGBT	Lesbian Gay Bisexual and Transgender
MSM	Men who have sex with men
NAT	National AIDS Trust
OHID	Office for Health Improvement and Disparities
PROMs	Patient Reported Outcome Measures
QoL	Quality of Life
SF-36	is a set of generic, coherent, and easily administered quality-of-life measures
SHS	Sexual Health Service
SIBS	Social Impact Bond
STI	Sexually Transmitted Infection
THT	Terrence Higgins Trust

Foreword: Rt Hon David Mundell MP and Steve Brine MP – Co-Chairs

The last 40 years have seen dramatic improvements in HIV treatments and people's understanding of the condition. Many people with HIV have lives that are not so different from those of people without the virus.

People who receive the most up-to-date treatments can usually enjoy full social and professional lives, as long as they follow their treatment plans. Also, people who receive an early diagnosis and effective treatment can expect to live nearly as long as people who do not have the virus.

As well as taking medication, a person with HIV needs to attend regular medical checks. Maintaining a healthful lifestyle and seeking treatment for any other medical issues right away can help an individual with the condition stay healthy.

A new perspective is required that recognises HIV to be a long-term condition, but one which poses very specific health and well-being challenges. These challenges include but are not limited to:

- an increased risk of developing a range of other health conditions (comorbidities);
- reduced quality of life due to the impact of long-term treatment, drug side effects, and multiple comorbidities;
- stigma and discrimination, both within the health system and outside of it, which can in turn result in mental health comorbidity, social isolation and loneliness.

Health care systems across the world need to develop effective, lifelong approaches to the treatment and care of People Living with HIV. The recommendations in this report aim to inform and inspire the development and adoption of such new approaches and policies.

The content of the recommendations, which should be reflected in any future national HIV strategies, aim to complement other initiatives focusing on HIV prevention, diagnosis, and universal access to treatment and care, where significant efforts are still needed in many countries.

Particular attention should be given to the needs of key populations. These are vulnerable or most-at-risk groups that may face specific challenges requiring targeted responses from policy makers and care providers.

Countries that criminalize key populations saw less progress towards HIV testing and treatment targets over the past five years—with significantly lower percentages of people living with HIV knowing their HIV status and achieving viral suppression than in countries that avoided criminalization. Even greater gains were achieved in countries where laws have advanced human rights protections, particularly those that protected rights to non-discrimination and responded to gender-based violence. Despite this compelling evidence, discriminatory and punitive laws remain alarmingly common.

Public health goals are not served by denying people their individual rights. Criminalization of same-sex sexual relations, sex work, drug possession and use, and HIV exposure, non-disclosure and transmission have been shown to block HIV service access and increase HIV risk.

We have come a long way in the past 40 years and with 2030 so close, now is the time to double our efforts to eliminating new transmissions of HIV, the stigma that surrounds HIV and to ensure the 37.7 million people living with HIV can live the same quality of life as those who don't live with HIV.

Rt Hon David Mundell MP and Steve Brine MP
Co-Chairs

Foreword: Professor Jeffrey V. Lazarus

Decades of global progress in prevention, detection and treatment have allowed HIV research and health policy measures to advance beyond the goal of viral suppression toward ensuring good health-related quality of life for all people living with HIV. This is especially true for an increasingly ageing population that manages HIV as a chronic condition. As their health needs continue evolving quickly, new health outcomes must be considered and measured.

Addressing co-morbidities and all the different factors affecting the quality of life of people living with HIV (e.g., non-communicable diseases like mental health, diabetes and respiratory diseases, frailty and physical health, social well-being, stigma and discrimination, inequities and the social determinants of health) demands implementing more multifaceted and integrated services focused on long-term well-being and health-related quality of life. This more comprehensive notion of HIV care is in line with the new World Health Organisation 2022-30 Global Strategy for HIV and is likely to favour a profound change in the delivery of healthcare services for this population.

World Health Organisation defines quality of life 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”. In other words, minimum standards. However, this can be achievable only by listening to and engaging with the community. It further requires a person-centred healthcare approach that focuses on what is important to people living with HIV and their community, including needs, experiences and preferences. The 2017 Positive Voice survey in the UK has proven instrumental in this effort, serving as inspiration for the world. Recently, for example, the European Commission funded a Joint Action that employed the. It is therefore essential that the survey be repeated, especially given the devastation caused by the COVID-19 pandemic. And across the European region, the HIV Outcomes initiative is engaging with key stakeholders to keep health-related quality of life on the political agenda and advocate for a world in which people living with HIV enjoy the highest possible health-related quality of life.

Whilst 2022 represented a landmark year for health-related quality of life among people living with HIV as it was included as an outcome in the new World Health Organisation 2022-30 Global Strategy for HIV, no indicator has been proposed to measure it. Without institutionalised targets, health systems may not recognise the significance of reporting on health-related quality of life of people living with HIV. Governments should, therefore, determine how they will best gauge it and decide to do just that. I hope the UK will continue doing so, because it boasts the resources, knowledge and experience as a leader in the field. I am confident it will happen due to the willing disposition of so many caregivers there to empower and lead this paradigm shift of HIV care towards a significant focus on chronic care and quality of life.

I welcome this report with the desire that the many recommendations made will be implemented and serve beyond the borders of the four nations. The vision set out in the report underpins our current path towards a much-needed transformation of health systems into person-centred healthcare delivery models that promote optimal well-being.

Prof Jeffrey V. Lazarus
Barcelona Institute for Global Health (ISGlobal), Spain and HIV Outcomes Europe Co-Chair

Foreword: Mike Podmore

Quality of life (QoL) is defined by the World Health Organization 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". This definition highlights the importance of self-direction in defining QoL for each community and individual. QoL encompasses mental, physical and social wellbeing and while the definition of QoL is broad and differs from population to population, the common threads are always agency, choice and human rights.

The successful expansion of antiretroviral therapy to millions of people living with HIV has fundamentally changed the way we think about Quality of Life (QoL). For People living with HIV, QoL is an essential component of everyday life and not an optional extra. It affects the ability to enter and stay within the continuum of care and, ultimately, 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. Rather than simply prolonging the lives of people living with HIV, initiatives should be taken to ensure they are healthy, happy and fulfilled.

Across STOPAIDS' membership, as highlighted in our 2020 Factsheet, there's so many innovative, person-centred programmes led by communities that are advancing the QoL of people living with HIV which should be further supported and taken to scale. STOPAIDS are proud to be members of the HIV Quality of Life Partnership with partners including GNP+, Y+, Frontline AIDS, NCD Alliance, IPPF, UNAIDS, and the WHO. The Partnership is an advocacy initiative to support integrated, person-centred and community-led interventions that optimise the health and wellbeing of people living with HIV globally.

STOPAIDS and the Partnership champion QoL in its broader sense. This means that we talk about three interconnected levels - HIV-specific components; health-related components: and the broader non-health specific well-being and wider social and economic aspects of quality of life. We need to consider QoL holistically and respond to the evidence accordingly with the necessary funding, programmes and legal reform.

As we enter the fourth decade in the response against HIV and seek to realise the 2030 targets, QoL should be the central framing in policy discussions for how we understand and organise HIV prevention, care, support and treatment. Our key step now is to articulate clearly what targets and objectives would be necessary to realise quality of life for people living with and affected by HIV but also, crucially, how we will effectively monitor and evaluate our work to ensure we are meeting these targets.

Measuring QoL is an area that needs further study and investment. Many tools are at the conceptualisation stage and require significant funding and support to be implemented. People living with HIV should be involved in the further implementation of QoL measurement tools in health facilities, including their development and linkage with community-based services. Countries should be supported to set up pilot programmes to advance the evidence base on equitable, impactful and cost-effective development of QoL measurement tools. There is a need for improved data collection on co-morbidity and multi-morbidity to develop future targets and respond to communities' evolving needs. More research needs to be done to combine QoL measures and key disease and treatment outcomes. Even more broadly, delivering QoL for people living with HIV will only be possible when we meaningfully connect systems of support for individuals across all areas of development. This will take time but it is essential work.

I therefore congratulate the APPG for conducting this vitally important inquiry and putting forward key recommendations for the UK Government and other stakeholders to support the QoL of people living with and affected by HIV. I urge the new Foreign Secretary and Secretary of State for Health & Social Care to be guided by the APPG's findings as we look to advance UK leadership for the HIV response at home and abroad.

Mike Podmore
Director STOPAIDS

Acknowledgements

Thank you to all of the 36 organisations and individuals who have worked with us throughout the course of the inquiry. This report was compiled by **Mark Lewis**, Senior Policy Advisor to the APPG on HIV and AIDS. If you would like further copies please contact **mark.lewis@parliament.uk**

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Methodology

The APPG put out a call for written evidence on 10th February 2021 and we received 36 submissions. This inquiry deals with Quality of life globally. We understand that every country has a different health care system and therefore the recommendations will be generic that each country could adopt.

The APPG held three oral evidence session to hear from a wide range of organisations who are working on difference aspects of quality of life.

Executive Summary

This year marks 41 years since HIV and AIDS was recognised and 34 years since the first World AIDS Day. Each year, it gives us a reality check. Where have we got to in the response to HIV? And what's still to do?

It is estimated that 6.1 million people living with HIV still do not know they have the virus. Meanwhile, 27% of people lack access to treatment and 34% are yet to achieve viral suppression and 680 000 people died of an AIDS related illness in 2020.

This particular reality check is driving a new focus on quality of life for people living with HIV. This recognises that – despite medical advances and the 'leave no one behind' promise of the international framework on sustainable development adopted in 2015 – AIDS is far from over and people living with HIV continue to need to have good health and wellbeing .

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

Current antiretroviral therapy reduces the amount of HIV in the blood (often referred to as someone's 'viral load' – a numerical expression of the quantity of HIV virus in a sample of blood) to a level so low that routine laboratory tests cannot detect it (a reference point commonly referred to as 'undetectable'). This means that HIV cannot be sexually transmitted (Undetectable = Untransmittable). While some countries have made great progress towards the UNAIDS 95 95 95 targets to improve diagnosis, continuous access and adherence to therapy, and viral load suppression by 2025, others still have work to do if they are to reach these targets.

People living with HIV have health needs beyond viral suppression. This includes non-communicable disease, mental health disorder, pain management and palliative care. From past inquiries we have heard that stigma and discrimination has an added detrimental impact on the well-being of People living with HIV [1].

Patient Reported Outcome Measures (PROMs) bring the opportunity for patients to raise issues of importance to their clinicians. These may include physical symptoms such as pain or gastrointestinal problems, mental health issues such as anxiety or low mood, as well as social problems such as poverty, unemployment and housing. Information needs around aging, long-term outcomes and treatment decisions can be addressed. Finally, there is the opportunity to highlight spiritual distress for people of faith living with HIV. PROMS allow person-centred assessments to support making every contact count.

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[1] Lazarus J et al. Beyond Viral Suppression of HIV – the new quality of life frontier https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-016-0640-4

Mirror Newspaper - Lloyd Russell Moyle MP

Knowledge of HIV transmission, U=U and HIV prevention is limited amongst healthcare professionals across disciplines outside of Sexual health and Infectious Diseases and may be a barrier to people accessing care[2]. Investment in mandatory training for healthcare professionals in understanding of these key concepts will be crucial in reducing HIV stigma in healthcare settings.

Quality of Life should be defined by more than a viral load number. Viral suppression does not mean eliminating all the other challenges that come with living with a chronic condition. Each individual living with and affected by HIV will have their own understanding of Quality of Life. In 2021, the HIV Outcomes initiative in the UK reported Quality of Life is subjective and must be assessed from an individual perspective[3]. As such, we believe establishing more general determinants for Quality of Life could help. They should include:

Management of co-morbidities – People living with HIV are disproportionately vulnerable to a wide range of other conditions (co-morbidities), including cardiovascular disease and chronic kidney disease and are more likely to develop certain types of cancer at a younger age[4]. All people living with HIV need ongoing support from across the care continuum to manage co-morbidities.

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[2] Shongwe M et al. Measuring healthcare HIV knowledge within our NHS Trust. British HIV Association conference, abstract O06, November 2020.

[3] HIV Outcomes Initiative, HIV Outcomes organises a roundtable on the HRQoL of people living with HIV in the UK, June 2021

[4] M. Daskalopoulou et al., 'HIV as a risk factor in the initial presentation of a range of cardiovascular, coronary, cerebrovascular, and peripheral arterial diseases', April 2018; V. Pourcher, et al., 'Comorbidities in patients living with HIV compared to matched non HIV controls', Poster #TUPEA0145, July 2017; M.L. Nguyen et al., Current Infectious Diseases Reports, 'Non-AIDS defining malignancies in patients with HIV in the HAART era', January 2010

Mental health support – Around half of people living with HIV express mental health concerns, compared to 24% of the general public. A wide spectrum of mental health and support services such as peer support, counselling, psychology and health and wellbeing related services, should be made available to all who need them.

Freedom from stigma and discrimination – People living with HIV continue to experience stigma and discrimination. These attitudes transfer to healthcare, with one in nine people with HIV having been refused healthcare or had their treatment delayed because of their HIV status[5]. Quality of life will not be improved unless these attitudes change. Public awareness campaigns, training for NHS staff, and education in schools would help tackle stigma and discrimination.

Person-centred care pathways and patient choice – Patient choice and a person-centred approach must be developed in partnership with the community and implemented across the entire care pathway to improve quality of life and equip people living with HIV to make the best choices for them[6]. This approach will help address barriers to accessing the best and most appropriate treatment.

Whilst incredible gains have been made towards ending the AIDS epidemic, these gains are not distributed equally. LGBTQ, People Who Use Drugs, Sex Workers, Young People, especially those adolescents who fall within these populations, have been consistently excluded and left behind in the HIV response. Stigma and/or discrimination towards these populations is reinforced by criminal laws and other structural barriers, which fuel violence, exploitation, and create a climate of fear. People living with HIV from key community groups face the dual or triple stigma of living with HIV and belonging to already marginalized groups.
These populations often face stigma in multiple settings (health facilities, schools, workplaces, in the community, in their homes) along with socio-political discrimination, punitive policies, criminalisation and exclusion. This context drives people underground away from vital HIV services, support, and care. Often, people cannot truly ‘live well’ if they live in fear of stigma, discrimination, violence, and prosecution, and are denied the holistic health (including mental health) services they need.

The COVID-19 pandemic has exacerbated the already deep-rooted inequalities and health disparities across the globe, with the most marginalised communities facing the greatest risk. In addition to struggling to meet their basic needs, communities are suffering increased levels of violence and discrimination.

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[5] Gilead Submission
[6] Gilead Submission

Although the complexity of both HIV stigma and discrimination makes these barriers difficult to address, rigorous operations research and impactful programming have been implemented. This work has helped drive our understanding of which delivery interventions and approaches are effective at reducing stigma and/or discrimination. Interventions targeting a combination of structural-level and individual risks and resilience hold promise for tacking self-stigma in particular. These include ART provision including treatment literacy, social empowerment, economic empowerment and strengthening, and cognitive-behaviour therapy.

As we have heard quality of life is a multidimensional concept; the HIV voluntary and clinical sectors must come together to agree on both what we mean by quality of life and how we can measure it.

As the response to ending AIDS continues into its fourth decade, our work is not just about prolonging the lives of people living with HIV. It is about ensuring that those lives are healthy, happy and fulfilled. Quality of life is not a 'luxury' or 'optional extra'. It is a human right – one that is more important than ever.

The following main measures should be introduced to make progress on global targets:

- People living with HIV are not a homogenous group; it is important that individual concerns and needs are considered when implementing measures and actions.
- Data collection should be improved to include a greater cross-section of society, including lesbian and bisexual women, transgender and non-binary communities, ethnic minority groups, people who use drugs and people who are homeless.
- Specific measures should be introduced to tackle areas of concern for people living with HIV such as mental health, social care, stigma and discrimination and education for healthcare professionals.
- Universal recognition and agreement on how we define quality of life for HIV - alongside clear national target setting to drive improvements.
- Universal recognition and agreement on the tools that should be used and implemented to drive improvements in quality of life.
- Annual measurements to assess improvements on a population basis.
- Technology appraisal bodies must ensure that their appraisal methods consider the role of technological innovation in delivering improved HRQOL and QOL outcomes, so that their true value can be recognised and so that patients can continue to receive access to them.
- Adopt an integrated, outcomes-focused, and patient-centred approach to long-term HIV care.
- Combat stigma and discrimination within health systems.

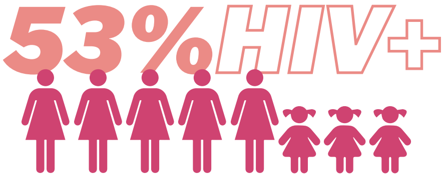
Statistics

GLOBAL HIV STATISTICS[7]

- 28.2 million people were accessing antiretroviral therapy as of 30 June 2021.
- 37.7 million people globally were living with HIV in 2020.
- 1.5 million people became newly infected with HIV in 2020.
- 680 000 people died from AIDS-related illnesses in 2020.
- 79.3 million people have become infected with HIV since the start of the epidemic.
- 36.3 million people have died from AIDS-related illnesses since the start of the epidemic.

People living with HIV

- In 2020, there were 37.7 million people living with HIV.
  - 36.0 million adults.
  - 1.7 million children (0–14 years).
  - 53% of all people living with HIV were women and girls.
- 84% of all people living with HIV knew their HIV status in 2020.
- About 6.1 million people did not know that they were living with HIV in 2020.

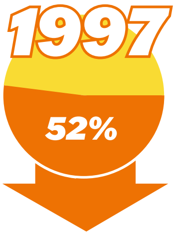


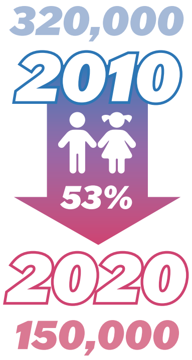
People living with HIV accessing antiretroviral therapy

- As of 30 June 2021, 28.2 million people were accessing antiretroviral therapy, up from 7.8 million in 2010.
- In 2020, 73% of all people living with HIV were accessing treatment.
  - 74% of adults aged 15 years and older living with HIV had access to treatment, as did 54% of children aged 0–14 years.
  - 79% [61–95%] of female adults aged 15 years and older had access to treatment; however, just 68% of male adults aged 15 years and older had access.
    - 85% of pregnant women living with HIV had access to antiretroviral medicines to prevent transmission of HIV to their child in 2020.

New HIV infections

- New HIV infections have been reduced by 52% since the peak in 1997.
  - In 2020, around 1.5 million people were newly infected with HIV, compared to 3.0 million people in 1997.
  - Women and girls accounted for 50% of all new infections in 2020.
- Since 2010, new HIV infections have declined by 31%, from 2.1 million to 1.5 million in 2020.
  - Since 2010, new HIV infections among children have declined by 53%, from 320,000 in 2010 to 150,000 in 2020.





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[7] https://www.unaids.org/en/resources/fact-sheet

AIDS-related deaths

- AIDS-related deaths have been reduced by 64% since the peak in 2004 and by 47% since 2010.
  - In 2020, around 680 000 people died from AIDS-related illnesses worldwide, compared to 1.9 million people in 2004 and 1.3 million people in 2010.
- AIDS-related mortality has declined by 53% among women and girls and by 41% among men and boys since 2010.

Key populations

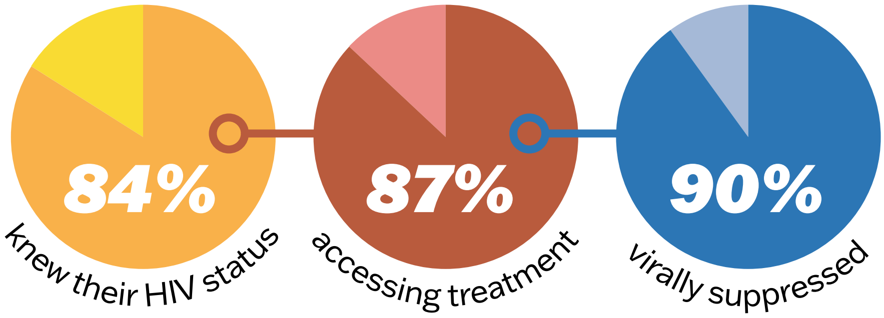
- The risk of acquiring HIV is:
  - 35 times higher among people who inject drugs.
  - 34 times higher for transgender women.
  - 26 times higher for sex workers.
  - 25 times higher among gay men and other men who have sex with men.

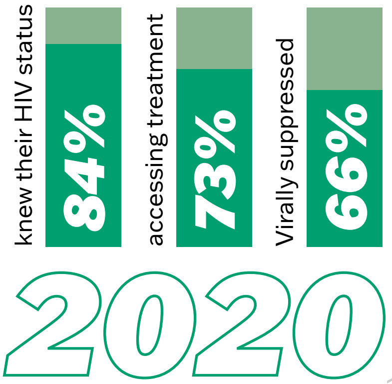
Women

- Every week, around 5000 young women aged 15–24 years become infected with HIV.
  - In sub-Saharan Africa, six in seven new HIV infections among adolescents aged 15–19 years are among girls. Young women aged 15–24 years are twice as likely to be living with HIV than men. Around 4200 adolescent girls and young women aged 15–24 years became infected with HIV every week in 2020.
- More than one third (35%) of women around the world have experienced physical and/or sexual violence by an intimate partner or sexual violence by a non-partner at some time in their lives.
  - In some regions, women who have experienced physical or sexual intimate partner violence are 1.5 times more likely to acquire HIV than women who have not experienced such violence.
- In sub-Saharan Africa, women and girls accounted for 63% of all new HIV infections in 2020.

90–90–90

- 🟧 In 2020, 84% of people living with HIV knew their HIV status.
- 🟫 Among people who knew their status, 87% were accessing treatment.
- 🟦 And among people accessing treatment, 90% were virally suppressed.
- 🟩 Of all people living with HIV, 84% knew their status, 73% were accessing treatment and 66% were virally suppressed in 2020.





Recommendations

1. Policymakers at all levels of government should update strategic and operational Action Plans to include a quality of life marker in strategies to meet the UN global AIDS 95-95-95 targets.

2. Professional bodies and universities should work with policymakers to provide all HCPs and community care providers with the education they need to eliminate stigma and discrimination across health systems.

3. Policymakers should address discriminatory practices and laws that contravene human rights by passing legislation that protects access to services, work, education, and travel. Independent oversight is required to hold government and health system policies and practices to account to ensure zero discrimination is achieved.

4. Policymakers should provide HIV community networks with the resources needed to establish programmes, including peer-to-peer networks, to boost the supportive ecosystem that people living with HIV need to not solely survive but to thrive.

5. Clinical services should ideally be able to either refer or directly provide opportunities for people living with HIV to meet and learn from peers.

6. Service providers should tailor care models to provide psychosocial and practical support to help people to prepare to live with HIV in the long-term.

7. Referral systems should be strengthened so that HCPs have access to information about the healthcare background and ongoing treatment of each person living with HIV.

8. Decision-makers and policy-makers at all levels should expand monitoring efforts to understand the reality of HIV as a life-long condition.

9. Patient-Reported Outcome Measures (PROMs) can fully account for HRQoL and should be developed and incorporated into national guidelines to enable better measurement of quality of life.

10. People living with HIV should be involved in the further implementation of quality of life measurement tools in health facilities, including their development and linkage with community-based services.

11. Co-production with service users should be embedded across HIV services to ensure they fully meet the needs of all people living with HIV.

12. The implementation of national HIV action plans should include strategies to address the structural inequalities that intersect with HIV, such as poverty and poor housing. Funders should better support HIV organisations to address poverty-related issues with poverty reduction strategies that specifically address the needs of PLHIV.

13. Funders and policy makers should work with community-led organisations to develop measurement tools based on data that is derived from programme implementation in order to identify effective and efficient programmes that are suitable for investment and scale-up.

14. Policymakers and experts should also work with people living with HIV to develop tools, such as case management quality of life plans, that measure how people’s basic needs (or lack thereof) affect the quality of life and link improvements to the ability to engage with and remain in the continuum of care.

15. Support for survivors of sexual and gender-based violence, including legal aid support, is essential. Data and reports from those on the front line have shown that violence against women and criminalized populations increased during the pandemic.

16. The efforts of key stakeholders to oppose punitive laws that endanger the lives of those already marginalized and criminalized must be supported throughout civil society.

17. To advance the Quality of Life of people living with HIV, support community-led programming and create an enabling environment for the HIV response, World Governments should continue to fund agencies including The Global Fund, UNAIDS, Unitaid and the Robert Carr Fund.

18. Stakeholders should adapt the concept of quality of life beyond HIV, towards a broad range of disease and programme specialties. A framework of quality of life should be used as a pathway for integrating services for person-cantered care and as a path to achieving Universal Health Care.

UK

1. A comprehensive strategy for reducing HIV stigma in the UK is urgently needed. The response to stigma currently significantly lags behind the gains we have made in prevention, testing and treatment. As a first step, there should be an overarching campaign to reduce stigma across the NHS.
2. There should be zero tolerance towards HIV stigma and discrimination within healthcare settings. The HIV stigma recommendations within the England HIV Action Plan should be fully implemented, with additional funding made available where needed. In addition, 'Stigma Free Hospital' initiatives should be adopted across the UK.
3. The UK Government Equalities Office and Department of Health and Social Care should lead cross-government efforts to address the remaining areas of HIV- related discrimination.
4. As recommended by the HIV Commission, every single HIV clinic should have access to psychological or mental health professionals within their multidisciplinary teams.
5. Perceived stigma" is a mental health issue which requires different interventions. People with HIV who are afraid to access mainstream services because of perceived stigma need to be able to access HIV specific services or health professionals who are trained in HIV stigma and its impact. Return to and retention in care must be a priority.
6. As recommended by the HIV Commission, local NHS decision-makers should work with local providers and community organisations to ensure better co-delivery between drug and alcohol services (including sensitivity to the specificity of chemsex), domestic violence, mental health and sexual health services.
7. The HIV Action Plan should capture a commitment to monitor, assess and benchmark health-related quality of life, using a measurement that is co-produced and agreed with the HIV community.
8. Peer support, one to one counselling and tailored group work, to meet the specific needs of all people living with HIV must be provided consistently across all parts of the UK.
9. BAME communities must be front and centre in the design and implementation of any strategy to reduce stigma, given the high prevalence of HIV within BAME communities, and the specific cultural attitudes and norms that affect treatment adherence.

Introduction

Since the discovery of HIV at the beginning of the 1980s, it has been one of the greatest global health problems. HIV and AIDS places an increasing burden on the health of the population, and causes further socioeconomic problems for individuals, families, communities, and governments in many countries.

Thanks to significant improvements in scientific understanding, medical innovation and clinical management of HIV for many people in the developed world, HIV is now considered a manageable chronic condition. With increasing numbers of people with the condition living into older age than ever before, HIV is now recognised as one of the greatest health success stories in recent times.

However, as we enter a new era of HIV management, there is growing recognition that there is more to living well than viral suppression alone. HIV affects people with different needs. Today people living with HIV continue to face health inequalities, social isolation, financial stress and stigma, which together impact overall wellbeing and engagement in care. These challenges have worsened as public health funding cuts have reduced spend on sexual health and HIV support services and will only continue to worsen as people living with HIV age.

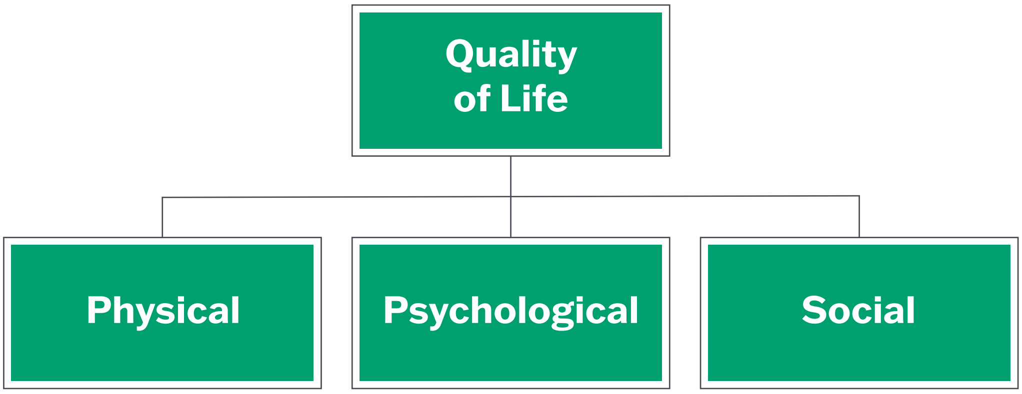
There is still much that we don’t know about the impact of age on the health, clinical and broader quality of life outcomes of people living with HIV.

But what actually is ‘quality of life’? Well, there’s no easy answer. It means different things to different people – depending on their specific requirements, culture, goals and expectations. It is comprised of multiple factors that, in combination, add up to an individual’s sense of ‘living well’.

The first use of HRQoL can be traced back to the 1970s when the academic community first began to consider quality of life (QoL) within health settings, and calls to improve patient HRQoL were first made.

We know that quality of life is a term that is popularly used to convey an overall sense of well-being, and includes aspects such as happiness, and satisfaction with life as a whole. The World Health Organization has defined Quality of Life as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns.”

We know that several factors associated with better Quality of Life among people living with HIV have been reported in the international literature, and mainly, the impact of HIV on Quality of Life as argued by many, falls under the following areas:



The physical addresses the medical needs of people living with HIV, and if they are virally supressed: psychological looks at how a person's status and the stigma that surrounds HIV affects them; and social reflects on the laws and perceptions surrounding both people at risk of HIV and those living with HIV.

As we know, with the advances in care and treatment, the global HIV population is ageing. As a result, new needs and issues are emerging that must be addressed, these include:

- **Rising comorbidities:** As the HIV population ages the impact of comorbidities will become greater and will require great clinical attention. To ensure this happens primary care professionals should receive training to ensure effective delivery of comorbidity checks for people living with HIV.

- **Growing socio-economic considerations:** Ageing HIV populations are more likely to be impacted by poverty.

- **Increasingly marginalised communities:** Advances in treatment and care have meant that the epidemic has been pushed to marginalised communities, such as injecting drug users. UNAIDS has warned that unless action is taken to provide support to these marginalised communities, we will not meet the 2030 target.

Issues such as employment, immunological status, presence of symptoms and/or depression, extent of social support and adherence to antiretroviral therapy were most frequently and consistently reported as key factors associated with QoL among people living with HIV[8]. The key determinants of good QoL for People living with HIV can include:

- Access to high-quality HIV treatment, prevention, care and support;
- Access to high-quality treatment, prevention, care and support for health conditions such as diabetes, Hep C or TB (multi-morbidities), mental health and sexual and reproductive health;
- The full enjoyment of social, cultural, civic, political and economic rights.

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[8] STOPAIDS SUBMISSION

There are also several cross-cutting determinants of QoL, these include:

- Social and economic determinants of well-being including housing, food and water, security, income, education and social protection;
- Protective laws such as equal opportunities and anti-discrimination legislation;
- Language and narrative framing-language plays a big role in creating an enabling environment but also to affirm People living with HIV, improving mental health and empowering us to participate in achieving desired health outcomes.

It is important to note that individual perception is an important part of QoL and the determinates of QoL will vary by population, culture and demographic being addressed. For example;

- In Belgium, dissatisfaction with the patient-physician relationship was identified as an important determinate of QoL[9].
- In Thailand, a study found that spiritual wellbeing was a determinant of QoL for people living with HIV in Suphanburi Province[10].
- In Estonia, being legally married was identified as a determinate of QoL for People living with HIV[11].

We must remember that HIV doesn't stop with the 2030 target of no new HIV transmissions and policy makers must never forget that.


UNAIDS

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[9] STOPAIDS SUBMISSION
[10] STOPAIDS SUBMISSION
[11] STOPAIDS SUBMISSION

Courtesy of Prevention Access Campaign

Report Format

Area 1: Physical

Area 2: Psychological

Area 3: Social

Area 4: Lessons learnt from Covid

Area 5: UK

Area 1: Physical

Jonathan Blake

Improving the health and wellbeing of the world's people is at the core of the Sustainable Development Goals (SDGs), reflected in targets that call for ending the epidemics of AIDS, tuberculosis, and malaria; achieving enormous improvements in maternal and child health; and tackling the growing burden of non-communicable diseases (NCDs). Focusing on Quality of Life is the means by which these ambitious health targets can be achieved.

All of the SDGs are sensitive to issues of social exclusion, inequality, and resource distribution among sub-groups, which have a great bearing on Quality of Life and sustainability, all around the world. In order for stakeholders to advance these goals, there is a need to contextualise, localise, and decentralise the production and utilisation of the Quality of Life knowledge systems[12].

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[12] STOPAIDS SUBMISSION

Quality of Life is also about agency, choice and human rights. Quality of Life views health as a public good with individual and collective dimensions. From the perspective of a rights approach, guaranteeing an effective response to social needs in quality of life and health is critical to the means of management in defence of rights[13].

Examples of the definition of Quality of Life include:

- The WHO defines Quality of Life 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"[14].
- Frontline AIDS defines Quality of Life as something that is:[15]
    - Multi-dimensional: it is not about one single thing, but is 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 (eg ill-health and poverty) and the presence of positive ones (eg social relationships and contentment)
- GNP+ defines Quality of Life as an essential issue for people living with HIV. It affects our ability to enter and stay within the continuum of care and, ultimately, become and remain virally suppressed. Quality of Life is person-dependent and means different things to different people. Quality of life comprises three core components[16]:
    - prevention, care, support and treatment for HIV;
    - prevention, care support and treatment for non-HIV-specific physical and mental health issues that lead to people living with multiple chronic conditions including disability;
    - and, well-being and wider social, cultural and economic rights.

CASE STUDY

The project Chukua Selfie, set up by The Elton John AIDS Foundation and run in partnership with the Menstar Coalition, addressed the issues that young men are not getting tested for HIV as an entry point to care, and that there are high rates of HIV transmission in Kenya. Its objectives were to increase the number of men aged 20 to 34 in Kenya who get to know their HIV status using HIV self-test kits, and to create awareness of HIV self-testing kits and normalise HIV self-testing. It used social media and other advertising to publicise the availability of HIV ST kits at pharmacies and offered training to pharmacies about how to promote and display the products. The project achieved 300m impressions (times seen), reached 19m people, with 10,921 kits sold. Our learning is that young men prefer to access information, products and services through digital media, that attractive branding accelerates demand, product availability has to be very convenient for young men, with direct consumer approaches important, and that the price has to be affordable.

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[13] STOPAIDS SUBMISSION

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[16] STOPAIDS SUBMISSION

Prevention

As with treatment, HIV prevention methods are advancing and are expected to make a huge difference in the fight against HIV.

We know about PrEP, condoms etc. There are different modes of delivering those prevention methods. However, we must ensure that everyone can access these methods across the world so that people can have the choice.

Pre-exposure prophylaxis (PrEP) is the use of HIV medication by people who do not have HIV to prevent infection. Vaginal rings containing Dapivirine were approved by the European Medicines Agency and World Health Organisation earlier this year.

Injectable PrEP is the use of long-acting cabotegravir to prevent HIV infection. The HPTN 083 and HPTN 084 studies tested long-acting cabotegravir and found it to be as safe and effective as PrEP.

Cabotegravir belongs to the same class of medication – integrase inhibitors – as the widely used HIV medication dolutegravir. For HIV treatment, injectable cabotegravir in combination with injectable rilpivirine is already used in Canada and is expected be available soon in Europe.

A recent HIV prevention study[17] has found that when young women have access to and experience with two biomedical prevention options, the Dapivirine Vaginal Ring (DVR) and Truvada, an oral pre-exposure prophylaxis (PrEP) drug, almost all of them choose to continue using one of them.

The study found that most of the girls enrolled for the trial preferred the dapivirine vaginal ring. The results from the study's third phase, during which participants were able to choose between the dapivirine ring and daily oral PrEP after having experience using each product, were presented on February15 during the Conference for Retroviruses and Opportunistic Infections (CROI 2022).

The 'Reversing the Epidemic in Africa with Choices in HIV prevention' study (REACH), was conducted by the Microbicide Trials Network (MTN) at four clinical research sites in Uganda, South Africa and Zimbabwe. It was designed to fill important gaps in information about the safety and acceptability of the Dapivirine ring and oral PrEP, especially in girls younger than 18.

With injectable PrEP nearing introduction, along with the ring and oral PrEP, there is expected to be an increase in choice available for people to ensure they can protect themselves against HIV while ensuring a good quality of life and sex life.

As with contraceptives, having a range of options makes it more likely there will be one that will meet an individual's needs and preferences and that it can and will be used. It is all about choice.

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[17] https://www.nih.gov/news-events/news-releases/study-prep-vaginal-ring-hiv-prevention-begins-girls-young-women


Garry Brough and Chris O'Hanlon

Peer Mentors

We have heard from organisations such as the Terrence Higgins Trust, George House Trust, HIV Outcomes and others that peer mentors can also play a key role in supporting people to access, engage, and sustain treatment.

During the oral evidence session, the Elton John AIDS Foundation advised us that in 2016 in partnership with OGAC and UNAIDS, they conceived of a nimble, inclusive, and effective mechanism called the LGBT Fund (the Fund). They advised that this fund had a focus on high HIV-burden countries in sub-Saharan Africa and the Caribbean. The Fund sought to address structural challenges and bridge critical gaps for LGBT people by improving access to HIV and sexually transmitted infections (STIs) prevention, care, treatment, information and services.

Through the Fund, in Kenya, Uganda and Mozambique, LGBT-led organisations supported LGBT people to access HIV services within communities and collaborated with private and public health facilities to ensure that LGBT people could access clinical HIV services in safe and friendly environments, without the fear of being discriminated against or turned away. EJAF suggests that this was achieved by employing LGBT peer mentors who then referred, and in certain cases directly accompanied, beneficiaries to the nearest participating health facility.

EJAF also highlighted mobile outreach activities in Mozambique, which were an innovative and successful approach to reach and improve HIV testing in hotspots (ie clubs, bars, pubs, festivals and beaches) mostly during the night.

The promotion of HIV testing, together with pre-counselling, they suggest were successful, and the trust and confidence in peer mentors was high enough to secure a consistent level of demand for an HIV test. The mobile clinics were organised through partnerships between clinical providers and LGBT-led CBOs. All health workers in the mobile clinics were trained on delivering quality, stigma-free services and LGBT people were mobilised by peer mentors through their own social networks. This was the first time in Mozambique that LGBT people have been trained as peer testers and counsellors, giving LGBT clients the choice to receive testing from a trusted peer in a setting that is convenient to them.

> ***“Peer mentors specifically played a key, transversal role reaching out to the LGBT community which, together with the safe spaces, led to intrinsic strengthening of this vulnerable group. It was confirmation that peer-led initiatives can have real impact”***
> ***– Mozambique Deep Engagement Grant, Evaluation report.***

The Elton John AIDS Foundation advised that it was highlighted by their LGBT Fund programme teams that future LGBT programming must recognise the transformative role peer-educators play; empowering peer mentors to become leaders within their own social networks is crucial to successfully reach LGBT people in the communities[18]. They also stated that the peer mentors the programme created had reached and tested more LGBT individuals than the other test providers through the Mozambique LGBT Fund Project; almost two thirds of the Mozambique HIV tests were completed by LGBT peer educators. They went on to advise that the peer mentors access individuals more quicky and more effectively with less discrimination. Future LGBT programming should ensure peer mentors are involved from project initiation, planning, execution, monitoring and closure, and recognise the pivotal role and skills of peer mentors with stipends and training. Ideally, peer mentors will be trained to provide psychosocial support to clients, along with HIV linkage services. The foundation argued that the outreach work conducted by trained LGBT peer mentors is the backbone of community-based service delivery, a vital link between the community and health facilities, and thus should be included in HIV prevention and care programmes that work with the LGBT community in the future. The main point they wanted to get across was that this is crucial for focusing on the actual needs of the communities.

The submissions form STOPAIDS, EJAF and the oral evidence from the Salamander Trust stated that peer-led models can also be effective in reaching People who use drugs (PWUD).

EJAF

As our project in Northern India showed, where the issue of HIV transmission among key communities especially PWUD is rising, there are challenges with linking PWUD, MSM and transgender communities to ART. So the project aimed to scale up community-based settings for integrated and decentralised HIV prevention, harm reduction and ART venues, with the intention of identifying people living with HIV who would be linked to care, sustained on ART and virally suppressed. To date, 266 PWUD and MSM linked to ART, including 44 young people; 345 sexual and needle-sharing partners of key communities were reached; and nearly 600 PWUD linked to community level Opioid Substitution Treatment (OST) services. Our learning from this is that a peer-led hybrid model increases HIV service uptake by ‘hidden’ PWUD while reducing harm and stigma through OST services.

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[18] EJAF submission

The one thing that is important to call out where peer support can help, is with marginalised and criminalised populations - like the LGBTQ community who live in fear and live hidden lives, which in turn has a negative impact on Quality of Life. There is a double stigma from both living with HIV and the marginalisation and criminalisation as an LGBTQ-identifying person. This is why the peer support model is so critical in these contexts. They not only give support with the biomedical aspect of living with HIV but also the psychosocial support that is critical for this group.

Measuring Outcomes

Recognition of the significant unmet needs in terms of quality of life and health-related quality of life faced by people living with HIV, has led to increasing interest in the concept of adding a '4th 90' to the UNAIDS 95:95:95 cascade, with a focus on quality of life[19], health-related quality of life, healthy ageing, or mental wellbeing amongst others[20,21,22]. Whilst there are clearly challenges in distilling such a broad concept as quality of life into one overarching indicator, the merits of setting a clear and overarching goal could be beneficial in driving improvements in the long term.

The recently published interim 2025 UNAIDS goals signal a move in this direction with a series of new measures – including the new target of ***"at least 90% of people living with HIV linked to services for other communicable diseases, non-communicable diseases, sexual and gender-based violence, mental health and the other services they need for their overall health and well-being."***[23]

The HIV Action Plan for England sets out a commitment for OHID to ***"review the current model sexual health service specification to strengthen pathways with other services, including drug and alcohol, domestic abuse and mental health services. This includes consideration of integrated services or collaborative commissioning"***[24]. This is a positive step – but it is crucial that funding is in place to ensure sufficient service provision and access to it for people living with HIV[25].

It is important to build on the understanding of Quality of Life especially at the grassroots level of the concept - for demand creation, for advocacy and to understand what Quality of Life means in the diversity of people living with HIV.

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[19] HIV Quality of Life. In search of the 4th '90' – Why do we care? Available at: https://www.hivqualityoflife.org/single-post/2018/07/01/In- search-of-the-4th-90---Why-do-we-care Last accessed: January 2022
[20] Harris et al. Achieving the fourth 90: Healthy ageing for people living with HIV. Available at: https://journals.lww.com/aidsonline/Pages/articleviewer.aspx?year=2018&issue=07310&article=00002&type=Fulltext#R15-2. Accessed October 2019. Last accessed: January 2022
[21] Webster, P. 'UNAIDS survey aligns with so-called fourth 90 for HIV/AIDS' The Lancet. Available at: https://doi.org/10.1016/S0140- 6736(19)31231-0 Last Accessed: January 2022
[22] Lazarus, J. et at. 'Beyond viral suppression of HIV – the new quality of life frontier' BMS Medicine. Available at: https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-016-0640-4 Last accessed: January 2020
[23] UN AIDS 2025 AIDS Targets Available at: https://aidstargets2025.unaids.org/#section-targetsLast Accessed: February 2022
[24] Gilead Submission
[25] Gilead Submission

Quality of Life must be included in multilateral strategies as a core concept that fundamentally links together HIV-specific services with broader health and development services, breaking down sector siloes that have plagued our ability to effectively meet the holistic needs of each individual. There needs to be a change amongst donors (esp GFATM), governments (esp USA's PEPFAR programme), the UN (esp WHO and UNAIDS) and other policy influencers/makers to recognise that top-down biological approaches to HIV only go part of the way, and often do not address the priorities/needs/desires of people living with/deeply affected by HIV.

HIV governance is too often guided by quantitative data and not qualitative data. Qualitative data can provide highly descriptive accounts of lived experiences that call attention to historical, socio-contextual, political, and structural factors and allow for a more comprehensive understanding of the cultural and gendered aspects of living with HIV.

The community of people living with HIV is excluded from policy, practice and research. If People living with HIV are meaningfully involved from the outset, then policy and practice might start to be more linked to Quality of Life.

Examples of programmes that have included Quality of Life as aims/ objectives/ targets/ measures for issues impacting people living with HIV beyond viral suppression include:

- **Mildmay Uganda:** A programme that focuses on the holistic needs and well-being of a client living with HIV in Uganda[26].
- **IPPF's Integration for Sustainability – Policy to Practice project:** A project to improve integration between HIV and SRH services – currently in Cameroon, Guinea-Conakry, Malawi and Togo[27].
- **Terrence Higgins Trust – At Home service:** A suite of digital living-well services to support people living with HIV (Online counselling and emotional support programme)[28].
- **Sophia Forum – WISE UP+ (Women Inspire Support and Empower to Unleash Positive Potential):** 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[29].

In general, Quality of Life measurement tools are divided into three areas as mentioned earlier: physical function; social/role function; and mental/emotional function. Some of these are used for a wide range of studies comparing people living with HIV with medical conditions to the general population.

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[26] Mildmay.or.ug. 2022. Mildmay Uganda | Empowering Communities for Healthier Lives. [online] Available at: https://mildmay.or.ug/

[27] IPPF. 2016. Sustainable Networks | IPPF. [online] Available at: https://www.ippf.org/our-approach/programmes/sustainable-networks

[28] Tht.org.uk. 2020. Online counselling for people living with HIV | Terrence Higgins Trust. [online] Available at: https://www.tht.org.uk/our-services/living-well-hiv/online-counselling-people-living-hiv

[29] Sophiaforum.net. n.d. WISE UP+ – Sophia Forum. [online] Available at: https://sophiaforum.net/index.php/wise-up/

A wide range of questionnaire tools have been developed that are general and disease-specific. Examples include:

- General tools: SF-36 survey[30] (36 items), or EQ5D[31] (5 domains, self-care, mobility, anxiety depression, pain, how able to cope with usual activities). - These tools are mainly used in relation to economic evaluation.

- Disease-specific tools: HIV-QL-31[32], MOS HIV[33], PRO QUALITY OF LIFE-HIV[34], WHO QUALITY OF LIFE-HIV[35]

A systematic review of some of these measures often found little validity/reliability and identified a need to validate some of these Quality of Life measures in people living with HIV[36].

Other global examples include:
- ALIV[H]E Framework[37]: commissioned by UNAIDS, this framework shows how research on the intersections between Violence against Women and Girls (VAWG) and HIV in communities can be based on participatory as well as more formal, research processes, which are both quantitative and qualitative.
- Positive Health Dignity and Prevention – Policy Framework GNP+[38]. Policy Framework outlining the holistic needs of people Living with HIV.
- Compendium of Gender Equality and HIV Indicators[39] - (UNAIDS, UN Women, USAID, Pepfar,) Measure Evaluation - Listing of indicators through a gender lens.
- SRH and HIV Linkages Compendium[40] - HIV – SRHR linkage indicators and
- assessment tools by IPPF, UNFPA, WHO.
- Positive Voices - a national HIV patient survey developed by Public Health England (now UKHSA)

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[30] Rand.org. n.d. 36-Item Short Form Survey from the RAND Medical Outcomes Study. [online] Available at: https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form.html

[31] EuroQuality of Life.org. n.d. EQ-5D instruments – EQ-5D. [online] Available at: https://euroQuality of Life.org/eq-5d-instruments/

[32] Cooper, V., Clatworthy, J., Harding, R. et al. Measuring quality of life among people living with HIV: a systematic review of reviews. Health Qual Life Outcomes 15, 220 (2017). https://doi.org/10.1186/s12955-017-0778-6

[33] Eprovide.mapi-trust.org. n.d. MOS-HIV - Medical Outcome Study-HIV Health Survey. [online] Available at: https://eprovide.mapi-trust.org/instruments/medical-outcome-study-hiv-health-survey

[34] Duracinsky, M., Herrmann, S., Berzins, B., Armstrong, A., Kohli, R., Le Coeur, S., Diouf, A., Fournier, I., Schechter, M. and Chassany, O., 2012. The Development of PROQUALITY OF LIFE-HIV. JAIDS Journal of Acquired Immune Deficiency Syndromes, 59(5), pp.498-505

[35] WHO.int. 2002. WHOQUALITY OF LIFE-HIV Instrument Users Manual. [online] Available at: https://www.who.int/mental_health/media/en/613.pdf

[36] Cooper, V., Clatworthy, J., Harding, R. et al. Measuring quality of life among people living with HIV: a systematic review of reviews. Health Qual Life Outcomes 15, 220 (2017). https://doi.org/10.1186/s12955-017-0778-6

[37] Salamander Trust. 2012. Salamander Trust Resources [online] Available at: https://salamandertrust.net/resources/alivhe-framework/

[38] Gnpplus.net. 2011. Positive Health, Dignity and Prevention: A Policy Framework – GNP+. [online] Available at: https://gnpplus.net/resource/positive-health-dignity-and-prevention-a-policy-framework/

[39] S. Bloom, S. and Negroustoueva, S., 2013. Compendium of Gender Equality and HIV Indicators. UNAIDS, UN WOMEN, USAID, PEPFAR, [online] Available at: http://file:///Users/aminababirye/Desktop/WORK/ms-13-82.pdf

[40] 2012. SRH AND HIV LINKAGES COMPENDIUM Indicators & Related Assessment Tools. [online] IPPF, WHO, UNFPA. Available at: https://www.unfpa.org/sites/default/files/pub-pdf/SRH%20HIV%20Linkages%20Compendium_rev.pdf

Measuring Quality of Life is an area that needs further study and investment. As we heard, there are many tools that are at the conceptualisation stage and require significant funding and support to be implemented. People living with HIV should be involved in the further implementation of Quality of Life measurement tools in health facilities, including their development and linkage with community-based services. Countries should be supported to set up pilot programmes to advance the evidence base on equitable, impactful and cost-effective development of Quality of Life measurement tools. There is a need for improved data collection on co-morbidity and multi-morbidity to develop future targets and respond to communities' evolving needs. More research needs to be done to combine Quality of Life measures and key disease and treatment outcomes.

Many of the organisations also argued that focusing on person-centred health care to address a range of determinants of poor health beyond viral suppression will enable people living with HIV to benefit from healthy aging along with ongoing viral suppression. Many symptoms, health behaviours, and life circumstances associated with living with HIV cannot be measured by laboratory values or other direct-observation approaches and are often under-addressed in clinical care. Rates, for example, of substance use, depression, intimate partner violence, and homelessness are higher among people living with HIV than the general population, and a better understanding of such issues, as well as other information beyond standard clinical measures, has the potential to improve outcomes for people living with HIV. ViiV gave the following example - clinician attempts to support people living with HIV to maintain adherence to a treatment regimen can benefit from understanding patient behaviours and risks to adherence, including substance use, depression, stigma, life circumstances such as housing status, and treatment satisfaction. These 'domains' of quality of life and others have validated measurement instruments to support and monitor clinical outcomes and should be considered as part of routine HIV care.

CASE STUDY

Positive Voices is a national HIV patient survey developed by Public Health England (now UKHSA) in partnership with University College London and Imperial College London[41]. The survey collects population-level information from people living with HIV across a range of domains including: satisfaction with HIV specialist services and GP services; health and social care needs; health-related quality of life; prevalence of co-morbidities and lifestyle risk behaviours; stigma and discrimination; housing, employment and finances. It provides valuable insights into the issues that most affect the health and lives of people living with HIV and is an important barometer of tracking improvements in the system[42].

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[41] Public Health England, 'Positive Voices The National Survey of People Living with HIV - Findings from the 2017 survey' Available at: Last https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/857922/PHE_positive_voices_report _2019.pdf Accessed: January 2022

[42] Public Health England, 'Positive Voices The National Survey of People Living with HIV - Findings from the 2017 survey' Available at: Last https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/857922/PHE_positive_voices_report _2019.pdf Accessed: January 2022

Ageing with HIV is also associated with increased incidence and earlier occurrence of multimorbidity and frailty[43]. UKHSA (formerly PHE) has projected that the prevalence of high cholesterol, hypertension, diabetes and 'heart conditions' in the ageing HIV population will double in the UK in the forthcoming decade[44]. Meanwhile, as highlighted in the Terrence Higgins Trust report "Uncharted Territory: A report into the first generation growing older with HIV", as people living with HIV age they also face a number of additional complex needs[45]. As previously discussed, people with living with HIV are more likely to suffer from poorer physical and mental health.

How can we measure Quality of Life and Health Related Quality of Life to help understand the care response to HIV and assess gaps in the Quality of Life and Health Related Quality of Life of people living with HIV?

It was argued by the majority of submissions that there are many validated patient reported outcome measures (PROMs) which could be used to assess gaps in the Quality of Life for people living with HIV, covering overall health and also specific areas of interest to HIV. For example, non-HIV specific instruments such as PHQ (depression), GAD (anxiety), UCLA loneliness scale, Social Support (MAPSS-SF) and alcohol/substance use; and HIV specific measures such as internalised stigma scale, measures of ART adherence and treatment burden/satisfaction. More succinct PROM applications may include the Positive Outcomes PROM - a brief, multi-dimensional HIV specific PROM covering several domains identified as important to people living with HIV[46].

PROMs in some format should be incorporated into routine clinical assessment, and there is a strong evidence base behind their effective application in routine HIV care[47]; studies have shown how PROMs help patients share information with their doctor about their health, needs and preferences that may otherwise not be discussed; they also improve patient-provider discussions to facilitate better-informed care and improve clinical efficiency.

Support materials are available for implementing PROMs within routine HIV care from www.progresshivcare.org, and these include an evidence review and an implementation toolkit.

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[43] Leak-Date, H. 'Optimising the health and well-being of older people living with HIV in the United Kingdom' Pharmaceutical Journal Available at: https://www.pharmaceutical-journal.com/research/review-article/optimising-the-health-and-wellbeing-of-older-people- living-with-hiv-in-the-united-kingdom/20204279.article?firstPass=false Last Accessed: January 2020

[44] Leak-Date, H. 'Optimising the health and well-being of older people living with HIV in the United Kingdom' Pharmaceutical Journal Available at: https://www.pharmaceutical-journal.com/research/review-article/optimising-the-health-and-wellbeing-of-older-people- living-with-hiv-in-the-united-kingdom/20204279.article?firstPass=false Last Accessed: January 2020

[45] Terrence Higgins Trust 'Uncharted Territory' Available at: https://www.tht.org.uk/sites/default/files/2018- 03/uncharted_territory_final_low-res.pdf Last accessed: January 2020

[46] Kings College London, New tool launched to help provide person-centred care for people living with HIV, February 2022

[47] Short, D., Fredericksen, R. J., Crane, H. M., Fitzsimmons, E., Suri, S., Bacon, J., Musten, A., Gough, K., Ramgopal, M., Berry, J., McReynolds, J., Kroch, A., Jacobs, B., Hodge, V., Korlipara, D., & Lober, W. (2022). Utility and Impact of the Implementation of Same-Day, Self-administered Electronic Patient-Reported Outcomes Assessments in Routine HIV Care in two North American Clinics. AIDS and behavior, 26(7), 2409–2424. https://doi.org/10.1007/s10461-022-03585-w

Humanise:

ViiV in their submission advised that studies have shown that when compared with individuals with other chronic diseases, people living with HIV report more anxiety/depression issues, and there is an intersection of higher rates of mental health problems in marginalised populations who are also at risk of HIV, such as LGBT populations, migrants, drug users, and prisoners - and furthermore people with mental health issues or psychiatric disorders may be more likely to acquire HIV[48]. Unrecognised and untreated mental health issues are associated with non-adherence and the increase of high-risk behaviour. This may facilitate HIV transmission and therefore, it is of importance to regularly screen for anxiety/depression issues in the provision of HIV-care and, if indicated, carry out a more in-depth assessment followed by an appropriate treatment plan, including a multidisciplinary team for people living with HIV with moderate to extreme anxiety /depression symptoms[49].

Health Related Quality of Life is impacted by different factors for older and younger people living with HIV, indicating the changing needs of the HIV population over the life course. Young people living with HIV mostly struggle with anxiety/depression issues, while elderly people living with HIV have additional problems with self-care and usual activities.

There have been significant advances in HIV treatment and care which mean that, with early diagnosis and stable treatment, people living with HIV can expect to achieve viral load suppression and attain life expectancy comparable to the wider general population. With appropriate treatment and care, HIV is now a manageable chronic disease. Therefore, it is increasingly important to assess and support the health-related quality of life (Health Related Quality of Life) for people living with HIV, including long-term physical, psychological and social health needs[50]. Health Related Quality of Life represents an important public health priority which supports health promotion and resilience[51].
For society-at-large, enhancing Health Related Quality of Life has the potential to improve the lives, livelihoods and living standards of people living with HIV, which can support economic productivity and performance as well as reduce social exclusion[52]. Securing affordable access to good quality health services (universal health coverage) is critical to improving HIV health outcomes, wellbeing and enhancing Health Related Quality of Life[53]. These factors are key to ending AIDS by 2030 and securing UNAIDS 95-95-95 testing, treatment and viral suppression targets. Ensuring Health Related Quality of Life for people living with HIV requires coordinated and integrated care and support that directly responds to unmet health needs and lived experiences[54].

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[48] Mental health and HIV/AIDS: the need for an integrated response, AIDS. 2019 Jul 15; 33(9): 1411–1420, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6635049/

[49] Robertson K Bayon C Molina JM McNamara P Resch C Munoz-Moreno JA et al.Screening for neurocognitive impairment, depression, and anxiety in HIV-infected patients in Western Europe and Canada. AIDS Care. 2014; 26: 1555-1561

[50] CDC. (2019). Health-Related Quality of Life (HRQUALITY OF LIFE). Retrieved 2 July 2020 from: www.cdc.gov/hrQuality of Life/index.htm

[51] Wood, S., Finnis, A., Khan, H., Ejbye, J. (2016). At the heart of health: Realising the value of people and communities. Retrieved 2 July 2020 from: www.health.org.uk/publications/at-the-heart-of-health-realising-the-value-of-people-and-communities

[52] WHO. (2019). Economic and social impacts and benefits of health systems. Retrieved 2 July 2020 from: www.euro.who.int/__data/assets/pdf_file/0006/395718/Economic-Social-Impact-Health-FINAL.pdf?ua=1

[53] World Bank. (2020). Universal Health Coverage. Retrieved 2 July 2020 from: www.worldbank.org/en/topic/universalhealthcoverage

[54] Engelhard, E. A., Smit, C., Van Dijk, P. R., Kuijper, T. M., Wermeling, P. R., Weel, A. E., ... & Nieuwkerk, P. T. (2018). Health-related quality of life of people with HIV: an assessment of patient related factors and comparison with other chronic diseases. Aids, 32(1), 103-112. doi: 10.1097/QAD.0000000000001672.

Summary:

To make improvements in understanding and knowledge of HIV in health and care settings, it is important to understand what patients want from their health care professionals. This could be achieved through:

- **Listening to the community:** Through hearing experiences first-hand, health care professionals would gain greater understanding of the extent of the problem. The findings from surveys such as Positive Voices in the UK can be useful in filling these gaps.

- **Regular collection of data on experience of stigma:** The European Centre for Disease Prevention and Control asked 55 countries in Europe and Central Asia whether they collected data about perceived discrimination against people with HIV; only four countries track data on stigma in health care settings[55].

- **Education and training:** Health care professionals need greater understanding and further education on HIV. Across the range of health care settings available, people living with HIV reported experiencing stigma across all of them. While these are not large numbers, there were still 14% of people living with HIV in the UK who experienced discrimination in a health care setting.

People living with HIV should be supported in managing their care, which includes managing co-morbidities. The management of these conditions, alongside managing medications and HIV can lead to anxiety, particularly if the right support is not available[56]. The education of health care professionals should extend to supporting people with HIV in managing co-morbidities alongside their HIV.

Over the course of the last four decades, we have seen continual advances in HIV care and treatment, including an exponential increase in life expectancy for people living with HIV. Anti-retroviral therapies (ARTs) have been transformative and innovations such as triple therapy and single tablet regimens have been at the heart of this trend. Furthermore, there have been longer-term benefits from innovative ARTs which minimise viral load, require less clinical monitoring, and are well tolerated by people living with HIV. This supports adherence, decreases footfall of people living with HIV in clinical settings, and reduces the burden on health care professionals. Similarly, advances in the technology of testing have enabled us to improve access and cost-effectiveness.

As further innovations and technologies are being developed, health systems must be flexible, promoting the uptake of value-added treatments and designating funds to ensure that people living with HIV who choose to access these new innovations can do so, and ensuring clinicians have the ability to prescribe them.

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[55] Politico, No '4th 90'- Why living well is not a goal when it comes to HIV, March 2021

[56] Positive Voices, Changing perceptions: Talking about HIV and our needs, accessed February 2022

To ensure and improve equal access to health care, the following areas should be prioritised:

- Reducing inequality in the experience of care:
  - Regional variation regarding the provision of specialist-HIV care services must be addressed
  - Provide and enhance peer support to address the needs of key populations
  - Ensure a smooth transition from paediatric to adult services
- Patient-centred care pathways: A person-centred approach should be implemented across the entire pathway to ensure each individual is informed and able to make the choices that are best for them.
- Education for people living with HIV and health care practitioners: Stigma and discrimination persists across the health service, particularly amongst non-HIV specialists. Health care sector-wide education programmes are needed to upskill clinicians and address these attitudes.

The use of tools to foreground and monitor Health Related Quality of Life depends on widespread awareness of them and understanding of their value, which in turn rely on recognition of the Health Related Quality of Life concept itself. There is no doubt that Health Related Quality of Life as ‘the 4th 90’ is an effective communications hook, in much the same way as U=U has been.

The 4th 90 is based on the Joint United Nations Programme on HIV/AIDS (UNAIDS) ‘90-90-90’ targets which stated the aim that, by 2020, 90% of all people living with HIV would be diagnosed, 90% of those diagnosed would be receiving treatment and 90% of those receiving treatment would achieve viral suppression. Following this continuum of care means that the 2020 target was for 73% of people living with HIV to be virally suppressed.

Following the same logic, if Health Related Quality of Life is the 4th 90, the target is only for 66% of people living with HIV to have good Health Related Quality of Life. Irrespective of the numbers, describing Health Related Quality of Life as the 4th 90 risks implying to people living with HIV and health care providers and commissioners that good Health Related Quality of Life is only for those who are virally suppressed.

We recognise that familiarity with the 90-90-90 targets is such that it creates a discursive power which supports the amplification of Health Related Quality of Life as a concept. However, it is vital that we foreground how Health Related Quality of Life is for everyone living with HIV – regardless of their state of health or viral load, at whatever stage of the life course they are, and whatever their life circumstances. This is important from an equality and rights standpoint, but also in terms of the known health benefits from improving Health Related Quality of Life among people living with HIV (adherence, retention in care, patient activation etc) being available to all.

Area: 2: Psychological

HIV is also heavily stigmatised. While treatment in the UK is now so advanced that living with HIV should be like living with any other long-term condition, the sad fact is that HIV stigma has not really moved on since the 1980s when millions of people were dying from AIDS.

Addressing mental health needs is crucial to the HIV response and our success in reaching the 2030 target of zero new infections.

Mental illnesses, such as depression, and neurocognitive impairment are prominent among people living with HIV. These conditions impact upon individuals' energy levels, mood and ability to perform daily life activities and engage in social relationships. They can add significantly to the burden of living with HIV and severely compromise health-related quality of life. Mental health conditions and neurocognitive impairment can also make self-management of HIV more difficult and undermine adherence to essential ART drugs and HIV care. Long-term care for people living with HIV should therefore integrate services to assess and manage any mental health and neurocognitive issues, including access to 'HIV appropriate' psychological and mental health support services. We also know that ageing with HIV impacts on neurocognitive issues and people feel more alone and suffer depression, especially people who have low family support – more likely among men who have sex with men and migrant communities.

Mental Health

A decade ago mental health did not have anything like the profile it has now. Thanks to campaigns like Time to Change and the growing numbers of people who have had the courage to speak out about mental health, we are starting to see an improvement in attitudes towards those of us with mental health problems.

Mental health and HIV are acutely related for a number of reasons. People with HIV are more likely to have mental health problems and people with mental health issues are more likely to acquire HIV[57]. Mental health and HIV disproportionately impact the same groups of people who are marginalised and suffer from socio-economic deprivation, such as the Lesbian, Gay, Bisexual, Transgender (LGBT) and Black, Asian, Minority Ethnic (BAME) communities. Chemsex, HIV and mental health are also closely associated. Chemsex drug use is a growing issue among men who have sex with men (MSM) living with HIV, and these men report frequent mental health symptoms[58]. Chemsex is also frequently reported in MSM who are at higher risk for HIV acquisition. The use of Chemsex drugs may be a way of dealing with a previously existing mental health condition or an HIV diagnosis, or can directly cause mental health issues because of the chemical effects of the drugs.

There are high rates of poor mental health among people with HIV, which is a harm in and of itself, and should be addressed with a 'parity of esteem' from commissioners. Such poor mental health can undermine clinic attendance and so have an impact on mortality and morbidity, as well as onward transmission. It also adversely affects self-care, social contact, employment and finances.

Older people with HIV access, value and rely on HIV support services to ensure a good quality of life. Needs relate to finances, sex and relationships, stigma, mental health, co-morbidities, and the physical challenges and unknowns of living with HIV.

In order to treat HIV effectively it is necessary to address any comorbid mental health conditions as these can affect adherence to medication, overall health outcomes and affect wellbeing generally – social relationships, employment etc. There is a clear public health incentive for investing in mental health services for people living with HIV. Failure to adhere to medication means you are more likely to pass on the virus because when you are Undetectable you are Untransmittable. **The lack of psychological support within HIV clinics is therefore a major barrier to effectively treating HIV and reaching the 2030 target of zero new infections.**

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[57] NAT submission and Terrence Higgins Trust submission
[58] NAM AIDS Map

There are a variety of issues in children and young people that contribute to poor mental health. These include HIV stigma, bereavement, secrecy, migration, child caring roles and social isolation. Children born with HIV are also more vulnerable to cognitive impairment issues as a consequence of living with HIV[59].

As a consequence, specific mental health issues such as anxiety, depression and psychosis may arise in older children and adolescents. Psychological support for children and families living with HIV is needed to promote good mental health within childhood and later life.

While not everyone living with HIV will suffer from mental health issues within their lifetime, there is clear evidence to show that mental health and HIV are closely interrelated and that in order to treat HIV effectively you cannot ignore a person's mental health. Late diagnosis is increasing – from 42% in 2016[60] to 43% in 2017[61] – in part, because of the fear of receiving an HIV diagnosis. Late diagnosis and lack of adherence to HIV medication are both linked to stigma and ultimately have the same effect - the longer people are left undiagnosed or not on effective treatment, the more likely they are to pass on the virus. The links between HIV stigma, mental health, and late diagnosis need to be made across the health system if we are going to meet the 2030 zero new infections target.

The link between HIV and mental health is complex and bi-directional; however, the key underlying factor that makes HIV stand out from other long-term conditions is stigma. The medical treatment of HIV is seen as gold standard in the UK, but there is a lack of appropriate referral pathways for associated issues which impact people beyond controlling the virus, especially mental health. This report will outline how that stigma affects mental health and make the case for why psychological support for people with HIV should be included within the service specification for clinical treatment of HIV and given greater importance by the NHS.

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[59] CHIVA submission
[60] Terrence Higgins Trust submission
[61] Terrence Higgins Trust submission

Respect My HIV march London October 2021

Stigma

Stigma ruins lives. It can make us feel isolated, ashamed and worthless. It can stop us from building relationships or accessing work. It can prevent us from seeking help or treatment. It can deny us the opportunity to live our lives to the full, as a recent report by National AIDS Trust showed for the UK[62].

The Cambridge definition of stigma is: "a strong feeling of disapproval that most people in a society have about something, especially when this is unfair"[63].
HIV stigma exists because of the many myths that still exist around how you can contract HIV. According to the National AIDS Trust website:

> ***"HIV is passed on through infected bodily fluids such as semen, vaginal fluids, blood, breast milk and rectal secretions. The most common ways HIV is transmitted are through sex without a condom and through sharing infected needles, syringes or other injecting drug equipment. You cannot get HIV through casual or day-to-day contact, or kissing, spitting or sharing a cup or plate. A small number of people living with HIV in the UK acquired it before or soon after birth."***[64]

'Actual' and 'Perceived' Stigma

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[62] https://www.nat.org.uk/publication/hiv-public-knowledge-and-attitudes
[63] https://dictionary.cambridge.org/dictionary/english/stigma
[64] NATwebsitehttps://www.nat.org.uk/we-inform/FAQs-%26-Myths

Erik McGregor/Getty Images

Through the evidence given by STOPAIDS, Elton John AIDS foundation, National AIDS Trust and Professor Lazarus, the impact of criminalisation (which we will touch upon in section 3 of this report) causes a great deal of actual and perceived stigma for a vast majority of people affected by HIV.

Stigma affects everyone living with HIV, but we have been told that cultural and community differences can make it worse. The submission from The HIV Liaison Service at South London and Maudsley Trust (SLAM) highlights that in Black, Asian and Minority Ethnic communities, cultural beliefs can lead to issues around shame and stigma, leading to non-diagnosis and barriers to treatment. A meta-analysis by Katz Ryu[65] concluded that there is a link between stigma and ARV adherence. As outlined by SLAM in written evidence to the APPG in 2017:

> ***"Stigma can be 'actual' or 'perceived' ("internalised"). Whereas actual stigma is a societal issue, perceived stigma is a mental health issue that occurs when an individual, as a result of repetitive external messages about HIV (for example, 'I am dirty', 'nobody will accept me'), develops negative core beliefs that fuel and/or exacerbate mood disorder".***[66]

The existence and the impact of stigma is widely recognised and measured through a number of tools, surveys and questionnaires in the UK. In addition to tools mentioned previously, such as the Positive Voices survey, the HIV Stigma Scale (HSS) is the most commonly used and is one of the few tools which covers all types of stigma and discrimination. We believe this should be included as part of an annual health review.

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[65] Katz, I.T., et al., Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. J Int AIDS soc, 2013. 16 (3 suppl 2): p.18640

[66] https://static1.squarespace.com/static/5b7d333855b02cc3853805ce/t/5e60ec83633a0705fb-4d4a32/1583410309413/The+Missing+Link+Web+version.pdf

The impact

Stigma and discrimination have a myriad of impacts on individuals living with HIV, including (but not limited to):

Poor mental health: Stigma and discrimination often lead to social isolation and marginalisation, fuelling mental health challenges[67].

Reluctance to access medical care: Prevailing stigma within healthcare systems means people living with HIV are less likely to seek medical care due to fear of having to disclose their HIV status to healthcare professionals, and many have concerns that their status will mean they are treated differently[68].

Poorer health outcomes: Mental health challenges make the accessing of healthcare and adherence to treatment regimens more challenging. Mental health support for people with depression and HIV has been found to increase adherence to medication in 83% of cases[69]. This will have an impact on prevention and adherence, both key to ending new transmissions by 2030.

It is important to note that while stigma and discrimination affect all people with HIV, it can be worse for certain groups - including those from lower socioeconomic backgrounds, communities where English may not be the first language, ageing populations, and groups with high HIV prevalence[70].

As mentioned previously, to tackle this stigma it's vital that we have a wide spectrum of education, training services and public awareness campaigns tackling prevailing stigma and discrimination in schools, the NHS, and among the general public. In addition to this, all national and local HIV treatment and prevention plans must contain strategies for tackling stigma and discrimination.

Stigma and discrimination means people are less likely to access healthcare and, when they do, report incidences of sub-optimal practice driven by a lack of understanding and stigma surrounding HIV. Research shows that:

Over the course of one year, one in ten respondents to the Positive Voices survey avoided seeking general healthcare in an effort to hide their HIV status[71].

In our the "Missing Link: HIV and Mental Health" we found that people living with HIV continue to report ongoing lack of HIV awareness amongst those treating them, particularly among non-specialist staff such as GPs and nurses, which impacts their relationship with these healthcare providers[72].

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[67] HIV Outcomes Initiative, HIV Outcomes organises a roundtable on the HRQoL of people living with HIV in the UK, June 2021

[68] HIV Outcomes Initiative, HIV Outcomes organises a roundtable on the HRQoL of people living with HIV in the UK, June 2021

[69] APPG on HIV & AIDS, The Missing Link: HIV and mental health, March 2020

[70] HIV Outcomes Initiative, HIV Outcomes organises a roundtable on the HRQoL of people living with HIV in the UK, June 2021

[71] APPG on HIV & AIDS, The Missing Link: HIV and mental health, March 2020

[72] HIV Outcomes Initiative, HIV Outcomes organises a roundtable on the HRQoL of people living with HIV in the UK, June 2021

It's important to acknowledge that some populations with HIV are more likely to be impacted by these issues than others. Research shows that Black, Asian and minority ethnic people are less likely to feel informed or ask questions about their conditions, and as such are more likely to feel uncomfortable with changes to their treatment programme, which can create barriers to accessing the best treatment[73].

59% of people living with HIV found difficulties in registering with a dentist in comparison with people without HIV[74]. Once patients with HIV are registered with a dentist, they can experience discrimination: 35% reported such treatment, with 6.2% having been refused dental treatment altogether.

CHIVA, George House Trust, STOPAIDS and others, in their submissions, stated that stigma associated with HIV, fear of disclosure, and daily dosing can be persistent reminders of HIV status. This may contribute to suboptimal adherence, leading to failure of ART and consequent loss of suppression and risk of onward transmission. Suboptimal adherence also adversely affects healthcare resources, including costs from disease management and new cases of HIV. In fact, a new case of HIV has estimated lifetime medical costs ranging from £185,200 to £360,800 in the United Kingdom and $326,500 to $597,300 in the United States[75,76].

Summary:

There have been remarkable advances in HIV treatment, prevention and care in the UK. Most people on HIV treatment have normal life expectancy, and live with the knowledge that they cannot transmit HIV. Rates of new infections are falling. Yet while there is much to celebrate, people living with HIV are still twice as likely to experience poor mental health as the general population.

We have heard how new challenges have arisen as many people living with HIV live longer and require life-long specialist care for a range of comorbidities (the presence of other health conditions alongside HIV), including gerontological related care as well as primary medical care. People living with HIV have a risk of some/certain chronic health challenges and comorbidities, while many also face stigma and discrimination in health systems, social services and in their public and private lives. Improving and sustaining quality of life influences not only individual wellbeing, but also contributes to global acceptance of the new reality of living well with HIV.

Incorporating the views of people living with HIV is essential to developing policies, services and changing attitudes that both meet their needs and reflect this new reality. Even with virologic suppression, people living with HIV tend to have significantly lower HRQOL (Health Related Quality of Life) outcomes than

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[73] APPG on HIV & AIDS, "Nothing about us without us." This report looks specifically at addressing the needs of Black, Asian and Minority Ethnic communities in relation to HIV in the UK

[74] S. Okala et al., 'The People Living with HIV Stigma Survey UK 2015: Stigmatising experiences and dental care' 2015

[75] Shackman BR, Fleishman JA, Su AE, et al. The lifetime medical cost savings from preventing HIV in the United States. Med Care. 2015;53(4):293-301.

[76] Nakagawa F, Miners A, Smith CJ, et al. Projected lifetime healthcare costs associated with HIV infection. PLoS One. 2015;10(4):e0125018.

the general population, and their HRQOL outcomes decrease further with disease progression[77,78]. These challenges reflect the need for a HRQOL target, ensuring that people living with HIV have a quality of life that goes beyond the continuum of treatment paradigm.

This builds on the UNAIDS global targets, which have been instrumental in advancing the current success of HIV care and continue to be the global standard to work to achieve. The HIV Outcomes initiative[79] successfully advocated for the explicit inclusion of quality of life in both the UNAIDS Global AIDS Strategy (2021-2026), which now references quality of life, and the United Nations Secretary-General Report, which captured the importance of adopting differentiated care models to improve quality of life.

It was strongly advised - and we agree - that long-term care for people living with HIV should therefore integrate services to assess and manage any mental health and neurocognitive issues, including access to 'HIV appropriate' psychological and mental health support services.

We must also address the ignorance in healthcare when it comes to the U=U message. This is a strong message and all healthcare workers should be educated. It is crucial for the Faith Based Community to root out HIV stigma. That requires us to have conversations with faith leaders to preach support beyond tolerance.

These initiatives are really important, bringing more attention to the structural drivers of stigma, discrimination in different settings, and of course the multi-level interventions that we need to address them.

Information is power. The more we know and understand about stigma and what we are up against, the easier it will be to fight it.

There is still a long way to go, particularly for those who may be experiencing stigma for other reasons too.

Stigma continues to have a pervasive impact on the lives of people living with HIV, many of whom will also have a mental health problem. It's hard enough for people to be living with a long-term health condition and experiencing a mental health problem, without having to face the judgement, shame and isolation that often surround them.

People with HIV very often come from communities already significantly affected by social and health-related disadvantage. Needs assessments should recognise the diverse experiences and needs of people with HIV, and be sensitive to the way HIV interacts with other structural needs and inequalities.

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[77] Degroote S, Vogelaers D, Vandijck DM. What determines health-related quality of life among people living with HIV: an updated review of the literature. Arch Public Health. 2014;72(1):40.

[78] Miners A, Phillips A, Kreif N, et al. Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: a cross-sectional comparison with the general population. Lancet HIV. 2014;1(1):e32-e40

[79] The HIV Outcomes initiative is enabled by sponsorship provided by Gilead Sciences and ViiV Healthcare

Area 3: Social

> ***"The decriminalisation of homosexuality is an essential component of a comprehensive public health response to the elevated risk of HIV acquisition and transmission among men who have sex with men."***

HIV prevention efforts - and the promise of antiretroviral therapy as prevention - are being undermined by punitive laws targeting those living with and at risk of HIV. In many parts of the world, legislation effectively criminalises populations living with HIV or vulnerable to HIV infection, such as sex workers, drug users, and men who have sex with men. These laws fuel stigma and discrimination, increase barriers to HIV information and treatment, and contribute to the spread of disease. Elsewhere, laws criminalising HIV transmission discourage HIV testing. This potentially subjects those who know their HIV status to criminal penalties while exempting those who are unaware of their infection.

Perceptions of public health and the criminalisation of homosexuality have been deeply entwined since at least Victorian times[80]. In the past and still today in some countries, criminalisation is defended using a range of standard, albeit ill-informed, justifications. Public health arguments in favour of criminalisation include the fallacy that it curbs sexually transmitted infections, such as HIV. This section summarises a wide range of global expert evidence that firmly establishes that these arguments are wrong. Experts have repeatedly concluded that, rather than slowing the spread of HIV, the criminalisation of homosexuality seriously impedes the effectiveness of measures designed to reverse the HIV pandemic.

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[80] JS Mill's 'harm principle' was influential in both Victorian times and when England and Wales debated decriminalisation in the 1950s and 1960s. This principle provides that states may legislate to regulate the conduct of individuals in order to protect the wellbeing of others, thus giving a perceived reason to criminalise homosexuality if it is believed that public health will be improved. See, for example, McSherry, B., et al, Regulating Deviance: The Redirection of Criminalisation and the Futures of Criminal Law, (2008), pp. 201-203.

Further, on an individual level criminalisation leads to increased morbidity and risk of death in those infected with HIV due to the barriers it creates to accessing treatment.

The Lancet, 'Common roots: a contextual review of HIV epidemics in black men who have sex with men across the African diaspora'[81] report of July 2012 found that disparities in the prevalence of HIV infection in several African and Caribbean countries were directly correlated to the status of criminalisation:

The odds of HIV infection in black MSM relative to general populations were nearly two times higher in African and Caribbean countries that criminalise homosexual activity than for those living in countries where homosexual behaviour is legal.

The odds of being infected with HIV are significantly greater in Caribbean countries that criminalise homosexual sex than those where it is decriminalised[82].

A study commissioned by the UN Development Programme focusing on Asia and the Pacific found that laws criminalising homosexuality are regularly used by police to[83]:

a) Prohibit HIV prevention activities on the grounds that they aid and abet criminal activities.
b) Harass HIV outreach workers, many of whom are MSM.
c) Confiscate condoms and lubricants as evidence of prostitution or illegal male-male sex.
d) Censor HIV education materials and otherwise prohibit the dissemination of public health information about safe sex practices.

There is also a strong correlation between criminalisation and under-investment in HIV services for MSM[84]. This is partly because these laws make it politically difficult for governments to justify the necessary funding for providing HIV support[85]. More broadly, criminalisation lowers the visibility of MSM and leads to inaccurate data on HIV sub-epidemics[86]. By the end of 2011, only 87 countries had reported prevalence of HIV in MSM, with data most sparse for the Middle East and Africa, 'regions where criminal sanctions against same-sex sexual behaviour can make epidemiological assessments challenging'[87]. This paucity of information means that HIV prevention programmes are less likely to be adequately resourced and driven by reliable data.

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[81] Fenton, K.A., Flores, S.A., Heilig, C.M., Jeffries, W.L., Lane, T., Malebranche, D.J., Millett, G.A., Peterson, J.L., Steiner, R., Wilson, P.A., 'Common roots: a contextual review of HIV epidemics in black men who have sex with men across the African diaspora', The Lancet, 28 July 2012, Vol. 380, Issue 9839, pp. 411-423. Available at: http://www.humandignitytrust.org/uploaded/Library/Other_Reports_and_Analysis/The_Lancet__Common_roots__a_contextual_ review_of_HIV_epidemics_in_black_men_who_have_sex_with_men_across_the_African_diaspora.pdf

[82] Ibid, p. 417.

[83] 'Laws in Asia hindering Aids fight, say UN health officials', South China Morning Post, 2 July 2013. Available at: http://www.scmp.com/news/asia/ article/1273330/laws-asia-hindering-aids-fight-say-un-health-officials

[84] American Foundation for AIDS Research, Achieving an AIDS-free generation for gay men and other MSM: financing and implementation of HIV programs targeting MSM, 2012.

[85] American Foundation for AIDS Research, Achieving an AIDS-free generation for gay men and other MSM: financing and implementation of HIV programs targeting MSM, 2012. Beyrer, C., 'Global prevention of HIV infection for neglected populations: men who have sex with men', Clin Infect Dis, 2010, 50, Suppl 3, pp. 108–113.

[86] Jenkins, C., 'Male sexuality and HIV: the case of male-to-male sex', Background Paper: Risks and Responsibilities, Male Sexual Health and HIV in Asia and the Pacific, New Delhi (2006): 11

Jenkins, C., 'Male sexuality and HIV: the case of male-to-male sex', Background Paper: Risks and Responsibilities, Male Sexual Health and HIV in Asia and the Pacific, New Delhi (2006): 11

Stigma and discrimination

Stigma and discrimination can cause low self-esteem, disruption to social relationships and limitations to obtaining housing and jobs. They hamper the prevention of mental health disorders, the promotion of mental well-being and the provision of effective treatment and care. They also contribute to the abuse of human rights. UNAIDS identify discrimination as a barrier to accessing health and community services, which prevents the attainment of universal health coverage. It leads to poor health outcomes and hinders efforts to end the AIDS epidemic and achieve healthy lives for all[88].

HIV-related stigma and discrimination refer to prejudice, negative attitudes and abuse directed at people living with HIV and AIDS. In 35% of countries with available data, over 50% of people report having discriminatory attitudes towards people living with HIV[89]. Discrimination, isolation and human rights violations can lead to negative health outcomes for people living with HIV.

The People Living with HIV Stigma Index found that from 50 countries, roughly one in every eight people living with HIV is being denied health services because of stigma and discrimination[90]. Stigma and discrimination are often targeted at key affected populations.

Stigma and discrimination can make accessing health care a traumatic experience for people living with HIV and can discourage them from doing so. Experience of stigma and discrimination can also compromise trust in health workers/officials. Trust is critical for people to access health care, especially if they have grown up with Adverse Childhood Experiences behind them, which can negatively influence lifelong health-seeking actions.

There have been many examples of discriminatory practices and policies against people living with HIV within health care systems especially, although not just, in contexts where health budgets are constrained. For example women living with HIV have been subject to forced sterilisations; and have received inadequate access to perinatal care, are then blamed for transmitting HIV to their unborn child and are treated as 'vectors of disease'[91].

Country data reported to UNAIDS show that the proportions of people belonging to key populations who avoid health care services due to stigma and/or discrimination remain disconcertingly high. Across all key populations, at least one in three reporting countries stated that more than 10% of respondents avoided health care, including three in four countries for people who inject drugs[92].

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[88] UNAIDS (2017) 'Agenda for zero discrimination in health-care settings'. Available at: https://www.unaids.org/sites/default/files/media_asset/2017ZeroDiscriminationHealthCare.pdf

[89] UNAIDS (2015) 'On the Fast-Track to end AIDS by 2030: Focus on location and population'. Available at: https://www.unaids.org/sites/default/files/media_asset/WAD2015_report_en_part01.pdf

[90] People Living with HIV Stigma Index. 2017. Home - People Living with HIV Stigma Index. [online] Available at: https://www.stigmaindex.org/

[91] Dunaway, K., Brion, S., Hale, F., Alesi, J., Assan, H., Chung, C., Moroz, S., Namiba, A., Ouma, J., Owomugisha, I., Ross, V., Strachan, S., Tholanah, M., Yuvaraj, A. and Welbourn, A., 2022. What will it take to achieve the sexual and reproductive health and rights of women living with HIV?. Women's Health, 18, p.174550572210803. Available at: https://journals.sagepub.com/doi/10.1177/17455057221080361

[92] Unaids.org. 2022. Many key populations avoid health services. [online] Available at: https://www.unaids.org/en/resources/presscentre/featurestories/2022/february/20220221_key-populations-health-services

Ending discrimination increases respect and support within health care and improves the social and psychological wellbeing of vulnerable communities - which in turn increases QoL. Trauma-aware care training for health care workers is also an important part of ending discrimination in HIV care[93].

In the Agenda for Zero Discrimination in Health Care, UNAIDS outlines priorities for the United Nations and development partners, civil society, professional health care associations, academics and other key stakeholders, for the following key actions[94]:

- Remove legal and policy barriers that promote discrimination in health care.
- Set the standards for discrimination-free health care.
- Build and share the evidence base and best practices to eliminate discrimination in health care settings.
- Empower clients and civil society to demand discrimination-free health care.
- Increase funding support for a discrimination-free health workforce.
- Secure the leadership of professional health care associations in actions to shape a discrimination-free health workforce.
- Strengthen mechanisms and frameworks for monitoring, evaluation and accountability for discrimination-free health care.

People living with HIV in all their diversity continue to be othered. There are many glass ceilings that prevent them from coming forward with their own HIV lived experience - eg racism, homophobia, transphobia, sexism/misogyny. As well as these categories, it affects people who use drugs, and sex workers. To tackle discrimination, the meaningful inclusion of all people living with HIV, especially those from marginalised communities, must be prioritised in HIV governance. These communities are not hard to reach, they are just not included from the outset in the policies and programmes that deeply affect their lives. Responding to these needs, the Global Fund's 2023-2028 Strategy places people and communities front and centre of the response and accelerates the shift to more integrated, people-centred models of prevention, treatment and care. To realise the Global Fund's strategy and unlock needed funding to community-led organisations, the international community should work to achieve the target of at least $18bn for the seventh replenishment.

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[93] Cep.health. 2020. CEP Providers | Women-Centred HIV Care. [online] Available at: https://cep.health/clinical-products/hiv/

[94] UNAIDS (2017) 'Agenda for zero discrimination in health-care settings'. Available at: https://www.unaids.org/sites/default/files/media_asset/2017ZeroDiscriminationHealthCare.pdf

There also needs to be more effort from the international community to ensure community-led organisations receive the funding they need via multilateral, bilateral and domestic resource channels. If this isn't possible in some country settings, Governments should expand social contracting to better equip community-led organisations within their country's HIV response. Funding needs to be flexible and receptive to the specific needs of community-led organisations.

CASE STUDY:

March 2022: Zimbabwe's parliament for repealing section 79 of the Criminal Law Code, which criminalises HIV transmission. A new marriage bill adopted by parliament that repeals the criminal code section is to be signed into law by the president.

UNAIDS has worked closely with Zimbabwe's National AIDS Council, Zimbabwe Lawyers for Human Rights, parliamentarians, civil society activists and communities to advocate for the repeal of the law criminalising HIV. Overly broad and inappropriate application of criminal law against people living with HIV remains a serious concern across the globe. More than 130 countries worldwide still criminalise HIV non-disclosure, exposure and transmission through either specific or general criminal legislation.

In 2019, Zimbabwe completed a legal environment assessment, which identified the criminalisation of HIV transmission as a barrier to health care and a driver of stigma and discrimination for people living with HIV and other key populations. Since then, the United Nations Development Programme has worked with key populations and other stakeholders, convening meetings with parliamentarians and other partners to advance the recommendations of the legal environment assessment.

Zimbabwe has made great progress in the response to HIV over the past decade. It is estimated that 1.2 million of the 1.3 million people living with HIV in the country are now on life-saving medicines. AIDS-related deaths have decreased by 63% since 2010, with new HIV infections down by 66% over the same period.

HIV Criminalisation

HIV criminalisation refers to the use of criminal and similar laws against people living with HIV based on their HIV-positive status. In many countries around the world, criminal laws have been introduced that punish the transmission of HIV, potential or perceived exposure to HIV, and even non-disclosure of HIV status. In some places, HIV has been added to the list of infectious diseases that were already criminalised, and in others specific legislation has been brought in.

The number of these laws (and their use) is increasing, despite them being ineffective, discriminatory and a significant barrier to HIV prevention, treatment and care[95]. Laws often fail to recognise that HIV is no longer a death sentence, that effective treatment eliminates the risk of transmission (U=U) and that, regardless of treatment, the possibility of HIV transmission from a single act of exposure is extremely low.

Globally at least 130 countries have criminal laws that can be, or have been, applied to allegations of HIV transmission, HIV exposure and non-disclosure of HIV status. Criminalisation includes the investigation, prosecution and conviction of people for transmitting or exposing others to HIV.

It is important to distinguish intentional (deliberate) acts and unintentional acts. Globally, most HIV criminalisation prosecutions involve the severe punishment of unintentional, or ‘reckless’ HIV exposure or transmission. In the Netherlands, only intentional HIV exposure or transmission are criminalised, making it one of the most progressive countries in the world when it comes to HIV criminalisation[96].

It is uncontested that deliberate and actual transmission of HIV to someone as a way to cause them harm is a crime. Cases of people living with HIV intentionally transmitting HIV to others are extremely rare, as are cases of medical negligence by health workers. Such cases can be prosecuted under existing law, rendering additional legislation that singles out HIV redundant. For this reason, South Africa took the decision not to introduce an HIV-specific law in 2001[97].

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[95] https://www.aidsmap.com/about-hiv/hiv-criminalisation-laws-around-world
[96] NAM Submission
[97] NAM Submission

Fortunately, as a result of medical developments and the finding that U=U, the concern of reckless transmission is minimised for the majority of people living with HIV in the UK who maintain an undetectable viral load. However not all people living with HIV have an undetectable viral load and furthermore some may never have. ART is not universally easily available due to a number of barriers. Therefore a minority of individuals remain at risk of investigation and prosecution for reckless transmission of HIV.

UNAIDS urges states to use the law only in cases of intentional transmission. As noted above, BHIVA's position remains that application of the criminal law to cases other than intentional transmission may be counterproductive to public health aims.

The most recent global audit published by the HIV Justice Network found a total of 75 countries with criminal laws that specifically mention HIV[98]. HIV-specific laws are particularly concentrated in three parts of the world: the United States, eastern Europe/central Asia and sub-Saharan Africa.

The United States was the first country in the world to introduce HIV-specific criminal laws, beginning in 1987, and there have been thousands of reported cases since. The audit stated that over half of the states (27) have HIV criminalisation laws with lengthy sentences, although some - including California, Colorado, Iowa, Michigan and North Carolina - have modernised these laws in the past few years. (Other states use general laws to prosecute HIV transmission and exposure.)[99]

The audit also shows that following the enactment of HIV-specific criminal laws in the second half of the 1990s, the eastern European and central Asian region now has the second-highest number of laws that specifically criminalise HIV.
We heard from EJAF, Global Fund, HIV Outcomes and the audit that Russia, Ukraine and Belarus have some of the most punitive HIV criminalisation systems in the world and very high numbers of reported cases. The audit stated that in Russia, any action that may put another person at risk of infection is punishable. The law in the Ukraine is very similar to Russia. In 2018 a successful advocacy campaign led to an amendment to the law in Belarus that removed individuals from criminal liability if they had disclosed their HIV status to their partner and their partner had agreed to any acts that might have led to HIV transmission. Rates of criminalisation remain high, however[100].

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[98] https://www.hivjustice.net/publication/advancing3/
[99] https://www.hivjustice.net/publication/advancing3/
[100] https://www.hivjustice.net/publication/advancing3/

HIV Justice Network state that Sub-Saharan Africa is the region with the most countries that have enacted HIV criminalisation laws, although in most countries the number of reported cases is not high compared with the number of people living with HIV. As in eastern European and central Asia, women are more likely to be prosecuted than men since they are usually the first in a relationship to learn their HIV status due to antenatal HIV testing. There have also been a number of cases in which women have been accused of intentionally passing on HIV to their own child, or the child of someone else, by breastfeeding. Many countries, particularly in west and central Africa, introduced very broad HIV-specific legislation in the mid-2000s. In recognition of the damage these laws pose to the fight against HIV, several countries have since decriminalised vertical transmission and limited criminal liability to acts involving a significant risk of transmission. In 2018, the Democratic Republic of the Congo repealed its HIV-specific law altogether as a result of community advocacy. Zimbabwe has also taken recent steps to repeal its HIV-specific laws and efforts are ongoing to challenge Kenya's HIV-specific criminal law as unconstitutional[101].

The 2021 Political Declaration on HIV and AIDS also commits Governments to create an enabling legal environment by reviewing and reforming, as needed, restrictive legal and policy frameworks, including laws related to HIV non-disclosure, exposure and transmission[102]. Governments should be kept accountable to their commitments to the Political Declaration and urgently review and reform these laws.

HIV-specific laws in the rest of the world

Professor Lazarus in his evidence to the inquiry stated that within the European Union, only a handful of member states have ever introduced HIV-specific legislation. Denmark, which introduced western Europe's only HIV-specific criminal law in 2001, suspended it ten years later. He also told the inquiry that under the guise of COVID-19 prevention, Poland amended the country's HIV-specific penal provisions in 2020, increasing the maximum penalty for HIV exposure from three years to eight years' imprisonment. The penalty for exposure to other STIs and/or infectious diseases was also increased. He advised that Romania and Latvia have also enacted HIV-specific criminal laws, although here have been very few reported cases to date.

UNAIDS have documented that In Latin America and the Caribbean, 14 countries have HIV-specific criminal laws, including a recently enacted law in El Salvador (2016), and proposed laws are pending in Chile and Jamaica. In Mexico, laws in several states were proposed and then withdrawn in 2017/2018. Similarly, following concerted advocacy, a proposed law was withdrawn in Brazil in 2017. The Constitutional Court of Colombia found their HIV-specific criminal law unconstitutional in 2019[103].

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[101] https://www.hivjustice.net/publication/advancing3/
[102] https://www.unaids.org/sites/default/files/media_asset/2021_political-declaration-on-hiv-and-aids_en.pdf
[103] https://www.unaids.org/en/resources/presscentre/featurestories/2019/july/20190731_mapping-hiv-laws-and-policies

They also document that the Asia-Pacific region has 11 countries with HIV criminalisation laws, including Pakistan, Viet Nam and a recently enacted law in Nepal (2018). In China, national regulations state that a person living with HIV must inform a prospective sexual partner of their HIV status and take necessary precautions to prevent HIV transmission, although those precautions are not defined[104].

Types of HIV criminalisation

The HIV Justice Network advises that countries may criminalise people with HIV for transmission, exposure or non-disclosure of HIV status. Some countries criminalise all three[105].

Criminalisation of non-disclosure to sexual partners

We know from the evidence that the inquiry has received that in some countries around the world you are legally obliged to inform your partner of your HIV-positive status before you have any sexual contact. A few HIV-specific criminal laws are written in such a way that they assume guilt on your part even if you have not been diagnosed but think you might have HIV. In some places, you can be prosecuted even if you disclosed to your partner that you are HIV-positive before you had sex and gained their informed consent[106].

The HIV Justice Network documented that in Singapore there have been at least ten cases prosecuted under the Infectious Diseases Act, which states that a person who knows they have HIV or has reason to believe they have been exposed to a significant risk of acquiring HIV, must not engage in any sexual activity with another person without informing the person that they have (or may have) HIV[107].

Criminalisation of potential or perceived HIV exposure

‘HIV exposure’ refers to an act which may have put another person at risk of HIV infection, even if that person did not acquire HIV. For example, many countries criminalise people living with HIV who have sex without a condom.

However the HIV Network state that the criminal law often assumes that HIV exposure always takes place when someone has any kind of sexual contact, or spits or bites or breastfeeds, disregarding up-to-date science. In some countries you can be prosecuted for HIV ‘exposure’ even if you used a condom, were on effective treatment, performed oral sex, or spat on someone. Increasingly these prosecutions are being challenged, but they still occur far too frequently[108].

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[104] https://www.unaids.org/en/resources/presscentre/featurestories/2019/july/20190731_mapping-hiv-laws-and-policies

[105] https://www.hivjustice.net/wp-content/uploads/2019/05/AHJ3-Full-Report-English-Final.pdf

[106] https://www.hivjustice.net/wp-content/uploads/2019/05/AHJ3-Full-Report-English-Final.pdf

[107] https://www.hivjustice.net/wp-content/uploads/2019/05/AHJ3-Full-Report-English-Final.pdf

[108] https://www.hivjustice.net/wp-content/uploads/2019/05/AHJ3-Full-Report-English-Final.pdf

Nigeria's *Sexual Offences Bill* makes it illegal for a person who knows they have HIV to intentionally, knowingly and wilfully do anything or permit anything to be done which they should reasonably know is likely to transmit HIV[109]. The law does not require HIV transmission, or for the person to have an intention to transmit HIV, and carries a penalty of between 20 years and life imprisonment. The law specifically states that it applies whether or not the parties were married.

Some states in Australia have recently passed laws that allow police to forcibly test anyone they think might have exposed them to HIV via spitting or biting, even though expert scientific consensus argues that this only leads to unnecessary worry for police – who will not have been at risk – and violates the rights of the people forcibly tested[110].

Criminalisation of HIV transmission

Many laws around the world appear to criminalise HIV transmission. However, the laws are often written so broadly or vaguely that they actually criminalise non-disclosure or HIV 'exposure'. Where courts are faced with allegations of actual HIV transmission, they often erroneously assume the person diagnosed first passed it on. They also frequently misunderstand how science is unable to definitively show timing and direction of infection. As the Expert Consensus Statement on the Science of HIV in the Context of Criminal Law states, it is extremely difficult to conclusively prove HIV transmission directly from one person to another[111].

Use of general laws to punish HIV

HIV criminalisation can still occur in countries that do not have laws that specifically mention HIV, instead using laws against endangerment, physical or sexual assault, or even attempted murder. Between 2015 and 2018, half of the globally reported cases of HIV criminalisation were based on general criminal laws[112].

It is stated by AIDSLAW that Canada has one of the highest numbers of reported cases of HIV criminalisation in the world, despite the absence of HIV-specific legislation. Courts there have defined non-disclosure when there is a "realistic possibility" of transmission as aggravated sexual assault, with a maximum penalty of life imprisonment. In some cases, people have been charged and imprisoned for acts with zero to negligible risk of transmission, including sex with an undetectable viral load, oral sex, or sex with a condom[113].

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[109] https://www.humandignitytrust.org/reform-tool/countries/nigeria/
[110] https://www.aidsmap.com/about-hiv/hiv-criminalisation-laws-around-world
[111] https://pubmed.ncbi.nlm.nih.gov/30044059/
[112] https://www.aidsmap.com/about-hiv/hiv-criminalisation-laws-around-world
[113] http://www.aidslaw.ca/site/wp-content/uploads/2019/05/HIV-criminalization-Info-Sheet-1.pdf

Most countries in western Europe also use general criminal laws to unjustly criminalise people living with HIV, although recognition of the prevention benefit of treatment has recently reduced the number of cases. The UK, France, Germany, Norway, Sweden and Switzerland are countries in western Europe with unusually high numbers of cases considering the number of people living with HIV[141]. Similarly, New Zealand has one of the highest rates of HIV criminalisation *per capita* in the world[115].

It is stated by UNAIDS that little is known about the extent of HIV criminalisation across the Middle East due to reporting restrictions. Most of the reported cases of HIV criminalisation in the region have used general or religious laws to prosecute people, who are most often gay men, sex workers and/or migrants.

Summary:

Improving health-related quality of life for women in their diversity is critical to improve health outcomes for people living with HIV, particularly in vulnerable communities. This diverse constituency is disproportionately impacted by HIV. 53% of the global population living with HIV are women and girls. Every week, 5,000 young women aged between 15 and 24 years become infected with HIV. In addition, the risk of acquiring HIV is 34 times higher for transgender women compared with the wider general public[116]. For women, being diagnosed with HIV may have profound implications socially, professionally, physically, sexually, and emotionally[117,118]. Many women living with HIV often learn about their HIV diagnosis during pregnancy, during which time treatment adherence can be particularly challenging[119]. A more holistic approach to health, addressing psychosocial and emotional conditions, beyond virologic suppression, may improve quality of life and accelerate progress towards national or international targets to avert HIV transmission and protect public health[120].

Understanding and improving the health of LGBTI+ communities is critical. Sexual and gender minority groups experience health disparities resulting from a myriad of overlapping social-economic, cultural, and political factors. LGBTI+ communities have higher incidences and prevalence of physical and mental health conditions, chronic and infectious disease risk, and experiences of violence and discrimination. These communities also experience significant barriers to accessing prevention and treatment services and being retained in care[121]. The disproportionate burden of HIV among LGBTI+ communities is stark:

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[114] NAM submission

[115] https://www.aidsmap.com/news/jun-2019/hiv-criminalisation-cases-recorded-72-countries-including-49-last-four-years

[116] UNAIDS Fact sheet 2021

[117] Kumar S, Gruskin S, Khosla R, Narasimhan M. Human rights and the sexual and reproductive health of women living with HIV - a literature review. J Int AIDS Soc. 2015;18(Suppl 5):20290. doi:10.7448/IAS.18.6.20290

[118] Kass NE. Policy, ethics, and reproductive choice: Pregnancy and childbearing among HIV-infected women. Acta Paediatr Suppl. 1994;400:95-98. doi:10.1111/j.1651-2227.1994.tb13344.x

[119] Nachega JB, Uthman OA, Anderson J, et al. Adherence to antiretroviral therapy during and after pregnancy in low-income, middle-income, and high-income countries: a systematic review and meta-analysis. AIDS. 2012;26(16):2039-2052. doi:10.1097/QAD.0b013e328359590f

[120] UNAIDS. Fact sheet - Latest global and regional statistics on the status of the AIDS epidemic. https://www.unaids.org/sites/d.... Published July 6, 2020. Accessed November 2, 2020.

[121] LGBTI+ Health Equity: A Global Report of 50 Fast-Track Cities August 18, 2021avaialble from: Fast-Track Cities for LGBTI Health Equity | ViiV Healthcare

- The risk of acquiring HIV among transgender and other gender minority individuals is 13 times that of the cisgender population
- Gay, bisexual, and other men who have sex with men are 26 times more likely to acquire HIV than other men

Criminalising the conduct of sex workers, men who have sex with men, transgender people, people who use drugs, and migrants exacerbates stigma and discrimination, and hinders access to and decreases the use of HIV services, resulting in poor health outcomes and increased HIV transmission - as we heard from our expert panel during our oral evidence sessions.

We have seen that addressing stigma and discrimination, including the criminalisation of people living with HIV, not only improves the quality of life of people living with HIV but can be linked to helping achieve and sustain viral suppression. As stated by Professor Lazurus in his evidence, this approach would advance the wider public health goal of averting HIV transmission.

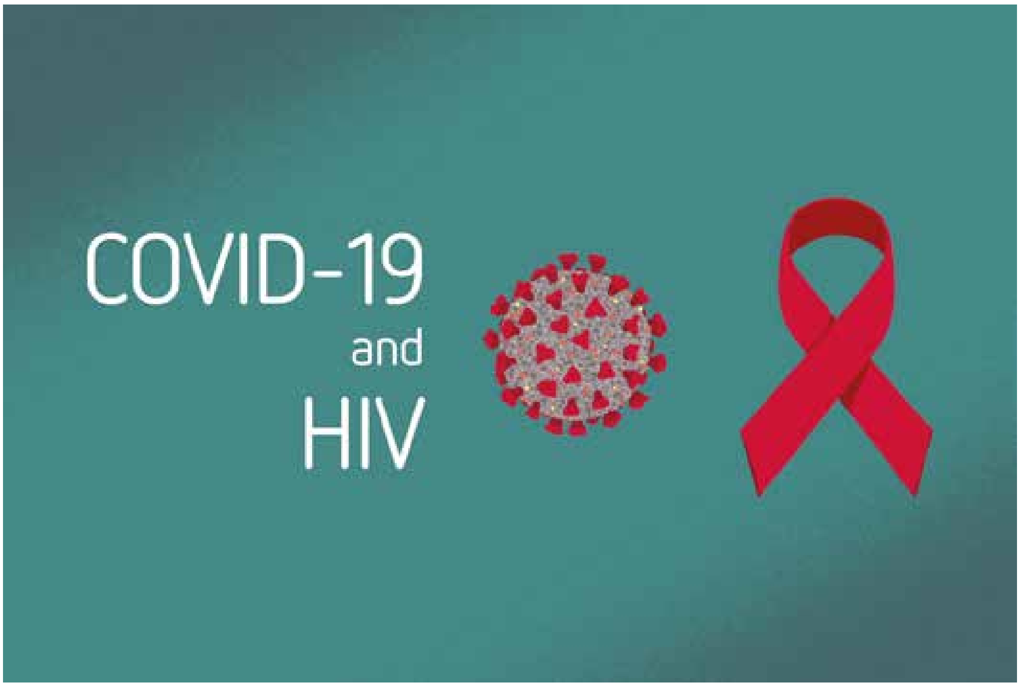
We, along with the organisations who submitted evidence, feel that legislators should address discriminatory practices and laws that contravene human rights by passing legislation that protects access to services, work, education, and travel. Independent oversight is required to hold government and health system policies and practices to account to ensure zero discrimination is achieved. Complaints procedures should be respectful, confidential, sensitive and enable citizens to report instances of discrimination, and include feedback mechanisms which protect confidentiality and provide whistleblower protection.

We have heard during this inquiry that the rights of people living with HIV often are violated because of their presumed or known HIV status, causing them to suffer both the burden of the disease and the consequential loss of other rights. Stigmatisation and discrimination may obstruct their access to treatment and may affect their employment, housing and other rights. This, in turn, contributes to the vulnerability of others to infection, since HIV-related stigma and discrimination discourages individuals infected with and affected by HIV from contacting health and social services. The result is that those most needing information, education and counselling will not benefit even where such services are available.

We also know that discrimination and stigma impedes an effective response. Strategies to address the epidemic are hindered in an environment where human rights are not respected. For example, discrimination against and stigmatisation of vulnerable groups such as injecting drug users, sex workers, and men who have sex with men drives these communities underground. This inhibits the ability to reach these populations with prevention efforts, and thus increases their vulnerability to HIV. Likewise, the failure to provide access to education and information about HIV, or treatment, and care and support services further fuels the AIDS epidemic. These elements are essential components of an effective response to AIDS, which is hampered if these rights are not respected.

We call for the reform of punitive laws targeted at key populations such as the LGBT+, women, sex workers and people who use drugs, along with the reform of HIV specific laws to mirror science. These actions would address not only the human rights of many millions of people across the world, but address the public health issue that is HIV and AIDS.

Area 4: Lessons learned from COVID



COVID-19 has created several challenges to the delivery of effective HIV care and at present we do not know completely what the long-term consequences for PLWH will be. COVID-19 presents an obstacle for the achievement of the UNAIDs 90 90 90 target. Quarantine and social distancing measures can lead to reduced access to routine HIV testing, resulting in difficulties in attaining 90% of all PEOPLE LIVING WITH HIV knowing their HIV status[122]. The commencement of treatment in those individuals who are able to be diagnosed, may also be hindered by them being deterred from attending health care services that are overwhelmed treating patients with COVID-19.

The impact of the COVID-19 pandemic on the global AIDS response is evident; the Global Fund to Fight AIDS, Tuberculosis and Malaria states that, in over 100 countries, up to 75% of lifesaving HIV, TB and malaria services have been seriously disrupted[123]. Factors across the health system, such as the conversion of health facilities for COVID-19 testing, the limited supply of medication and commodities, budget constraints and funding being diverted away from HIV to COVID-19 programmes, have and will continue to impact HIV outcomes and treatment adherence.

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[122] Jiang H, Zhou Y, Tang W. Maintaining HIV care during the COVID-19 pandemic [Internet]. Vol. 7, The Lancet HIV. Elsevier Ltd; 2020 [cited 2020 Oct 2]. p. e308–9. Available from: https://www.

[123] Global Fund Oral evidence session

An individual's ability to continue taking Antiretroviral Treatment (ART) is impeded by hospital restrictions and the implementation of lockdowns. A survey in China had shown that 30% of participants were at risk of ART discontinuation and almost half were uncertain about where they would obtain their ART in the near future[124]. There are likely to be a variety of biological, psychological and social factors that contribute to this. With an already high burden of depression among PEOPLE LIVING WITH HIV, physical distancing measures may have an additive effect by increasing loneliness. This may in turn exacerbate symptoms of loss of interest, feelings of worthlessness and thoughts of death, resulting in a negative impact on an individual's desire to take medication or to engage in activities that contribute to a lifestyle that benefits their health[125,126].

The impact of COVID-19 on people who may be living in fragile circumstances cannot be underestimated. Appreciating the effects on employment, furlough schemes and the reduction in services like food banks that people may rely on is crucial to prevent the most vulnerable and marginalised being negatively affected. Although telemedicine has increased access to health care for some, it is important to consider individuals who may not have a phone or may be living in homes where they have not disclosed their diagnosis, making telephone consultations difficult. In this way, COVID-19 has unmasked many existing inequalities that have also disproportionately affected people living with HIV for many years.

Being able to identify those most vulnerable to the effects of the pandemic can lead to targeted interventions. Strategies that are already used for individuals who are failing HIV treatment and for those who have been lost to follow-up can be utilised pre-emptively. Care bundles for those most at risk of disengagement with services following peaks of the pandemic may involve regular MDT discussions, regular text messaging to support adherence, or telephone call appointments.

Appreciating and understanding what impact COVID-19 has had on people living with HIV will not only directly benefit patients now, but will also prepare services for the pressures that will come with this pandemic and also for future pandemics.

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[124] Wei G, Huiling W, Hua B, Jie L, Xiangnan W, Kai Z, et al. Quick community survey on the impact of COVID-19 outbreak for the healthcare of people living with HIV. Chinese J Endem [Internet]. 2020 May 1 [cited 2020 Oct 2];41(5):662–6. Available from: https://pubmed.ncbi.nlm.nih.gov/32223840/

[125] Blashill AJ, Perry N, Safren SA. Mental health: A focus on stress, coping, and mental illness as it relates to treatment retention, adherence, and other health outcomes. Curr HIV/AIDS Rep [Internet]. 2011 Dec [cited 2020 Oct 2];8(4):215–22. Available from: https://pubmed.ncbi.nlm.nih.gov/21822626/

[126] Gonzalez JS, Batchelder AW, Psaros C, Safren SA. Depression and HIV/AIDS treatment nonadherence: A review and meta-analysis [Internet]. Vol. 58, Journal of Acquired Immune Deficiency Syndromes. Lippincott Williams and Wilkins; 2011 [cited 2020 Oct 2]. p. 181–7. Available from: /pmc/articles/PMC3858003/?report=abstract

COVID-19 and HIV

UNAIDS have reported that people living with HIV experience more severe outcomes and have higher comorbidities from COVID-19 than people not living with HIV. In mid-2021, most people living with HIV did not have access to COVID-19 vaccines.

HIV Outcomes, in their submission, set out that the following areas where affected by people living with HIV in Europe due to COVID-19:

- **Mental health:** Case studies across WHO Europe show that around 40% of people living with HIV have had mild to severe psychological distress since the COVID-19 outbreak and require psychosocial support. Among this group, 70% reported feeling more depressed and anxious and 19% had considered suicide.
- **HIV treatment:** Case studies across WHO Europe show that 4% of people living with HIV (approximately 60,000) reported an interruption of Antiretroviral therapy (ART) due to lockdowns and that 6% (around 120,000) were unable to collect ART due to lockdown restrictions. Approximately 30% of people living with HIV in the WHO Europe region had to adapt their HIV care during the pandemic, facilitating an increase in the use of telehealth services. In addition, some EU countries experienced shortages in HIV medicines and PrEP.
- **HIV testing:** Due to the pandemic, an estimated 100,000 HIV tests were not performed in 2020 among the 8 EU/EEA countries that reported data on testing. We have also been advised by the Global Fund that HIV testing decreased by 22% across the world.
- **HIV co-infection on mortality:** People living with HIV have between a 78%-95% higher risk of death from COVID-19 than the general population and a 20% higher risk of hospitalisation. The risk is higher for people who are not on antiretroviral therapy or have several HIV comorbidities.
- **HIV stakeholders:** In the WHO Europe region, up to 50% of HIV stakeholders stopped face-to-face HIV services since the beginning of the pandemic and almost 20% reported that users did not use their alternative service arrangements.
- **HIV care:** Up to 70% of HIV clinics were disrupted in WHO Eastern Europe countries with 60% of physicians sharing HIV and COVID-19 care duties.
- **HIV consultations and enrolments:** Case studies across WHO Europe show that HIV consultations fell by 50% and HIV enrolments by 20% at the outbreak of the pandemic (April 2020).
- **COVID vaccines for people living with HIV:** People living with HIV were not prioritised for COVID-19 vaccinations in approximately 60% of countries in WHO Europe and only 14% had national guidelines to support the vaccination of people living with HIV.
- **HIV diagnosis In WHO Europe:** an estimated 25,143 individuals living with HIV were not diagnosed in 2020 due to the pandemic. This resulted in 104,765 new diagnoses in 2020, down from 136,449 in 2019 (a 26% decrease in HIV diagnoses).

In STOPAIDS' oral evidence they argued that Covid had some positive impacts.

In the oral evidence we received from STOPAIDS, The Global Fund and Elton John AIDS Foundation, communities that had come together to respond to HIV quickly mobilised and refocused to fight COVID-19.

In the evidence we received from Fast Track Cardiff and Vale, STOPAIDS, Salamander Trust and others, HIV self-testing, multi-month dispensing of medicines and the use of telehealth and virtual platforms for information and support have been accelerated, reversing many initial setbacks in HIV service provision.

STOPAIDS and Elton John AIDS Foundation argued that affected communities involved in the definition, implementation and follow-up of COVID-19 programmes have helped to reduce stigma around the disease.

We know that UNAIDS, THT and partners reached out to people living with HIV affected by lockdowns to help them to access HIV treatment.

COVID-19 Vaccines

Sub-Saharan Africa is home to two thirds (67%) of people living with HIV. But the COVID-19 vaccines that can protect them are not arriving fast enough. In July 2021, less than 3% of people in Africa had received at least one dose of a COVID-19 vaccine[127].

Studies from England and South Africa have found that the risk of dying from COVID-19 among people with HIV was double that of the general population[128].

As reported by The Global Fund and UNAIDS, COVID-19 lockdowns and other restrictions disrupted HIV testing and in many countries led to steep drops in diagnoses and referrals to HIV treatment. The Global Fund to Fight AIDS, Tuberculosis and Malaria reported that, according to data collected at 502 health facilities in 32 African and Asian countries, HIV testing declined by 41% and referrals for diagnosis and treatment declined by 37% during the first COVID-19 lockdowns in 2020, compared with the same period in 2019[129].

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[127] https://ourworldindata.org/grapher/share-people-vaccinated-covid

[128] https://www.aidsmap.com/news/apr-2021/risk-dying-covid-19-doubled-people-hiv-england

[129] https://www.theglobalfund.org/en/results/

Integrating psychological support with health care projects is critical to ensure the holistic health needs of PLHIV are met, particularly during a global pandemic. Our work on the COVID-19 response reinforces the lessons from other workstreams – there is a vast unmet need for mental health support. Mental health issues increase risk for HIV acquisition and result in negative health outcomes among people at each step in the HIV care continuum. A survey of the needs of young key populations and young people living with HIV in Asia and the Pacific during COVID 19 revealed that 70% of respondents felt "anxious or very anxious" about COVID 19; 50% viewed counselling for anxiety and depression as key to their HIV treatment adherence; and almost all expressed desire for counselling and mental health support services.

A Kaiser Family Foundation study found that 74% of LGBT surveyed[130] people say worry and stress from the pandemic has had a negative impact on their mental health. In response, projects should include peer mental health support to vulnerable populations, both online and in person, enhance community health worker efforts to better identify and connect those with mental health disorders with services that can help them, and train on and/or disseminate best practices for integrating mental health assessment and treatment into routine clinical and emergency health care services so those who need it can find it.

As the World Health Organization highlights "It is time to invest, innovate and integrate HIV services with broader health care and the pandemic response, to help us get back on track to end HIV by 2030."

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[130] EJAF Submission

Summary:

It's important to recognise both the similarities and the differences between COVID-19 and HIV from an epidemiological, social and political perspective, in order to gauge how we best respond to both pandemics. For example, in both pandemics, equitable access to tests and treatments (and in the case of COVID-19, vaccines) have been key in reducing new infections. However, there have been significant barriers to accessing these in LMICs due to lack of supply (which has been more of an issue for Covid-19) and high prices (which is an issue for both). The key to increasing the volume and stability of supply chains lies in strengthening the local manufacturing capacity of pandemic tools.

Linked to this, both pandemics have also reaffirmed the importance of having strong and resilient health systems. Investment in the training and retention of staff as well as into critical infrastructure is required to be able to respond to emergencies when they arise.

The social determinants of health also need to be analysed. Although there are some differences between COVID-19 and HIV, the connecting factor is that social determinants of health need to be recognised as key underlying drivers - created through economic and social policies and attitudes - and need to be addressed systemically. COVID-19 has also reaffirmed how critical community-led health care is, something we've known for many years through the HIV response.

COVID-19 upended the global health security movement in ways that hark back to the tough times of the early AIDS pandemic. The infrastructure that the HIV community built over the last forty years was instrumental in responding to the COVID-19 pandemic quickly and effectively. What we knew in March 2020 when COVID-19 made shockwaves across the globe, and which sadly has only been emphasised with the passage of time, is that similar to AIDS, this is not just a health crisis.

COVID-19 has manifested social and economic challenges that continue to stress every community and government it touches, exacerbating already deep-rooted inequalities and health disparities, with the most vulnerable communities facing the greatest risk. The HIV sector has a vital role to play in pandemic preparedness and response. The HIV sector moved quickly to act and respond to COVID-19 where governments could or would not react in the manner or timeframe needed and this will continue to be the case. Community organisations can utilise their networks, relationships with health facilities, and marginalised communities to reach and engage particularly vulnerable populations with compassion, equity, flexibility, and realism.

Area 5: UK

Terrence Higgins Trust at London pride 2019

With an estimated 97,740 people living with an HIV infection in England, including 4,660 people[131] who remain undiagnosed, we cannot afford to be complacent. To successfully end new HIV transmissions, we must place people living with HIV at the centre of any "Ending the Epidemic" approach. This includes, as argued by a majority of the organisations who submitted evidence to this inquiry, making treatment and retention a key component of any Combination HIV Prevention efforts as highlighted by the latest HIV Action Plan published in England.

The HIV action plan published by the UK Government to tackle HIV in England set out the following objectives in meeting the 2030 target of no new HIV transmissions and help those living with HIV:

- Getting to zero new HIV infections
- Living and ageing well with HIV
- Tackling discrimination, stigma and mental health issues

However, in our own inquiries into testing and HIV in the BAME community, we advised that the four Governments within the UK needed to include the following if we are to help those living with HIV:

- Reducing inequality in the experiences of care
- Improving commissioning of HIV services
- Preparing the system for innovation
- An effective long-term plan for HIV

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[131] UK Health Security Agency, HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report, December 2021

Since the emergence of HIV in the UK the demographics of this population have evolved, including the presence of an ageing population (by 2028, 54% of people living with HIV in the UK will be over 50 years of age[132]) and shifts in where new diagnoses are occurring (with heterosexual HIV diagnosis now overtaking those in gay and bisexual men). Given these demographic changes, evolution in the way we support these communities is also required. Changes argued by Gilead, ViiV, STOPAIDS and others include:

- Information on HIV should be increasingly accessible outside traditional health care settings including community and educational settings. Testing kits too should be made available in these settings
- Data collection systems should be reviewed to best capture the ethnic and racial diversity of local communities. For example, the national HIV self-sampling service in England reported that Latino Americans have the highest reactive rate across all demographics in England[133]. However, HIV data on this community is not systemically collected or reported[134,135],
- Educational materials published in a range of languages and adhering to cultural specificities
- HIV knowledge should be increased across the care continuum to ensure a holistic and 360 approach to care that moves away from a focus on ill-health and viral suppression, to co-morbidities, economic independence, housing, education and social wellbeing
- Collaboration with non-HIV specific patient organisations and charities should be sought to reach these key populations who may not engage with traditional HIV populations

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[132] The King's Fund, The future of HIV services in England: Shaping the response to changing needs, April 2017
[133] Public Health England, National HIV self-sampling service – November 2018 to October 2019, 2020
[134] UK Health Security Agency, GUMCAS STI Surveillance System, Data specification and technical guidance
[135] NHS Digital, NHS Data Model and Dictionary, access February 2022

Women and HIV

The UK has the largest female health gap in the G20 and the 12th largest globally[136]. Women also receive less health monitoring and make fewer visits to the GP than men[137]. This data shows that women are already at a disadvantage when it comes to health care without the added complications and gender-specific inequalities that affect women living with HIV. These gender-specific inequalities include:

Late diagnosis – Women make up one third of people living with HIV in the UK[138] yet late HIV diagnosis is highest in heterosexual women and men (50% and 59% respectively)[139]

Stigma and discrimination – Stigma (including self-stigma and perceived stigma) continues to play a major role in the lives of women living with HIV. Nearly a third of women (31%) avoided or delayed attending health care because of their HIV status[140]

Children and reproductive choices – 42% of women felt that HIV was impacting their decision to have children due to the possibility of passing HIV on[141]

Menopause – 47% of women did not have access to the information they needed to manage their HIV and the menopause[142]

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[136] Manual, The men's health gap, accessed February 2022

[137] House of Lords Library, Women's health outcomes: Is there a gender gap?, July 2021

[138] Sophia & Terrence Higgins Trust, Women and HIV: Invisible No Longer, 2018

[139] Sophia & Terrence Higgins Trust, Women and HIV: Invisible No Longer, 2018

[140] Sophia & Terrence Higgins Trust, Women and HIV: Invisible No Longer, 2018

[141] Sophia & Terrence Higgins Trust, Women and HIV: Invisible No Longer, 2018

[142] Gilead, Striving towards health equalities in HIV, 001/UK/18-11/CI/1576a

Access to HIV testing services – Women face difficulty in accessing HIV testing services in primary care. Patients are often referred from an initial contact point (eg a GP) to sexual health services meaning there are several appointments before they are tested, adding to delays in diagnosis. Sexual health clinics and sexually transmitted diseases also carry a further stigma for women, particularly for those from BAME communities, which can prevent these individuals from getting tested[143]

Socioeconomic challenges – Women with HIV face greater socioeconomic challenges than men[144]

Mental health – Women with HIV are at a greater risk of poor mental health than men[145]

The experiences of women living with HIV as argued by the Sophia Forum and the Terrence Higgins Trust are under-assessed and under-recognised. To address these inequalities, it's important that women are prioritised in policy and research agendas and community groups are included to ensure this work is community-led. Additionally, greater collaboration between HIV services and sexual health and reproductive services would provide a stronger health care network for women with HIV.

Studies in the UK have shown high rates of intimate partner violence in women living with HIV, but data from the UK are lacking[146].

Intimate partner violence is defined as physical, sexual or psychological harm by a current or former partner or spouse[147]. The World Health Organisation's multi-country study found that lifetime prevalence of physical and/or sexual partner violence was between 15 and 71%[148]. Intimate partner violence is estimated to affect 28% of women living in the UK in their lifetime[149]. The social, psychological and physical consequences of IPV are considerable and it has been shown to have adverse effects on health in both the short and long term[150]. Women experiencing Intimate partner violence are more likely to be in regular contact with health care professionals than women who are not experiencing Intimate partner violence, providing important opportunities to identify women and offer support[151]. This led the UK's Department of Health to recommend that all National Health Service trusts work towards routinely asking women about their experiences of Intimate partner violence in clinical settings[152].

It is argued that due to the associations between Intimate partner violence and mental health problems, younger age and other Black ethnicity, there should be greater awareness of Intimate partner violence among HIV health care professionals, and universal screening is recommended[153].

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[143] NICE, Increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among black communities living in England: Barriers to HIV testing
[144] House of Lords Library, Women's health outcomes: Is there a gender gap?, July 2021
[145] House of Lords Library, Women's health outcomes: Is there a gender gap?, July 2021
[146] https://onlinelibrary.wiley.com/doi/full/10.1111/hiv.12009
[147] www.cdc.gov/ncipc/pub-res/ipv_surveillance/Intimate%20Partner%20Violence.pdf
[148] Garcia-Moreno C, Jansen H, Ellsberg M, Heise L, Watts CH. Prevalence of intimate partner violence: findings from the WHO multi-country study on women's health and domestic violence. Lancet 2006; 368: 1260– 1269.
[149] Smith K, Flatley J, Coleman K, Osborne S, Kaiza P, Roe S. Homicides, Firearm Offences and Intimate Violence 2008/09. Supplementary Volume 2 to Crime in England and Wales 2008/09. 2010 Home Office Statistical Bulletin.
[150] Bonomi AE, Anderson ML, Reid RJ, Rivara FP, Carrell D, Thompson RS. Medical and psychosocial diagnoses in women with a history of intimate partner violence. Arch Intern Med 2009; 169: 1692– 1697.
[151] Domestic violence London: a resource for health professionals. Available at www.domesticviolencelondon.nhs.uk/
[152] www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4126619.pdf
[153] https://onlinelibrary.wiley.com/doi/full/10.1111/hiv.12009

Children

The Children Living with HIV Association in their submission that was compiled by young people living with HIV argued that for them to have a good quality of life, being able to share HIV information without prejudice helps facilitate inclusion and would help prevent isolation and depression[154].

CHIVA's youth committee pointed out in the submission that the stigma within health, education, peer groups, media and national and local governmental organisations can impact access to and engagement with services to which PLHIV are entitled. This in turn creates issues to their self-esteem and self-worth, impacting individuals' ability to fulfil their potential.

The struggle with medicine was raised, in that it reminds young people daily of their HIV status and the associated stigma. The stigma they face frames HIV as a source of shame rather than a chronic illness to be successfully managed[155]. This, they advised, impacts on interactions with parents re-testing their children for HIV. This they argued would lead to a risk of disengagement[156].

They also argue that opportunities for age-appropriate peer support both through the hospital and HIV charities is needed. They argued that this would allow a young person who is coming to terms with living with HIV to speak to someone who has already gone through the same thing, and help them answer any questions they might have[157].

When it comes to access to care, CHIVA in their submission argued that there was a need for the provision of age-appropriate care settings for children, adolescents and young adults and flexible appointment times that take education, employment and family life into account (eg priority school holiday appointments for children preparing for exams and weekly walk-in clinics for young adults where possible, ie sufficient patient numbers). There was also a call for individualised transition plans to ensure young people are in the most appropriate environment for their developmental needs.

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[154] CHIVA Submission
[155] CHIVA Submission
[156] CHIVA Submission
[157] CHIVA Submission

AFP/Getty Images

Stigma

The HIV Commission that was set up by Terrence Higgins Trust, National AIDS Trust and the Elton John AOIDS Foundation found that stigma and misinformation about HIV remains prevalent within health and social care settings[158]. This creates clear barriers to support for people living with HIV.

In December 2021 the UK Government released its national HIV Action Plan for England. The Action Plan includes a focus on addressing stigma and improving the quality of life of people living with HIV. Welcome commitments included ensuring that HIV is an element of every health care worker's standard induction and regular mandatory training, assessing the levels of HIV awareness amongst health care staff, monitoring levels of stigma that people living with HIV face, and establishing regional working groups to focus on tackling HIV-related stigma.

There are local NHS trusts, like University Hospital Lewisham, that are engaging with 'Stigma Free Hospital' initiatives - these should be encouraged and supported UK-wide.

The trend to move from specialist HIV services towards a more integrated care model provides opportunities to ensure comprehensive training for care providers addressing myths around HIV. It is also an opportunity to deliver a more holistic approach to the health of people living with HIV that reflects the additional health requirements people may need support with.

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[158] HIV Commission final report, 2020

TERRENCE HIGGINS TRUST

Terrence Higgins Trust ran a national project, 'building resilience against stigma', funded by MSD, which provided a series of facilitated online workshops focused on building personal resilience. The programme aimed to encourage PLHIV to recognise the assets they already have and build upon them to increase resilience and effectively manage negative feelings resulting from stigma and self-stigma.

Four co-design sessions were held in February and March 2021 to bring together a group of PLHIV to design the outcomes, content, delivery method and marketing plan for the workshops. Following the co-design session, three peer facilitators were trained to deliver the sets of workshops. All facilitators were peers living with HIV, from diverse backgrounds.

Four sets of three workshops (cohorts) were successfully delivered from April to November 2021 to PLHIV from diverse age groups, gender, sexuality and ethnic backgrounds. The target for people attending the programme was 50 and in total there were 73 unique attendees over the four cohorts, plus 11 co-production attendees.

The outcomes varied across cohorts, showing the different journeys to acceptance people living with HIV face.

- ***79% of participants agreed they had increased confidence enabling them to overcome stigma***
- ***82% of participants agreed they had gained tools and techniques to help them feel more resilient***
- ***93% of participants agreed that the training was enjoyable***
- ***92% of participants agreed that the training was beneficial***
- ***82% of participants agreed that they recognise and are able to draw upon strengths that help them deal positively with change and difficult situations.***

Peer support

There are now over 100,000 people living with HIV in the UK, a quarter of whom are undiagnosed. Advances in medications mean that HIV is now a long-term condition, and with a timely diagnosis people can expect a normal life expectancy. However, planning effective care for people living with HIV requires several factors to be considered. There is the need to strictly adhere to medications. People living with HIV are often from vulnerable groups that have experienced discrimination, including gay men and migrant communities.

It's been argued by Positively UK in their submission that people living with HIV can benefit greatly from peer support services, and these should be accessible and available whenever and wherever they are demanded[159]. The support they offer delivers advice and expertise to enable people living with HIV to make decisions about their care, and support their general wellbeing[160]. Some people report that they are never signposted to peer support services – even though this should be provided as standard and form an essential component of the HIV care pathway[161].

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[159] Positively UK submission
[160] Positively UK submission
[161] Positively UK submission

Positively UK and others have argued that peer support at diagnosis has been identified as essential[162]. It is argued that advice and support from someone with experience of living with HIV is invaluable to people who are newly diagnosed, providing understanding, support and practical advice and reassurance on what the diagnosis means for the patient's life, relationships, employment and general health and wellbeing[163].

Terrence Higgins Trust argues that the National HIV Action Plan for England recognises that the "availability of HIV peer support, psycho-social and mental health services is variable across the country…" They advised that the action plan did not set out a clear set of recommendations to overcome this. Overall, mental health support for people living with HIV remains patchy, with nearly 40% of HIV clinics not having access to a psychological or mental health professional within their multidisciplinary teams[164]. The UK Government has committed to drafting "an audit tool to enable local areas to understand provision, availability and accessibility of HIV mental health, psycho-social and peer support services available to people living with HIV across the life-course", as well as sharing evidence of the effectiveness of voluntary sector-led peer support networks. Terrence Higgins Trust went on to say that there is however still a lack of clarity on which body is responsible for commissioning HIV support services at the local level, and no additional funding announced to improve access to support services across the country.

In their submission Terrence Higgins Trust advised that in their study of older PLHIV, 58% of survey respondents were defined as living on or below the poverty line[165]. The situation had deteriorated since 2010 when 48% of respondents to Terrence Higgins Trust's HIV and Ageing survey were found to be living in poverty. Statistics available for the general population at the time of the report indicate that levels of poverty seen in people living with HIV aged 55+ are double those seen in the general population. Over a third of individuals aged 50 and over living with HIV were reliant on welfare benefits. A third had not made financial plans for the future and 84% were concerned about future financial difficulties.

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[162] Positively UK submission
[163] Positively UK submission
[164] The Missing Link: HIV and mental health report, APPG on HIV and AIDS, 2020
[165] Uncharted Territory, A report into the first generation growing older with HIV January 2017

Return to care

Every submission we received, especially from Terrence Higgins Trust, emphasised that return to and retention in care must be a priority for HIV clinics and their funders. Better post-diagnosis support and outreach workers should be considered by both.

Terrence Higgins Trust argued that opt-out testing in Emergency Departments and GPs has proved effective at returning people to care, according to the Elton John AIDS Foundation's HIV Testing Social Impact Bond. As part of the programme, they engaged a high number of previously diagnosed people to HIV care, this group was disproportionately likely to be women and of Black African, Black Caribbean and Black Other heritage. This further makes the case for opt-out testing to be extended to high HIV prevalence areas, not just funded in extremely/very high HIV prevalence areas.

It has been argued by Dr Dhairyawan that Black and minority ethnic groups may need additional support to stay engaged in care and on treatment. Dr Dhairyawan also argues that clinics should be proactive in signposting and referring patients to advice and community services for help with issues such as benefits, housing and immigration, as this would help to retain them in care[166]. Dr Dhairyawan goes on to argue that within the clinics, they should ensure they have access to interpreters and are informing migrants about their entitlement to NHS care[167] as this would help also.

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[166] Dhairyawan R et al. Differences in HIV clinical outcomes amongst heterosexuals in the United Kingdom by ethnicity. AIDS, 35: 1813-1821, September 2021. doi: 10.1097/QAD.0000000000002942

[167] Dhairyawan R et al. Differences in HIV clinical outcomes amongst heterosexuals in the United Kingdom by ethnicity. AIDS, 35: 1813-1821, September 2021. doi: 10.1097/QAD.0000000000002942

Non-HIV related health care

According to data from the Positive Voices survey, 72% of people diagnosed with HIV have at least one other long-term health condition, with the most prevalent being high cholesterol, hypertension and diabetes (all known precursors of cardiovascular disease, for which people with HIV have double the risk), arthritis, peripheral neuropathy, and kidney disease[168]. In particular, there is a higher incidence of non-HIV specific illness – kidney and cardiovascular disease, and certain cancers – among those who are diagnosed late or were on more toxic medications in the early stages of treatment[169].

Research has shown that people living with HIV are especially worse off in relation to the general population when it comes to anxiety and depression[170]. NAT's research has shown that while generic 'Improving Access to Psychological Therapies' (IAPT) services, which are often the only service available, work for about half the people living with HIV who access them, there are still many who do not find them useful and would not use them again[171]. It is vital that more specialist provision embedded in HIV clinics is commissioned and provided with clear pathways both in and out of services. As well as ensuring that psychologists are part of multi-disciplinary teams, commissioners and providers should seriously consider drawing on third-sector specialist HIV support services to provide in-clinic support. Until that specialist provision is available, generic services must be made more HIV literate and have greater understanding of HIV related stigma.

NAT's research reveals a variety of problems for people living with HIV and comorbidities, arising from fragmented care provision, ranging from disengagement from care - through lost confidence in health care following receipt of contradictory advice from clinicians responding to different aspects of a person's health care needs - to lack of access to good information to allow people to self-manage their health.

The response to managing comorbidity must include models of shared and collaborative care, as appropriate, with access to effective care coordination support, thus improving management of comorbidity and increasing patient confidence in the health care system[172]. For example, the Silver clinic in Brighton is a joint HIV/geriatric clinic that responds to the high proportion of ageing MSM living in the area. One clinician estimated that a single appointment in the frailty clinic can replace five separate single-issue appointments, benefiting both the individual and providers. As the cohort of people living with HIV ages, prevalence of comorbidities will create even greater pressures for integrated care and coordination support.

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[168] M Kall, C Kelly, M Auzenbergs, and V Delpech. Positive Voices: The National Survey of People Living with HIV - findings from the 2017 survey. January 2020. Public Health England: London

[169] Lazarus, J.V., Safreed-Harmon, K., Barton, S.E. et al. Beyond viral suppression of HIV – the new quality of life frontier. BMC Med 14, 94 (2016).

[170] Miners A, Phillips A, Kreif N, et al. Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: a cross-sectional comparison with the general population. Lancet HIV. 2014;1:e32-e40.

[171] NAT, 2021, HIV and mental health: improving generic NHS talking therapy services for people living with HIV in England. Available at https://www.nat.org.uk/publications

[172] NAT, Providing coordinated care for people living with HIV, 2020. See also BHIVA, 2017, Shared Care: how can we do it? Findings from the BHIVA Primary Care Project. Available at https://www.nat.org.uk/publications

NAT argue that alongside new care models, some Primary Care Networks now have HIV leads or champions who are working to improve access to health care, increase HIV awareness and reduce stigma among primary care providers, and support provision of things that matter to people living with HIV – such as continuity of provision. All of these go toward increasing the likelihood that people living with HIV will have a positive experience of non-HIV related care.

In the oral evidence session NAT argued that we have less evidence to suggest that clinical and social care is starting to be well integrated, even to the extent that people reported not being able to get appointments at times that allow their social care support to get them up, dressed and ready for the day in time for collection for appointments. This can be very stressful for people living with HIV with considerable social care needs.

We know that most people living with HIV in the UK are on effective antiretroviral therapy, the model of care has become one of long-term condition management with ‘person-centred care’ as the goal. NAT, THT and others argue that person-centred care responds, holistically, to people’s health conditions and their wider determinants of health and, as such, good QoL and HRQoL are key outcomes for care, alongside specific markers like CD4 count and bone density scores. NAT argue that with the forthcoming shift to Integrated Care Systems (ICSs), there is a great opportunity for re-integration of services that respond to needs related to physical health, mental health and social care and foreground holistic management.

NAT also argued that as well as offering a holistic approach, person-centred care models recognise the importance of an individual’s preferences and opinions in determining their care. While this relies on an attitudinal shift, by both clinician and patient, away from normalised hierarchical models of care, it also requires information and patient records to enable people living with HIV to make informed choices.

Criminalisation

Criminalisation for non-intentional transmission remains a complicated and contentious subject in the UK. The United Nations is clear that criminalisation in this context is unhelpful, and does not result in the desired effect of decreasing infection rates. It is disappointing in 2022 that prosecution remains possible in the UK. BHIVA argues that the use of criminal law in relation to HIV transmission does not contribute to public health aims of reducing the number of new infections or reducing stigma. This position is consistent with international recommendations including those of the Global Commission on HIV and the Law[173] and the Joint United UNAIDS)[174,175]. BHIVA's position is further supported by the 2018 expert consensus statement on the science of HIV in the context of criminal law[176].

The UK has three legal systems (jurisdictions) within its boundaries, covering the four devolved administrations (England and Wales has a shared legal system, and Scotland and Northern Ireland each have separate systems). The broad approach is the same in that all have provision to criminalise sexual transmission of HIV, using the mechanisms of their particular legal system. England and Wales and Northern Ireland have the least restrictive systems as there is no possibility of prosecuting for reckless exposure (where someone is exposed to the risk of transmission but where transmission does not take place). Prosecution is possible in Scotland in instances where a person has been exposed to the risk of transmission but transmission has not in fact taken place, although legal guidance makes clear that this should only be used in exceptional circumstances[177].

In England and Wales, only intentional or reckless transmission of HIV and deliberate (but unsuccessful) attempts to transmit are criminalised. The applicable law in HIV criminalisation cases is the Offences Against the Person Act 1861, which enables prosecution of intentional transmission under section 18, and reckless transmission under section 20[178]. Deliberate attempts to infect are charged under the Criminal Attempts Act 1981[179].

In the UK the courts appear to place the burden of reducing HIV transmission on the person living with HIV. This approach is inconsistent with public health initiatives aimed at reducing HIV transmission, such as pre-exposure prophylaxis (PrEP), which promote and enable individual responsibility within the HIV-negative population. As a result, it is considered by BHIVA that prosecution for reckless transmission promotes stigma and may be counterproductive with regard to public health aims. It has also been shown that prosecution for reckless transmission is associated with harms[180].

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[173] Global Commission on HIV and the law. Risks, rights and health. Available at: https://hivlawcommission.org/report/ (accessed November 2021)

[174] UNAIDS Policy Brief : *Criminalization of HIV transmission*. Available at: https://www.unaids.org/sites/default/files/media_asset/jc1601_policy_brief_criminalization_long_e n.pdf (accessed November 2021).

[175] UNAIDS. Ending overly broad criminalization of HIV non-disclosure, exposure and transmission: Critical scientific, medical and legal considerations. Available at: https://www.unaids.org/sites/default/files/media_asset/20130530_Guidance_Ending_Criminalisatio n_0.pdf (accessed November 2021).

[176] Barré-Sinoussi F, Abdool Karim SS, Albert J et al. Expert consensus statement on the science of HIV in the context of criminal law. J Int AIDS Soc 2018; 21: e25161.

[177] Crown Office and Procurator Fiscal Service (COPFS). Prosecution policy on the sexual transmission of infection. Available at: https://www.copfs.gov.uk/images/Documents/Prosecution_Policy_Guidance/Guidelines_and_Policy / Prosecution%20policy%20on%20the%20sexual%20transmission%20of%20infection%20- %20July%2014.pdf (accessed April 2022).

[178] The National Archives. Offences Against The Person Act 1861. Available at: https://www.legislation.gov.uk/ukpga/Vict/24-25/100/contents (accessed March 2022).

[179] The National Archives. Criminal Attempts Act 1981. Available at: https://www.legislation.gov.uk/ukpga/1981/47 (accessed December 2021).

[180] Adam BD, Elliott R, Corriveau P, English K. Impacts of criminalization on the everyday lives of people living with HIV in Canada. Sex Res Soc Policy 2014; 11: 39–49.

Summary:

Much of the narrative on HRQoL so far has been concerned with monitoring, but we also need to focus on impact and pathways to improvement. There are a set of measures that need to be in place to allow this to happen.

ICSs need to ensure that commissioning is based on agreed models of shared and collaborative care which promote genuine service integration and achieve a wraparound service based on a person-centred approach. To do this effectively they will need to engage with people living with HIV, third sector organisations, HIV clinicians and other health care providers, and social care providers. Moreover, it is vital that this is done in a timely fashion to ensure that the transition of HIV commissioning from specialised services to ICS level is done in a seamless fashion, without loss of service.

There are certain services, including mental health, drug and alcohol support, and HIV community support which have, since 2012, fallen through commissioning gaps. The introduction of ICSs provides a vital opportunity to close that gap and avoid situations where clinicians have nowhere to refer or signpost people living with HIV to if they raise an HRQoL-based need.

HIV support services have been stripped of funding since the demise of the AIDS Support Grant a decade ago. These services provide trusted, cost-effective peer support; information, advice and advocacy; advice and support around HIV self-management; sex and relationships support; and psychosocial support, all of which are vital for ensuring good HRQoL is available to all.

Information systems need to be in place that allow cross communication between providers, but also allow people access to, and control of their own data. Government proposals are built into the current Integration White Paper, but these need to take account of confidentiality concerns.

As recognised in the HIV Action Plan for Englad, there needs to be pro investment in work to counter general HIV-related stigma, and stigma within health care settings.

The HIV Action Plan is lacking on HRQoL actions generally. However, various pieces of work have been conducted by a range of organisations on health inequalities and needs among specific communities (people of African and Caribbean descent, trans people, older people, sex workers, migrants, people who inject drugs) with an array of recommendations that all UK governments should look at adopting.

While this section has focused on structural mechanisms, QoL and HRQoL are about understanding the experiences and preferences of people living with HIV. Therefore, we urge that people living with HIV must be involved in prioritising the actions that will foreground progress related to HRQoL.

Conclusion

As many people living with HIV living longer, comorbidities (the presence of other health conditions alongside HIV) emerge. A higher prevalence of comorbidities has been observed people living with HIV compared to those living without HIV. Disease burden, measured by the presence of multiple comorbid conditions, has also been found to be higher in the people living with HIV. Some of the main attributes are age, number of medications as well as risk factors for chronic diseases the direct effecs of the virus itself as well as inflammation associated with HIV can also lead to end-organ damage. Non-AIDS conditions associated with high levels of immune activation and inflammation due to HIV include kidney disease, liver disease, cardiovascular disease, Non-AIDS associated malignancies and neurologic complications.

As we have seen while conducting this inquiry, mental health conditions left undiagnosed, untreated or poorly managed can degrade overall health, quality of life and, in some cases, the ability to take antiretroviral therapy exactly as directed. Research comparing rates of mental health conditions (also called major mood disorders) between HIV-positive and HIV-negative people found that, overall, rates of diagnosed mental health conditions were twice as high among people living with HIV (people living with HIV). It also found that people living with HIV who had milder forms of mental health conditions and/ or substance use were likely to subsequently develop more serious mental health problems.

Finally, we were also told that there are lifestyle and social factors issues such as poverty, poor housing, education, employment level that exist in every country which intersect and can affect an existing HIV diagnosis.

With different health care settings in different countries we heard that health systems must shift to meet the evolving needs of people living with HIV as a chronic and complex long-term health condition. The need to rethink how medical and social support services are delivered is increasing alongside the growing numbers of people living with HIV. UNAIDS estimates that the number of people living with HIV globally reached 37.9 million in 2018 and this number is expected to increase.

Over several years there is a growing recognition that health systems must go beyond a solely medical focus which primarily strives only for viral suppression as the endpoint for successful HIV care. To understand the complexity of HIV and AIDS, it is vital that we consider and address the entirety of the health needs of people living with HIV – physical, emotional, mental and psychosocial – within the individual's unique and varied social and cultural circumstances, so that quality of life is optimised now and in the long-term.

It is imperative that community involvement is a vital precondition for effective HIV and AIDS management and good quality of life for people living with HIV as it enables health-related behaviours and reduces HIV transmission and stigma. As a result there is now a strong call to action that was developed by a multidisciplinary panel of 44 global HIV experts to articulate how health systems can advance the long-term well-being of people living with HIV by addressing multimorbidity, health-related quality of life, stigma and discrimination using an holistic and patient-centred approach. The 31 consensus points presented in “Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV” have been endorsed by numerous organisations globally.

An optimal quality of life includes the prevention and treatment of HIV and associated comorbidities as well as self-perceived quality of life which includes the elimination of structural barriers and policies that impede access to good health. However, for people living with HIV, wellbeing and wider social, cultural, legal and economic rights are important components of a good quality of life. For people living with HIV quality of life is based on the same needs, desires and aspirations as any other person, which are often negatively impacted in association with HIV. These often include stigma (in families, communities and healthcare settings), discrimination, isolation and human rights violations. As a result, achieving quality of life for people living with HIV requires particular attention to factors such as happiness, social connectedness, fatigue reduction and freedom from violence.

Assessing health-related quality of life is useful for documenting the patients’ perceived burden of chronic disease, tracking changes in health over time, assessing the effects of treatment and quantifying the return on health care investment.

People living with HIV, quality of life is often about the same things as anyone else – such as good health, social relationships and economic opportunities. However, it is also about attention to the challenges of living with a virus that continues to be wrought with uncertainty, fear and prejudice. Examples of such we have touched upon in this inquiry such as human rights violations, stigma and discrimination – all of which can be especially hard-hitting for marginalised populations.

Quality of life matters even if a person living with HIV has achieved viral suppression. This is because the type of measures it entails – such as peer support and stigma-free health services – help people maintain their treatment in the long-term. It is also because the measures help people deal with the new era of issues brought by ‘ageing with HIV’. These days, people living with HIV have almost the same life expectancy as anyone else, but face disproportionately high levels of other chronic physical conditions (such as cardiovascular disease and cancer) and mental health conditions.

People living with HIV are a diverse group, coming from all ages, cultures, and genders, as a result QoL is hard to measure as it can mean something different for everyone. As discussed previously measuring quality of life is also difficult and it is difficult to detect small changes which might have larger consequences.

However, it is key that a universal metric is in place and is embedded in responses to measure the quality of life for people living with HIV. Improvements must be made in the existing and current measures and tools available. The Positive Outcomes HIV PROM could also have a multi-national applicability as it was developed across 5 European countries and reflects the multidimensional outcomes relevant to people living with HIV.

Annex 1

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HIV POSITIVE LIVING

HIV LANGUAGE Guide

HIV is a long term, manageable medical condition like may others but some of the words used about HIV, and people living with HIV, can have stigmatising connotations.

Language is powerful and can affect the way we view or treat people and how people view themselves.

This guide offers alternatives to some commonly used words and phrases about HIV.

✗ TRY TO AVOID	✓ BETTER TO USE
HIV positive person	Person living with HIV *Put the person before the diagnosis*
Person infected with HIV	Person living with HIV *Avoid use of the words 'infected' or 'infection'*
HIV virus	HIV *Human Immunodeficiency Virus*
Became infected with HIV	Contracted or acquired HIV *Avoid use of the word 'infected'*
Catch/caught HIV	Acquire/acquired HIV
HIV/AIDS	Use either HIV or AIDS *HIV and AIDS are not the same thing, HIV is a virus, AIDS is a clinical syndrome*
AIDS	Essentially a historical term standing for 'Acquired Immunodefiency Syndrome' – meaning a collection of illnesses which might occur as a result of a severely weakened immune system. As more and more people have access to effective HIV medication which keeps the immune system strong, the term is not now in regular use. Some clinicians may use the term 'advanced HIV' in situations where someone has not benefitted from anti-retroviral medication
AIDS test	HIV test *AIDS is a clinical syndrome and therefore there is no 'test' for it*
Victim/sufferer	Person living with HIV *Words like 'victim' or 'sufferer' can have extremely negative connotations*
Disclose/disclosure	Tell, talk about, share *The word 'disclose' has negative and secretive connotations which can magnify feelings of shame and self-stigma*
Clean - as in 'are you clean?'	Do you know your HIV status? *Using the word 'clean' can be highly offensive and implies that people living with HIV are 'dirty'*
Comply/compliant with HIV medication	Adhere/adherence to HIV medication *'Comply' implies following instructions.* *Adhere recognises active engagement in care*
Serodiscordant couple	Mixed status couple *A relationship where one person is living with HIV and the other is not*
Mother to baby transmission of HIV	'Vertical' or 'perinatal' transmission of HIV *'Mother to baby' implies blame*
Eradicating HIV by 2030	Ending all new transmissions of HIV by 2030 *The word 'eradicating' is aggressive and stigmatising*
Ending HIV	Ending all new transmissions of HIV *There will be many people still living with HIV when there are no new transmissions*
Number of HIV infections	Number of HIV acquisitions *or* number of people diagnosed with HIV
Zero new infections	Zero new infections of HIV *Avoid using the word 'infection'*

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GMCA GREATER MANCHESTER COMBINED AUTHORITY

NHS in Greater Manchester

Manchester Health & Care Commissioning

Annex 2

Organisations who gave Oral evidence

- Elton John AIDS Foundation
- The Global Fund
- HIV Outcomes
- National AIDS Trust
- Salamader Trust
- STOPAIDS

Organisations who gave written evidence

- BASHH HIV-BBV Special Interest Group
- British Psychological Society
- The Children's HIV Association (CHIVA)
- Clinical Health Psychology (Psychological Medicine)
  - Chelsea & Westminster Hospital
- Elton John AIDS Foundation
- Fast Track City Cardiff and the Vale of Glamorgan
- George House Trust
- Gilead
- The Global Fund
- The Haemophilia Society
- HIV Outcomes
- LGBT Foundation
- Mark Ward
- MSD
- National AIDS MAP
- National AIDS Trust
- Shema Tariq and Bakita Kasadha
- STOPAIDS
- Terrence Higgins Trust
- UK Health Security Agency & Office for Health Improvement and Disparities
- UNAIDS
- ViiV Healthcare
- Waverley Care

Members of the APPG inquiry Committee

- Steve Brine MP
- Rt Hon David Mundell MP
- Baroness Barker
- Florence Eshalomi MP
- Alison Thewliss MP
- Lord Black

Notes

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