

NAVIGATING HIV

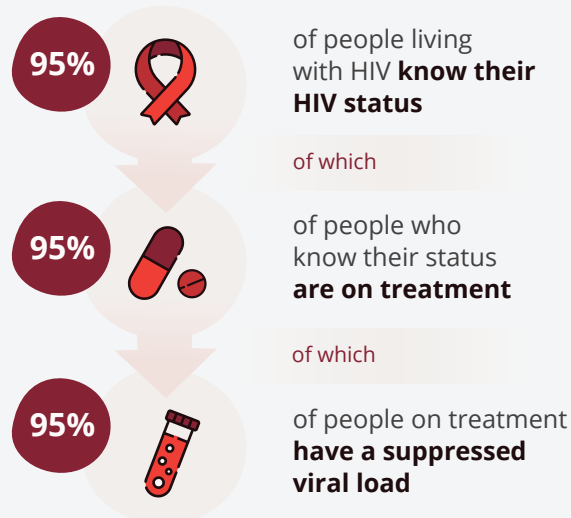
# Progress and challenges in achieving the best health-related quality of life of people living with HIV in the WHO European Region

Insights from the European Parliament's study on Health-related quality of life (HRQoL) for people living with HIV



Since its first discovery in the early 1980s the human immunodeficiency virus (HIV) **continues to spread and impact** the health and well-being of millions of people in the European Region.

To address the HIV epidemic, the United Nations Joint Programme (UNAIDS) established three targets to advance progress towards ending the epidemic.



**+ less than 10%** of people living with HIV experience stigma and discrimination

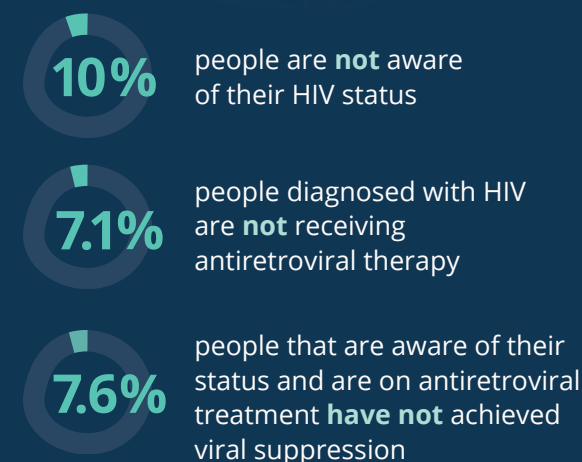
Source: Noori, T. et Al., 2022, Health-related quality of life in people living with HIV, publication for the Committee on Environment, Public Health and Food Safety (ENVI), Policy Department for Economic, Scientific and Quality of Life Policies, European Parliament, Luxembourg.

## Current status of HIV spread in the EU/EEA

Today, ca.

**2.3 million** people live with HIV in the WHO European region.

The European Centre for Disease Prevention and Control (ECDC) reported that approximately:



Despite a lack of data in the EU/EEA countries on stigma and discrimination, **7/30** countries record **>10%** of people living with HIV experience stigma and discrimination in healthcare settings.

## Why does it matter?

### HIV: A chronic disease with complex challenges

#### Long-term care needs

People with HIV require lifelong care and treatment.

#### Co-morbidities and complications

Common issues include non-communicable diseases, mental health disorders, and stigma.

#### Impact of COVID-19

The pandemic worsened access to services and intensified mental health and stigma issues, affecting overall quality of life.

### Beyond health: Stigma and discrimination



#### Increased risk of co-morbidities

People with HIV face a higher risk of additional health issues.



#### Impact of stigma

Stigma and discrimination worsen the HIV epidemic.



#### Limited data on shame and reluctance

Few countries in the WHO Europe region collect data on stigma and discrimination faced by people living with HIV, creating an important gap in accurately measuring how many people feel ashamed and reluctant to disclose their status.



#### Mental health and help-seeking

Shame affects self-esteem and mental health, reducing the likelihood of seeking help and treatment.

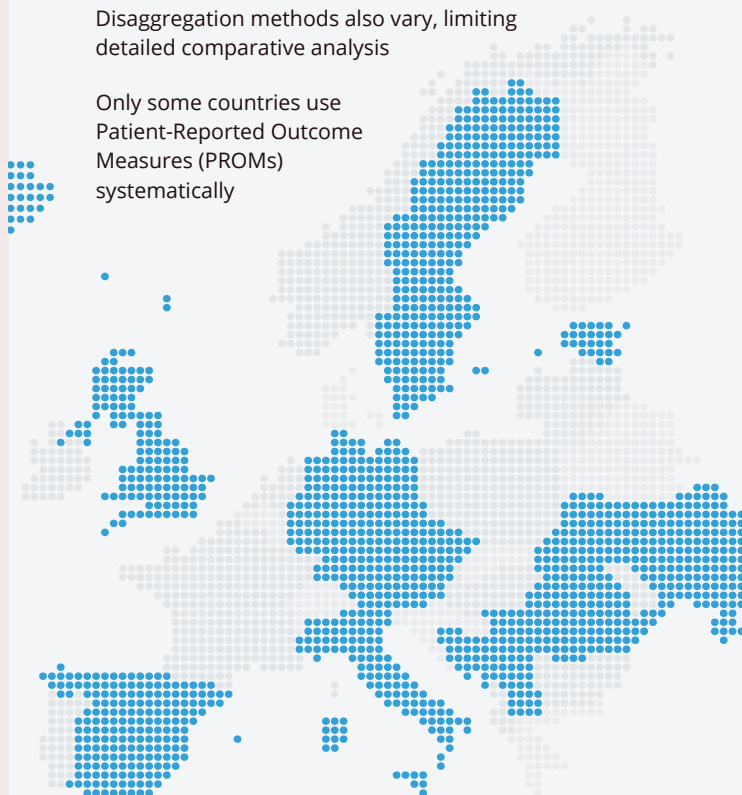
## Is HRQoL of people living with HIV adequately measured?

In the WHO Europe Region, **only 13 countries** assess HRQoL as part of national monitoring of people living with HIV.

There is a lack of consistency and standardisation in the recency and frequency of HRQoL data collection

Disaggregation methods also vary, limiting detailed comparative analysis

Only some countries use Patient-Reported Outcome Measures (PROMs) systematically



● countries assessing HRQoL as part of national monitoring

Additionally, only a few countries compare the **quality of life** of people living with HIV with HIV-negative individuals, highlighting a gap in understanding the broader impact of HIV on overall well-being.

## What does this all mean?



### Lagging progress

Few countries are on track to meet UNAIDS targets for ending the HIV epidemic, highlighting the need for stronger national policies.



### Importance of integrated services

Adapting people-centred, context-specific integrated services is crucial. This includes testing for diseases associated with HIV and continuous surveillance of comorbidities.



### Challenges in HRQoL data collection





Improved standardised and regular data collection practices are needed to enhance health assessments and interventions for people living with HIV, including monitoring HIV-related stigma in healthcare settings.



### Need for an holistic approach to HIV care

A holistic approach is essential to understand and address the full spectrum of health, mental, and social outcomes for people living with HIV.

## Find us online:

-  [hivoutcomes.eu](https://hivoutcomes.eu)
-  [@HIVOutcomes](https://twitter.com/HIVOutcomes)
-  [HIV Outcomes - Beyond Viral Suppression](#)
-  [secretariat@hivoutcomes.eu](mailto:secretariat@hivoutcomes.eu)