

Building political momentum: Towards Ending HIV in Europe

29 November 2023, on the occasion of World AIDS Day

Event report

On 29 November 2023, HIV Outcomes organised on the occasion of World AIDS Day an event in the European Parliament in Brussels, focusing on “Building political momentum: Towards Ending HIV in Europe”. The event was co-organised and hosted by a cross-party group of MEPs gathering **MEP Frédérique Ries** (Renew Europe Vice-President, Belgium), **MEP Sara Cerdas** (Socialists and Democrats, Portugal), and **MEP Sirpa Pietikäinen** (European People’s Party, Finland) and was **moderated by Jacki Davis**.

Opening remarks

Moderator Jacki Davis opened the event and reminded the audience that ending HIV remains an ongoing battle, with next year providing a unique opportunity to reflect on and strengthen the momentum for Europe’s commitment to end HIV. She notably mentioned the 2023 ECDC study on the health-related quality of life (HRQoL) of people living with HIV, commissioned by the European Parliament, emphasising that more than 15.000 people in the European Union are still living with HIV and that additional work is required to achieve both 95-95-95 UNAIDS targets for diagnosis, treatment, and viral suppression, as well as eliminating the AIDS pandemic by 2030, under the United Nations Sustainable Development Goal 3.3.

In that context, Jacki Davis highlighted areas identified by experts to pursue ongoing efforts, namely: 1) Comorbidity prevention, treatment and management, 2) Ageing with HIV, 3) Measurement of person-reported outcomes (PROs) and monitoring of health-related quality of life, and 4) Combatting stigma and discrimination.

Keynote: European Commissioner for Health Stella Kyriakides

Commissioner for Health Stella Kyriakides stressed the already implemented and numerous actions to fight HIV and end the pandemic by 2030, notably in the field of medical innovation and the fight against stigma and discrimination. She nevertheless emphasised that a lot has still to be done, notably in the context of the creation and deepening of a Health Union, in a staunch call for HIV to remain a political priority in the coming years. Among other things, this includes what Commissioner Kyriakides calls the “three As” (accessibility, affordability and availability), increased equity, patient-centred care, solidarity and innovation.

Commissioner Kyriakides also reminded the audience her pioneering role in Cyprus to fight against HIV and associated stigma and discrimination – a work which requires to also focus on children living with HIV and not only on most vulnerable populations. She reminded her utmost respect for people ageing with HIV, who fought and enabled better living conditions at times when stigma and discrimination were omnipresent.

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Commissioner Kyriakides concluded that even though HIV / AIDS are now considered as chronic conditions, they remain a global public health challenge, as highlighted by the COVID-19 pandemic. Notably to reach the UNAIDS targets, she highlighted the Commission's first comprehensive approach on mental health issued in 2022, and the establishment of a Public Health Expert Group to translate best practices on communicable diseases.

Keynote: European Commissioner for Equality Helena Dalli

Commissioner for Equality Helena Dalli reflected on medical innovation's key role in increasingly making HIV a chronic disease. Nevertheless, she deplored the stigma associated with AIDS / HIV, including in medical settings. She reminded that the European Union is deeply committed to reach the UNAIDS 2030 targets and that efforts in that regard are still needed, notably in the fields of education, awareness and 'equality mainstreaming' for all populations.

Keynote: UNAIDS Executive Director for Policy, Advocacy and Knowledge Branch Christine Stegling, Shedding light on inequalities in ending HIV in Europe

Christine Stegling highlighted the importance of communities to end HIV: their role in linking prevention services to those most needed is particularly important, as they have shown by strongly decreasing innovative medicines' prices in the past and ensuring in some countries the fight against HIV becomes a political priority. She welcomed that several countries already reached the 95-95-95 targets, and that 16 more are close to doing so.

She also stressed that UNAIDS is strategizing how to maintain the progress already achieved and how to go beyond the 95-95-95 targets. In this context, particular attention needs to be paid to gaps in under-scrutinised populations living with HIV (e.g., adolescents girls, young women, children) and geographies globally. UNAIDS is also working on an evidence-based evidence review, to give further indications on how to act and protect gains obtained in a multi-sectorial fight against HIV.

Accelerating HIV prevention for achieving the elimination targets

Magdalena Bartnik, European AIDS Treatment Group member, and Executive Director of the Prekursor Foundation for Social Policy, Poland, reflected on her experience of working on the frontline with marginalized populations and people who use drugs in the Polish society. She reminded the utmost importance to engage with people in a non-judgmental way, and the crucial role of non-governmental organisations (NGOs) in that regard.

Magdalena Bartnik called for all EU governments to develop prevention strategies, especially among vulnerable groups, and to become legally accountable for implementing those, working collaboratively with NGOs, despite political orientations, highlighting this has not been her experience so far.

Ending HIV requires also facing the 'war on drugs' and other root causes of social marginalisation (e.g., poverty, violence, mental health, awareness, stigma and discrimination), hindering efforts to provide life-saving care for all, including all minorities and people living with HIV.

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Advancing HIV Care: A person-centred approach to long-term health and the HRQoL among people living with HIV

- a. Improving the HRQoL of people with HIV: addressing structural stigma and discrimination, as well as mental health

Professor Oana Sandulescu, Carol Davila University of Medicine and Pharmacy and member of the National Institute for Infectious Diseases "Prof. Dr. Matei Bals" in Romania called for Patient Reported Outcomes (PROs) to be recorded in clinical practices and to be evaluated on a regular basis - at least yearly, to ensure people living with HIV all have equitable and equal access to appropriate comprehensive treatment and care, based on data coming from clinical practices. If models already exist, each clinic has its own system, hindering European Union-wide efforts. Additional work is therefore needed to design and implement a harmonized system that would fit all regional and national systems.

Professor Sandulescu also reminded that mental health is a key element to include in strategies to fight HIV. Mental health strategies should focus on several elements, including social wellbeing, physical and psychological wellbeing. In this context, stigma should be a primary focus and HIV infection should be normalised in mainstream perception and medical testing, as reflected in the ongoing ECDC and EACS study to measure stigma across healthcare settings.

- b. Comorbidity prevention, treatment, and management

Mario Cascio, Chair Quality of Life Programme at European AIDS Treatment Group and HIV Outcomes Steering Group member, emphasised the impact of the fragmentation of care with regards to HIV outcomes and the subsequent frailty of EU healthcare systems. He also reminded the potential role of the European Commission Public Health Expert Group on Non-Communicable and Communicable Diseases to initiate best-practices pilot projects (e.g. facilitating nurses and doctors visits to centres of excellence).

Mario Cascio stressed that by 2030, the average age of people living with HIV will be over 50, leading to other challenges, including an average life expectancy gap of 16 years compared to non-HIV positive populations. Among others, 30% of people living with HIV suffer from 3 to 4 comorbidities, resulting in less healthy years and strongly hampering HIV care. Initiatives to tackle this growing issue encompass integrated care plans and multi-disciplinary teams to evaluate mental health, nutritional and physical deficits. This would notably enable to address self-stigmatization, a strong barrier to HIV care.

- c. Measurement and monitoring of the health-related quality of life of people living with HIV

Professor Jeffrey Lazarus, HIV Outcomes Co-Chair and Head of Health Systems Research Group ISGlobal at Hospital Clinic at the University of Barcelona, reflected on the importance of measuring Health-Related Quality of Life (HRQoL) for people living with HIV, especially as they are more likely to suffer from comorbidities. If HRQoL is usually used to measure drug-drug interaction, measuring it for

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people living with HIV requires more focus on discussing with patients and is therefore challenging to implement.

Professor Lazarus urged for the ECDC to further address infectious diseases and for HIV to remain on the political agenda so that the European Union Member States can collectively reach the UNAIDS 95-95-95 targets – via their national institutions but also the European institutions, notably the European Parliament. On this, he welcomed the ongoing work done by the European Parliament’s subcommittee for public health, and called for greater involvement of communities and health experts in public health policy-making and HIV-related public initiatives.

Last, Professor Lazarus also emphasised the difference between stigma and discrimination, calling for Member States to further enforce national regulations on the former, and the European Union to initiate discussions on the latter.

d. Ensuring healthy ageing for people living with HIV

Dr Nicoletta Policek, UK CAB Chairperson and HIV Outcomes UK Co-Chair, stressed the need to tackle health-related quality of life for people living and ageing with HIV, including women, who are often overlooked in HIV policies. In that regard, the Glasgow Manifesto, a community-led initiative, reiterates that additional efforts are needed in this regard. Among other topics, the Manifesto tackles mental health and sexuality, while keeping an age-friendly language and keeping at its core the problematic of equity.

Among successful initiative, Dr Policek mentioned the role of communities to drive up the political momentum at local and regional level. Additionally, Dr Policek made a strong call for the European Union to tackle root causes of inequities and stigmatisation of people living with HIV, including issues affecting the entire population, particularly such as violence against women and poverty.

Call for Action: Towards Ending HIV in Europe

MEP Sara Cerdas reminded that ECDC statistics on stigma and discrimination are appalling, with more than 60% of people living with HIV still suffering from stigma by health practitioners. She reminded as well that confidentiality, notably in the context of the European Health Data Space (EHDS), thanks to which patients will be able to choose who can access their data.

MEP Cerdas concluded her intervention with a strong call for the momentum to fight HIV to be sustained beyond the European Parliament elections, despite other topics increasingly at the top of the agenda (e.g., mental health, cancer).

Closing remarks and next steps

MEP Sirpa Pietikäinen reminded that the European Union has gone a long way from “dreadful times” where treatments were almost non-existent and that stigma was omnipresent, calling this situation a “crime against human rights”. In a context where the fight against HIV is far from being won yet, self-care, including testing and mental health care are essential, and it is crucial to support and embrace

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people living with HIV, banishing negative attitudes towards this population in public policies and initiatives, as well as in day-to-day life.

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