

WHAT IS HIV OUTCOMES?

For those diagnosed and treated early, HIV is now **a long-term, rather than fatal, condition**. Approximately 37 million people¹ globally are living with HIV, with this figure likely to increase as diagnoses continue to rise and more people live longer with the condition. It is estimated that 2.3 million people² are currently living with HIV in the WHO Europe region. As people age with HIV, they are **more likely to develop serious comorbidities** (other medical conditions) than the rest of the population. While substantial progress has been made in tackling HIV, **now is not the time for complacency**.

The HIV Outcomes initiative began its campaign 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** – to ensure that they can live longer in good health, and participate fully in society.

HIV Outcomes seeks to **improve the long-term health outcomes and quality of life of all people living with HIV across Europe** – and thereby improve the sustainability of European healthcare systems – by sharing evidence-based best practices and innovative approaches to care, while implementing policy and clinical changes in European countries.

VISION

A world in which people living with HIV enjoy good long-term health outcomes and quality of life

HIV OUTCOMES RECOMMENDATIONS

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 from the centre-left, centre-right and liberal groups. 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.

1. Adopt an integrated, outcomes-focused, and patient-centred approach to long-term care
2. Expand national monitoring of long-term care and outcomes
3. Fund studies to provide information on the long-term health of people living with HIV
4. Combat stigma and discrimination within health systems
5. Upscale involvement of the HIV community in priority setting at country level

Delivering impact at country level

Local groups have since been created in **Germany, Italy, Romania, Spain and Sweden** to determine which recommendations could make a significant impact in their local setting, to overcome any barriers to their adoption, and to advocate for the necessary policy and clinical changes.

Italy and Sweden have identified the need for an **interdisciplinary, cross-functional approach to HIV care**, and **combatting stigma within health systems** was reported as a problem in both countries. In Sweden, long-term education programmes to reduce stigma among non-HIV specialist healthcare professionals were recommended, while Italy highlighted the need to improve models of care by developing multi-disciplinary networks of specialist centres.

A Call to Action for European Policy Makers

Well-being and long-term health are increasingly recognised as **important drivers for an equitable and prosperous Europe**.

HIV Outcomes strongly believes that the promotion of well-being and the prevention of diseases and social exclusion are of major importance and that they are also key aspects in reducing future public expenditure, increasing productivity and extending working life.

HIV Outcomes is therefore calling for **political leadership** to ensure that the long-term health outcomes and quality of life of people living with HIV are high on the political agenda and that **Europe delivers on its commitment to tackle communicable diseases**.

The following concrete actions from policy makers are needed to deliver on this agenda:

- 1.** Call on the European Commission to adopt an **action plan to support EU Member States in reaching the Sustainable Development Goals (SDG)** relevant to HIV and common comorbidities, such as TB and hepatitis. Member States and the Commission should ensure a sufficient level of resources needed to achieve the target within SDG 3 – on health and well-being – of ending the AIDS epidemic by 2030³. This should entail:
 - Achieving the **UNAIDS global 90-90-90 goals**⁴ and moving beyond these to focus on ensuring people living with HIV have **good health-related quality of life** and that **stigma and discrimination are reduced to zero**.
 - Promoting a **multidisciplinary, people-centred and outcomes-focused approach to long-term HIV care** as people living with HIV require access to a range of health services beyond just HIV treatment, such as services for the prevention, treatment and management of comorbidities, mental health support and sexual health advice.
- 2.** Call on the European Commission to mandate the **European Centre for Disease Prevention and Control (ECDC)** and provide adequate resources to ensure that Member States are collecting data about health system responses to long-term health challenges faced by people living with HIV. Current monitoring efforts should be expanded to reflect the reality of HIV as a long-term condition. For the first time, the 2018 assessment of how countries meet the targets of the Dublin Declaration on HIV⁵ collected information on how countries monitor quality of life.
- 3.** Commission a **study from the Parliament's Research Services to understand the evolution of HIV as a long-term condition** and how to ensure healthcare system sustainability given the ageing population and increased comorbidities. This study would provide policy makers with an evidence base for decision-making, and could form the basis of a Motion for Resolution or other parliamentary act, highlighting the need for continued action to ensure good long-term health outcomes and quality of life for people living with HIV. The findings would also provide learnings for other chronic disease areas.
- 4.** Call for significant funds to be dedicated to making concrete progress in addressing the long-term health needs of people living with HIV at both the national and local level (see above). This should include **specific funding calls under the new Horizon Europe programme (2021-2027)** and projects under the **EU Health Programme** aimed at developing innovative and people-centred approaches to combatting HIV.
- 5.** **Cooperate with Members of national Parliaments to support the HIV Outcomes' agenda to address issues for people living with HIV at country level.** The exchange of best practice is needed among all countries to meet the 90-90-90 goals. This could entail, for example, meeting MPs from countries in which HIV Outcomes is active together with representatives of these local groups (which currently exist in Italy, Germany, Spain, Sweden and Romania) to gather experience and learnings to then be shared in a pan-European event in the European Parliament.
- 6.** **Hold regular meetings with civil society representatives to increase understanding of the issues at stake for people living with HIV.** This would also enable MEPs to draw on expert knowledge to propose EU level initiatives to ensure good long-term health outcomes and quality of life for people living with HIV.

¹<https://www.unaids.org/en/resources/fact-sheet> ²<http://www.euro.who.int/en/health-topics/communicable-diseases/hiv/aids> ³<https://www.un.org/sustainabledevelopment/health/> ⁴The UNAIDS 90-90-90 goals aim to end the AIDS epidemic by 2030: to diagnose 90% of all people with HIV; to provide ART to 90% of those diagnosed; to achieve viral suppression for 90% of those treated by 2020 (see <https://www.unaids.org/en/resources/909090>) ⁵The Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia was signed in February 2004 (see <http://www.euro.who.int/en/health-topics/communicable-diseases/hiv/aids/policy/guiding-policy-documents-and-frameworks-for-whoeuropes-work-on-hiv/dublin-declaration-on-partnership-to-fight-hiv-aids-in-europe-and-central-asia>)