

Enhancing the long-term health and wellbeing among people living with HIV

World AIDS Day, 1 December 2022

Event Report

On 1 December 2022, World AIDS Day, HIV Outcomes launched its new 'Policy Asks' on 'Enhancing long-term health and well-being among people living with HIV' at the European Parliament in Brussels. The event took place under the auspices of the auspices of the **Czech Presidency** of the Council of the EU and was co-hosted by **MEP Frédérique Ries** (Renew Europe Vice-President, Belgium), **MEP Sara Cerdas** (Socialists and Democrats, Portugal), and **MEP Sirpa Pietikäinen** (European People's Party, Finland). The event was moderated by **Nicola Bedlington**, Senior Adviser and former Secretary-General of the European Patients' Forum.

Keynote: European Commissioner for Health, Stella Kyriakides

In her keynote address, **Stella Kyriakides**, European Commissioner for Health, said she was 'proud' to stand alongside HIV Outcomes on World AIDS Day, stating that it had a 'simple but powerful vision': 'that all people living with HIV should enjoy the highest possible quality of life, free from stigma and discrimination'. It is not enough, Kyriakides said, that people with HIV are able to live long lives, they should also live healthy and fulfilling lives. The HIV Outcomes policy asks are 'an important step' towards this 'shared vision'. Kyriakides confirmed that the new EU Expert Group on Public Health will cover chronic and communicable diseases including HIV, which responds directly to one of the HIV Outcomes policy asks.

The lived experience of HIV

Stéphan Vernhes, a Steering Group member of HIV Outcomes and Coordinator of the European Platform AIDES, reflected on his experience of living with HIV for 21 years. For many years after contracting HIV, Vernhes said that he came across people who made him feel guilty for having HIV. That has left scars and it took him 21 years to be at peace with himself. Some people never recover.

People with HIV are linked by the shared experience of stigmatization, discrimination, and comorbidity management. "Stable viral load is not enough", Vernhes said, "we need to improve the quality of life of people living and ageing with HIV". Health systems must monitor health-related quality of life (HRQoL) and address the challenges posed by ageing with HIV. In France in 2020, 50% of people living with HIV were 50 years or over.

In order to end HIV/AIDS by 2030, there is a need to promote undetectable = untransmissible. There is also a need for stronger political engagement on pre-exposure prophylaxis (PrEP) – to stop key populations acquiring the condition. There must also be an end to the discrimination of trans-people, sex workers, drug users, and LGBT+ people. In concluding his remarks Vernhes asked the audience and speakers to join him in observing a one-minute silence – on World AIDS Day – to remember all those that have died from HIV/AIDS.

ECDC report on HRQoL of people living with HIV

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Dr Anastasia Pharris, Principal Expert on Infectious Diseases at the European Centre for Disease Prevention and Control, presented key findings from a [new ECDC report on HRQoL of people living with HIV](#), which was commissioned by the European Parliament committee responsible for public health. Pharris began by highlighting that 106,000 people were newly diagnosed with HIV in the WHO European Region in 2021. More than half of those people were diagnosed late. There are now 2.3 million people living with HIV in the European Region.

Pharris drew attention to the new UNAIDS target that less than 10% of people living with HIV and key populations should experience stigma. However, Pharris noted that there is currently a lack of tools to measure stigma across countries. To address this gap two new projects have been initiated:

- i. *Measuring stigma in the community* – for which ECDC is collaborating with European AIDS Treatment Group and AIDS Action Europe
- ii. *Measuring stigma in the healthcare setting* – for which ECDC is collaborating with the European AIDS Clinical Society and the International Association of Providers of AIDS Care.

An initial survey to measure stigma in the community gathered more than 3,000 responses. It shows that HIV-related stigma is highly prevalent. For example:

- More than a quarter of respondents reported being ashamed of their HIV status and having low self-esteem because of their HIV status.
- 1 in 6 people with HIV have not told a single friend about their HIV status and 1 in 4 have not told a single family member.
- Nearly a quarter reported being rejected by friends and more than half were worried about being treated differently by healthcare staff.

Other important challenges to health and well-being highlighted by the ECDC report include:

- A higher prevalence of co-infections – notably tuberculosis and hepatitis B and C
- Co-morbidities – both non-communicable diseases and mental health conditions
- Legal restrictions on people living with HIV which exist in 48 countries globally.

Presentation of HIV Outcomes ‘Policy Asks’

Beyond viral suppression: the impact of mental health and other co-morbidities

[The HIV Outcomes’ policy asks on comorbidity prevention, treatment and management](#) were presented by **Professor Jane Anderson**, HIV Outcomes Co-Chair and Consultant Physician at Homerton Healthcare NHS Foundation Trust in the United Kingdom. Professor Anderson reflected on the fact that, in the early days of the HIV epidemic, the overriding concern was to enable people with HIV to live. We now know more about the challenges associated with living with HIV. For example, in addition to physical comorbidities, mental health morbidity among people with HIV is nearly twice as high as in the general population. A more integrated, holistic, person-centred approach is needed – one that is organised around the needs of the individual, including co-morbidities and peer support services. Mental health services for people living with HIV need to take into

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account the specific needs of people living with HIV, which are often closely related to the experience of stigma and discrimination.

Ageing with HIV

Professor Giovanni Guaraldi, HIV Outcomes General Member and Associate Professor at the University of Modena and Reggio Emilia, presented the HIV Outcomes policy asks on ageing with HIV. He outlined data showing that people with HIV (of any age) have a higher prevalence of frailty than the general population. The trajectory of ageing is also different; frailty is less easily reversed among people with HIV, who also experience more loneliness. Furthermore, comorbidities increase the likelihood of polypharmacy. There is a need for specialised services for older adults living with HIV, as well as training programmes for carers working in social care settings. The EU can help by providing funding for pilot studies related to aging with HIV.

‘What gets measured gets done’ – measuring person-reported outcomes (PROs) and monitoring HRQoL

Professor Jeffrey Lazarus, HIV Outcomes Co-Chair and Head of the Health Systems Research Group ISGlobal at Hospital Clinic, University of Barcelona, Spain presented the HIV Outcomes policy asks on PRO measurement and HRQoL monitoring. He said that the ECDC report shows that, since the launch of the HIV Outcomes Recommendations in 2017, progress has been made. However, more needs to be done: there has been only limited integration of PROs into routine HIV care, while only five European countries have made efforts to measure HRQoL at an aggregate level. Action should be taken by HIV clinics/care providers to improve the measurement of PROs and to use them for shared decision-making and health outcomes monitoring. National and regional health authorities should establish annual surveys of people with HIV and document data on HRQoL as well as experiences of stigma and discrimination. HIV Outcomes also recommends that the EU allocate funding for the inclusion of HIV within the OECD patient-reported indicators survey (PaRIS).

Combatting stigma and discrimination

The policy asks on stigma and discrimination were presented by **Mario Cascio**, HIV Outcomes Steering Group Member and Quality of Life Programme Manager at the European AIDS Treatment Group (EATG), and **Anton Basenko**, EATG Programme Manager. Cascio said that HIV remains one of the most stigmatised diseases worldwide. Examples of the stigma and discrimination faced by people with HIV include: verbal and physical abuse; difficulties getting/keeping a job; people avoiding/keeping away from you; and discrimination in healthcare settings. Stigma and discrimination within health systems has impacts across the HIV continuum of care – from diagnosis to viral suppression and comorbidity management. It can result in delayed initiation of, and poor retention in, care. Cascio also strongly emphasized the negative impact of stigma and discrimination on mental health and HRQoL. Basenko highlighted the persistence of laws that discriminate against or criminalise people with HIV.

HIV clinics/care providers should offer peer-to-peer and community-based interventions to address the stigma and discrimination experienced by people with HIV. National and regional health authorities should implement interventions to strengthen empathy toward people with HIV among healthcare staff and decrease stigma and

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discrimination in health settings. Any future EU strategy on mental health should include a focus on reducing stigma and discrimination among groups at risk, including people with HIV.

National perspective: UK and Romania

Baroness Barker, House of Lords Member and All-Party Parliamentary Group HIV and AIDS Co-Chair shared the findings of the recent Quality of Life report. 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. Baroness Barker called governments and international organisations to come together to agree on a base line what quality of life means.

Dr Anca Streinu-Cercel, PhD Senior Lecturer at Carol Davila Medicine and Pharmacy University, Clinician at National Institute for Communicable Diseases “Prof Dr Matei Bals”, shared the Romanian experience of treating people with HIV over the last 30 years. Dr. Streinu-Cercel explained that clinicians were crucial in Romania in developing tailored programmes and involving people living with HIV in creating integral policies and care packages.

Cross-party MEP support

MEPs Ries, Cerdas and Pietikäinen pledged their continued support for the HIV Outcomes initiative. MEP Ries who presided over the first part of the event, welcomed the ECDC report on HRQoL of people and emphasized the need to also give voice to those living with the condition.

Vytenis Andriukaitis, HIV Outcomes Ambassador and WHO Special Envoy for Europe commended all members of HIV Outcomes for the work they are doing and stressed how much he had learned from the event. He called for sharing of best practices among clinicians as well as community members to improve integrated, holistic care for people with HIV.

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