

Our Journey

While important progress has been made in the global response to HIV/AIDS in Europe, the WHO European region, and in particular Eastern Europe, now has the fastest growing HIV epidemic globally. At the same time, people living with HIV are living longer, which has created new challenges relating to the prevention, treatment, and management of comorbidities (co-existing medical conditions) as well as their health-related quality of life.

HIV Outcomes began its journey in 2016 by bringing together patient organisations, medical professionals, academics, public institutions and the private sector to align on a new policy and clinical agenda to address the crucial unmet needs of people living with HIV, and to ensure that they can live longer in good health, and participate fully in society. **The initiative was formally launched in December 2016** with support from cross-party members of the European Parliament.

In 2017, HIV Outcomes launched [recommendations](#) in the European Parliament on the long-term health, well-being and chronic care of people living with HIV with cross-party support at the European Parliament from the Alliance of Liberals and Democrats for Europe, the European People's Party and the Socialists and Democrats as well as former European Commissioner for Health, Vytenis Andriukaitis. 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.

HIV Outcomes has been present at a number of other important conferences since its inception, with abstracts showcased at the [International AIDS Society conference in Paris 2017](#), [HIV Drug Therapy Glasgow 2018](#) and the International Conference on Integrated Care 2019 in San Sebastian. HIV Outcomes also hosted a workshop in Amsterdam during the AIDS 2018 conference to contribute to our [Compendium of Good Practices](#). In 2019, HIV Outcomes Co-Chairs Jeffrey Lazarus and Jane Anderson led and published '[The Lancet HIV Series on HIV Outcomes: Beyond Viral Suppression](#)', whose key learnings were later discussed in 2020 at [webinar](#) hosted by HIV Outcomes on the Health Policy Platform.

In 2021, HIV Outcomes contributed to the development of the [Global AIDS Strategy for 2021-2026](#) led by UNAIDS. Our purpose was to shift the focus beyond viral suppression and factor in the Strategy

the issues affecting the health-related quality of life of people living with HIV. In late 2020, we held a virtual [Focus Group Discussion alongside UNAIDS](#) in which we agreed on six recommendations on how the Strategy could consider the well-being and health-related quality of life of the HIV population with input from over 30 HIV-related stakeholders from all over the world. The output of this discussion fed into a later [Workshop also held with UNAIDS](#) on how to define the health-related quality of life of the people living with HIV. The Steering Group and General Members of HIV Outcomes, together with representatives of the World Health Organization and UNAIDS, identified at this Workshop the main physical, mental/emotional, and social challenges affecting the health-related quality of life of people living with HIV. The conclusions that emerged were captured in a formal communication to UNAIDS. In the final draft of the Global AIDS Strategy for 2021-2026 approved in March 2021, UNAIDS took on board many of our suggestions concerning the need to support progress in ensuring a better quality of life for people living with HIV.

In 2022, HIV Outcomes welcomed Vytenis Andriukaitis, former European Commissioner for Health & Food Safety and current WHO Special Envoy for the European region, as [Ambassador of the initiative](#). This year also saw the launch of the [HIV Outcomes policy asks and recommendations](#) at a high-level event for [World AIDS Day](#) in the European Parliament. This update of the 2017 recommendations is the result of a year-long collaboration between over 60 experts and organizations with the ambition to identify areas of action and guide policy for HIV clinics, care providers, national and sub-national health authorities, and the European Union. HIV Outcomes's successful advocacy efforts to prioritise the Health Related Quality of Life (HRQoL) of people living with HIV have been recognised, as the input provided by the initiative has been captured in a wide range of key EU policy files, such as the European Care Strategy, the European Health Data Space and the ECDC Mandate extension, among others. Additionally, HRQoL has been included in key guidance documents from both the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). At national level, thanks to the evidence generated and gathered by our in-country colleagues, HIV Outcomes national initiatives have successfully advocated and implemented evidence-based policy and clinical change at country-level across Europe.

