

# HIV Outcomes

BEYOND VIRAL SUPPRESSION



**RECOMMENDATIONS LAUNCHED AT  
THE EUROPEAN PARLIAMENT**

**NOVEMBER 2017**



**GILEAD**



## **A NEW PERSPECTIVE ON HIV: LONG-TERM HEALTH, WELL-BEING, AND CHRONIC CARE**

The nature of the HIV epidemic has changed. As a result of advances in antiretroviral therapy (ART), HIV need no longer be a fatal disease. For people living with HIV (PLHIV) who are diagnosed early and receive effective ART to suppress viral replication, HIV has become a chronic condition, with lifespans approaching those of the general population. However, a long life expectancy is not the same as living in good health and with a good quality of life. The evidence is that for many PLHIV this is currently not the case.

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.

European health systems need to develop effective, lifelong approaches to the treatment and care of PLHIV. The recommendations in this booklet aim to inform and inspire the development and adoption of such new approaches and policies.

In some health systems, action is already being taken in the directions outlined by the recommendations. However, further work is needed to upscale, coordinate and mainstream those actions. Best practices should be shared and disseminated not only among HIV specialists, but also to contribute to wider debates about the management of complex conditions.

The content of the recommendations, which should be reflected in any future national and European-level 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 European 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. This includes action in relation to undocumented migrants, who in many European countries do not have guaranteed access to healthcare, and may face cultural or linguistic barriers, as well as long-term health challenges resulting from compromised adherence and ART toxicities.

## HIV OUTCOMES RECOMMENDATIONS: BACKGROUND INFORMATION

On 29 November 2017, the multi-stakeholder European initiative “HIV Outcomes: Beyond viral suppression” launched recommendations on the **long-term health, well-being and chronic care of people living with HIV (PLHIV)**.

The recommendations are the outcome of a year-long collaborative process to capture the perspectives and expertise of people living with HIV, clinicians, public health professionals, and the wider HIV community. Two expert roundtables were held – in December 2016 and June 2017 respectively – to identify priority issues in relation to the long-term health and well-being of PLHIV. In September 2017, an expert workshop was used to develop and discuss draft recommendations.

The final recommendations were then launched at the European Parliament with cross-party support from Members of the European Parliament (MEPs) **Christofer Fjellner** (European People’s Party, Sweden), **Eva Kaili** (Socialists and Democrats, Greece) and **Gesine Meißner** (Alliance of Liberals and Democrats for Europe, Germany). In a joint statement, the hosts said that: *“Having addressed the issue of longevity, society now needs to help people with HIV to retain good health and lead rewarding lives. As representatives of the European Parliament’s leading political groups, we fully support the aims of this initiative”*.

Delivering the keynote address, **European Health Commissioner, Vytenis Andriukaitis**, emphasised that while HIV need no longer be a fatal disease, it *“still damages the lives of so many people, and causes not only much suffering and illness, but also discrimination and stigmatisation”*. On the occasion of World AIDS Day, the Commission called for increased efforts to improve long-term health outcomes for PLHIV.

Ihor Perehinets of the Division of Health Systems and Public Health at **WHO Europe** said that broader health system reforms are needed to fully implement the HIV Outcomes recommendations. To address the challenges posed by long-term chronic disease and multi-morbidity, to which HIV Outcomes draws attention, progress is needed in the implementation of integrated care – an area where the WHO provides advice and support to its member governments.

**UNAIDS** also participated in the launch. Peter Ghys, Director of the Strategic Information Department said that the recommendations are highly relevant to all countries, and particularly those that have already made progress with the 90-90-90 targets.

It is the intention for the recommendations now to be disseminated at **national level** with a view to identifying best practices as well as recurring challenges in improving both quality of care and quality of life for PLHIV.

## RECOMMENDATIONS

*The recommendations contained in this booklet are the outcome of a year-long multi-stakeholder process focusing on the long-term health and well-being of people living with HIV. Two expert roundtables were held (in December 2016 and June 2017 respectively), which enabled the identification of priority issues. In September 2017, an expert workshop was held in Brussels in order to develop recommendations that respond to these issues. The results of that workshop, and subsequent written contributions from participating experts, are reflected in these recommendations. The contributors to the development of the recommendations are listed on page 11.*

### Recommendation 1:

#### **Adopt an integrated, outcomes-focused, and patient-centred approach to long-term HIV care**

People living with HIV require access to a range of health services beyond just their HIV treatment. This includes services for: prevention, treatment and management of comorbidities; mental health and neurocognitive impairment; and advice and support in relation to sexual and reproductive health. Such multidisciplinary, multispecialist care requires systematic coordination and a personalised approach – not only to ensure that all relevant services are provided, but also streamline service provision, ensure patient-safety (for example, in relation to polypharmacy and drug-drug interactions), and to enable effective communication between the different care providers involved. A designated healthcare professional responsible for care coordination should be assigned to each person diagnosed with HIV. The care coordinator should develop, in partnership with the patient, a personalised care plan that addresses individual circumstances in relation to clearly defined health outcomes. The care plan should be regularly reviewed and updated, and implemented with the support of communication tools and protocols.

*More detail on this recommendation can be found on pages 7-8 of this booklet, under the heading: ‘Elements of an integrated and patient-centred approach to long-term care for people living with HIV’.*

## Recommendation 2:

### **Expand national monitoring of long-term HIV care and outcomes**

We know far too little about the quality of health system responses to long-term health challenges faced by PLHIV. Key questions on which data are needed include: what are the leading causes of mortality among PLHIV? What are the leading causes of hospitalisation? Has there been an audit of services provided for prevention, treatment and management of comorbidities? Is there an assessment of health-related quality of life? If so, what are the results among PLHIV in general and among key populations? Current monitoring efforts should be expanded to reflect the reality of HIV as a long-term condition. Improved monitoring would enable assessment of national progress over time, and analysis of within country variation (for example, in relation to key populations).

## Recommendation 3:

### **Fund cohort studies to provide information on the long-term health of people living with HIV**

As a powerful mechanism for clinical research and monitoring, which can in turn provide evidence for policy, cohorts and clinical databases of PLHIV have been established in several European countries. Most of these have worked together (since the early 1990s) in collaborative networks through European Union funding mechanisms – culminating in EuroCoord, a European Network of Excellence. The European Union should recommit to providing stable funding to enable future collaboration and establish cohorts/databases in European countries where none currently exist. These studies are uniquely designed to understand the evolution of complex and multifaceted diseases. They can flexibly adapt to new data requirements and complement the information provided by surveillance structures.

## Recommendation 4:

### **Combat stigma and discrimination within health systems**

Healthcare professionals are vital to effective responses to HIV. However, this role can be severely compromised by stigma and discrimination within health systems. For example, the 2016 ECDC report on ‘The Status of the HIV Response in the European Union and European Economic Area’ highlights that 60% of countries reported that stigma and discrimination among healthcare professionals is a barrier to the provision of adequate HIV prevention services for men who have sex with men (MSM) and people who inject drugs (PWID). In Eastern Europe and Central Asia, legal and policy barriers restricting access to health services among key populations are also a continuing cause for concern. Training and education of healthcare staff should be a priority, both in order to raise awareness of stigma and discrimination within healthcare settings, and to help combat the underlying attitudes that

give rise to it. Actions to combat stigma and discrimination within health systems should form an integral part of EU action in relation of the Sustainable Development Goals.

#### Recommendation 5:

### **Upscale involvement of the HIV community in priority setting at country level**

Priority setting in relation to the HIV response at national level will inevitably depend upon local circumstances. For example, there is wide variation across countries with respect to the UNAIDS 90-90-90 targets for diagnosis, treatment, and viral suppression, and it is right that first priority should be given to attaining those targets. In addition, there are differences across countries in the way that health systems are organised, and in the resources available to them. Against that background, a key role should be played by HIV community organisations, drawing upon their local knowledge, in working with national policy-makers to identify and agree priorities for action. This should include defining and formalising the role that community organisations can play in supporting the delivery of HIV services within those countries.

## **ELEMENTS OF AN INTERGRATED AND PATIENT-CENTRED APPROACH TO LONG-TERM CARE OF PEOPLE LIVING WITH HIV**

*The additional recommendations below supplement and provide further detail on Recommendation 1 (see page 4).*

### **1. Put comorbidity prevention, treatment and management at the centre of long-term HIV care**

People living with HIV are more likely than the general population to develop serious comorbidities and to develop them at an earlier age. These include: cardiovascular diseases, cancers, bone loss, respiratory, renal and liver diseases, mental health conditions, and co-infections such as tuberculosis, hepatitis and sexually-transmitted infections (STIs). If these conditions are not properly treated and managed in a timely manner they can greatly complicate HIV care, have a negative impact on health and health-related quality of life for PLHIV, and significantly burden health systems. Prevention, diagnosis, treatment and ongoing management of comorbidities should therefore be core components of long-term care for all PLHIV – including through public health interventions (encouraging beneficial steps such as a healthy diet and exercise), and routine screening.

### **2. Coordinate outcomes-focused care delivery using a personalised care plan**

The multi-disciplinary nature of long-term HIV care requires a coordinated response in all European countries. For each person diagnosed with HIV, there should be a designated healthcare professional responsible for coordinating that person's care and ensuring efficient communication between the different disciplines and specialists involved. A key tool for care coordination in this context is the development of a personalised care plan. The care plan should be developed in partnership with the patient, and be regularly reviewed and updated in light of that person's changing needs. The adoption of tools and protocols for communication and information sharing across disciplines is vital. Implementation barriers relating to insufficient knowledge and/or skills concerning the specific needs of key populations must also be addressed.

### **3. Integrate services for mental health and neurocognitive impairment**

Mental illnesses, such as depression, and neurocognitive impairment are prominent among PLHIV. 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

PLHIV should therefore integrate services to assess and manage any mental health and neurocognitive issues, including access to psychosocial support and other relevant specialists.

#### **4. Ensure an ongoing focus on sexual and reproductive health**

Fulfilling sexual and reproductive health, underpinned by knowledge of how to maintain protective behaviours, is a key aspect of the health and quality of life of PLHIV. Access to accurate information and advice on HIV transmission and methods of contraception should be complemented with services relating to conception, childbirth, and parenting options available for all. PLHIV should have access to regular sexual health assessments as part of an integrated, outcomes-focused care plan that includes counselling and support services that are sensitive to the particular needs of individuals in different population groups. Action to address stigma and fear related to the sexuality of PLHIV is also crucial. Biomedical interventions available today can play a key role in this respect.

#### **5. Increase systematic participation of PLHIV in decisions about their care**

PLHIV should have the opportunity to become involved in decisions about their care. Decision aids explaining the advantages and disadvantages of different treatment options can empower PLHIV to discuss these options with care providers, and make informed choices in the light of personal circumstances. Building upon existing initiatives in this area, the development of such tools should harness the expertise of HIV community organisations.

## KEY DOCUMENTS

### European Union

Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia (2004)

European Commission, 'Communication on combating HIV/AIDS in the EU and neighbouring countries' (2009)

European Commission, 'Action plan on HIV/AIDS in the EU and neighbouring countries, 2014-2016'

European Centre for Disease Prevention and Control (ECDC), 'The Status of the HIV Response in the European Union/European Economic Area, 2016'

ECDC, 'Evidence brief: Impact of stigma and discrimination on access to HIV services in Europe' (2017)

ECDC, 'Thematic report: Continuum of HIV care' (2017)

ECDC, 'Thematic report: HIV and migrants' (2017)

### World Health Organisation

WHO, 'Global health sector strategy on HIV, 2016-21' (2016)

WHO, 'Consolidated guidelines on person-centred HIV patient monitoring and case surveillance' (2017)

WHO, 'Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations' (2016)

WHO Europe, 'Action Plan for Sexual and Reproductive Health: Towards Achieving the 2030 Agenda for Sustainable Development in Europe – leaving no one behind' (2016)

### Organisation for Economic Cooperation and Development

OECD, 'Improving Value in Health Care: Measuring Quality' (2010)

OECD, 'Geographic Variations in Health Care: What do we know and what can be done to improve health system performance?' (2014)

## **United Nations**

UN General Assembly, 'Political Declaration on HIV and AIDS: On the Fast-Track to Accelerating the Fight against HIV and to Ending the AIDS Epidemic by 2030'

(Resolution adopted on 8 June 2016)

UN General Assembly, 'Transforming our world: the 2030 Agenda for Sustainable Development' (Resolution adopted on 25 September 2015)

## **Medical Societies & Associations**

European AIDS Clinical Society, 'Guidelines' (October 2017)

HIV Medicine Association (US), 'Essential components of effective HIV care' (2011)

## **Think Tanks & Civil Society**

Terrence Higgins Trust Report, 'Uncharted Territory: A report into the first generation growing older with HIV' (2017)

Terrence Higgins Trust, National Aids Trust, British Association for Sexual Health & HIV, Positively UK, NAZ and MSD, 'No-one left behind: A declaration on 'Whole Person Care' in HIV care and support' (2017)

The Commonwealth Fund and LSE Health and Social Care, 'Designing a High Performing Health and Social Care System for Patients with Complex Needs: Ten Recommendations for Policy Makers' (2017)

The King's Fund, 'Coordinated care for people with complex chronic conditions' (2013)

The King's Fund, 'The Future of HIV Services in England: Shaping the Response to Changing Needs' (2017)

Paris Community Declaration 2017 (launched at the 9th IAS Conference on HIV Science, July 2017)

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*With support from the HIV Outcomes Secretariat*



*This initiative is enabled by sponsorship provided by Gilead Sciences and ViiV Healthcare*