

## ***HIV Outcomes World AIDS Day 2021***

### **HIV 40 years on: Time to focus now on Health-Related Quality of Life!**

#### **Event Report**

#### ***Measuring health-related quality of life for people with HIV***

**HIV is no longer a death sentence – now is the time to shift the focus from survival to health-related quality of life.**

40 years since the first cases of AIDS were reported, much has changed. At least 30 million people have died, but the outlook for people diagnosed with HIV today has been transformed. HIV is no longer a death sentence. Thanks to improved diagnosis and better therapies, people living with HIV have a life expectancy similar to that of the wider population.

While this is a cause for celebration, there is still much work ahead in addressing health-related quality of life (HRQoL). This includes tackling mental and physical health issues, as well as stigma and discrimination. HRQoL should be measured so that concrete actions can be taken to drive improvements.

These were among the recurring themes at a high-level online conference convened by [HIV Outcomes](#) to mark World AIDS Day 2021. The event focused on the policy steps needed to enhance HRQoL and improve outcomes for people living with HIV.

Participants included the European Commissioner for Health and Food Safety **Stella Kyriakides**, the Special Advisor to the UNAIDS Executive Director **Vinay P. Saldanha**, along with HIV experts and civil society representatives. The event was hosted by a cross-party group of Members of the European Parliament (MEPs): **Frédérique Ries** (Renew Europe Vice President, Belgium), **Cyrus Engerer** (Socialists & Democrats, Malta) and **Frances Fitzgerald** (European People's Party, Ireland).

#### **Reflections on four decades of HIV**

40 years of progress, which accelerated significantly from the mid-1990s, have changed the needs of the HIV community. This demands a shift in thinking from policymakers, clinicians and wider society, to ensure people living with HIV can enjoy 'a long life, well lived'. To make this a reality, universal indicators and metrics tracking HRQoL must be embedded at national and regional level. At present, most European countries do not collect data on HRQoL.

Despite the positive clinical outlook for people with HIV, several speakers put the spotlight on the persistent problem of stigma and discrimination. This can have a profoundly negative impact on wellbeing, often discouraging people living with HIV from seeking health services.

Education and awareness are essential to addressing this, alongside stronger efforts to remove discriminatory laws and regulations. The EU and national governments should also do more to highlight the human rights issues faced by the LGBTQI communities in Poland, Hungary, Belarus and elsewhere, according to several contributors.

## Ending AIDS: time for policy action

The new Global AIDS Strategy adopted at the UN General Assembly in June, with strong backing of the EU and EU Member States, sets out a bold vision for a world without AIDS. Governments have committed to a set of granular targets on diagnosis and treatment by 2025, along with measures to tackle inequality and support marginalised populations. UNAIDS is expected to issue new Global AIDS Monitoring Guidelines shortly which will require countries to submit reports in the spring of 2022.

Across the EU, progress towards these targets is mixed. Some cities, regions and countries have made significant strides in recent years, while others lag far behind. Sharing best practices among stakeholders is seen as a vital step towards raising standards across Europe.

To help move health-related quality of life centre stage, the European Parliament Health Committee will commission the European Parliament Research Service (EPRS) a new study to explore best practices across Europe and share insights on how to improve well-being for people with HIV. As the EU moves towards a Health Union and the EU4Health programme offers new funding streams, policymakers aim to make Europe a leader in meeting the UN targets.

Participants agreed that this could best be achieved by engaging with civil society groups in line with the GIPA Principle (Greater Involvement of People Living with HIV/AIDS). By placing people at the heart of policy, Europe can advance the outcomes that matter to the growing number of citizens living with HIV.

### INITIATIVE PARTNERS



### OBSERVER MEMBERS

- European AIDS Clinical Society (EACS)
- European Center for Disease Prevention and Control (ECDC)
- Fast-Track Cities
- UNAIDS
- UNITE

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