

HIVOutcomes

BEYOND VIRAL SUPPRESSION



2024

ANNUAL REVIEW



HIV Outcomes began its journey in 2016 by bringing together patients, healthcare professionals, academics, public institutions and industry to align on a new policy and clinical agenda. Our shared goal is to address the crucial unmet needs of people living with HIV, to ensure that they can live longer in good health and fully participate in society.



ANNUAL REVIEW **2024**

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FOREWORDS



John Bowis
President

The year 2024 has been a pivotal moment of political renewal within the European Union and among key players in the global HIV response. As the Union's health agenda loses momentum, we must reflect together on the impact this shift has on people living with HIV, and on how our initiative can help ensure that their access to timely and respectful care remains a priority.

The 2024-2029 EU mandate is the last one able to prompt the decisive actions needed to reach UN Sustainable and Development Goals (SDGs) target 3.3 on ending the HIV/AIDS epidemic by 2030. In 2024, none of the UNAIDS 95-95-95 targets were met in the EU/EEA region and only 20% of all SDGs are on track globally. Now is the time to raise our voices and take the necessary action to tackle health challenges faced by people living with HIV.

By adopting a holistic and age-sensitive lens, the EU can set a global example in pioneering robust, integrated care for the first generation ever to age with HIV. Europe is facing

an important demographic transition, and investing in long-term care and active ageing is key to ensuring a healthy future for Europe. Indeed, almost 10 million people living with HIV globally are over 50, and about 40% of people living with HIV in high-income settings will be at least 60 years within the decade. They must not be left behind, and their health should always be considered beyond viral suppression and with a special understanding for the stigma and discrimination they continue to face today.

Both the EU and the WHO have emphasised that a people-centred approach is the only way to achieve SDG 3.3 and end the HIV/AIDS epidemic. These are not just words; they must continue to translate into tangible commitments and actions. I am therefore proud of the work carried by HIV Outcomes, including its contribution to keeping HIV on the EU health agenda and the release of its call to action for 2025-2030. It gives us direction and determination in furthering the impact of the initiative for all people living with HIV in Europe and beyond.

Mario Cascio & Caroline Sabin

HIV Outcomes Co-Chairs



Mario Cascio
HIV Outcomes
Co-Chair

Board Member of NPS Italia APS (Italian network of people living with HIV), Italy

HIV continues to be a public health threat because too many people living with or at risk of HIV are not accessing the services they need nor served with the respect and dignity they deserve. This is especially true today in a rapidly changing and challenging environment, where the voices of those most vulnerable are unheard

and their needs neglected. In a world in which we are losing the sense of solidarity, HIV Outcomes calls on European and global institutions to commit to ending the HIV epidemic by ensuring equitable access to HIV services and dignity, well-being and good health related quality of life (HRQoL) to all people living with HIV.



Caroline Sabin
HIV Outcomes
Co-Chair

Professor of Medical Statistics and Epidemiology, University College London (UCL), United Kingdom

It has been tremendously satisfying to witness the achievements of HIV Outcomes over the past year. But there is much more to be done. We will not end the HIV epidemic until we can ensure that everyone living with HIV, wherever they are, has access to the services

they need to live a long, happy and fulfilling life. To do this, we must continue to raise awareness of the importance of monitoring not only clinical and biological markers of health, but also HRQoL, with systems in place to support the changes needed to improve this.

“ ‘Our vision is a world in which people living with HIV enjoy the highest possible Health-Related Quality of Life’ ”

WHO WE ARE

HIV Outcomes is a pan-European multi-stakeholder initiative working to protect and improve the well-being and health-related quality of life (HRQoL) of every person living with HIV across Europe. As life expectancy has greatly increased for people living with HIV, it is imperative that we move beyond the prevailing focus on viral suppression to ensure that the HIV population not only lives long, but also healthily.

Our **mission** is to build political support and policy measures to deliver integrated person-centred healthcare and clinical changes. By raising awareness around the value of HRQoL for people living with HIV, we seek to have this indicator featured more prominently in HIV policy. We want to ensure that policymakers pay due attention and address issues that challenge the HRQoL of people living and ageing with HIV, including stigma, discrimination, and a higher risk of comorbidities.

HIV Outcomes is proud to partner with over 60 like-minded organisations and individuals active in the HIV space. Our Steering and General Members, Strategic Partners and Observer Members include patient organisations and representatives, healthcare professionals, academics, public institutions, and industry. At the national level, in 2024 we were present in Italy, Romania, and the UK.

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ABOUT THIS REPORT

This report is a testament to HIV Outcomes' ambition to make HRQoL an integral and essential part of the HIV response by focusing on well-being, long health and access to integrated care for people living with HIV.

It will reflect on the initiative's objectives and achievements in 2024, and outline the way ahead through our updated 5-year strategy and 2025 workplan. HIV Outcomes brings together a wide range of experts and organisations across academic, clinical and advocacy fields, whose collective efforts breach national and disciplinary boundaries.

Throughout 2024, HIV Outcomes worked towards fostering holistic commitment to achieving the SDG 3.3 on ending the HIV/AIDS epidemic by engaging with European and national leaders across the region.

We extend our warmest thanks and appreciation to the multiple contributors, partners and individuals who have made our work and achievements possible, and who continue to shape our collective future both within this initiative and beyond by helping to ensure a healthy and fulfilling life to all people living with HIV.

HEALTH-RELATED QUALITY OF LIFE

Viral suppression was once seen as the final stage within the HIV care continuum. While it remains a crucial target for HIV treatment, it is now recognised that living long-term with HIV presents numerous other challenges to health and well-being, which health systems must consider. Addressing the long-term well-being of people living with HIV has become of paramount importance, and HRQoL is central to achieving this goal.

HIV Outcomes views HRQoL as a more actionable and measurable sub-domain of quality of life (QoL). The concept of health expands beyond the absence of illness or infirmity to encompass physical, mental and social dimensions. HRQoL has been reported to be lower among people living with HIV than among those without HIV. Stigma, discrimination and comorbidities are important determinants of HRQoL and play an important role in addressing the long-term well-being of people living with HIV.

Nevertheless, challenges persist. The principle of HRQoL as a policy goal and measurement tool remains underdeveloped at both EU and national levels. The gap between policy engagement and practical implementation is evident, with only a limited number of European countries monitoring HRQoL, as outlined by the Dublin Declaration.¹

In the realm of change, HIV has a history of transformative impact in various disease areas and has sparked important health advocacy campaigns. Notably, the concept of well-being and HRQoL is gaining momentum at the European policy level, paralleled by positive efforts to break down silos between communicable and non-communicable diseases, promising encouraging change drivers.

HIV Outcomes is committed to addressing these challenges, working towards advancing and improving the HRQoL of those living with HIV.

OUR MEMBERS



John Bowis
PRESIDENT



Dr. Vytenis Andriukaitis
MEP CHAMPION



Tomislav Sokol
MEP CHAMPION



Prof. Caroline Sabin
CO-CHAIR



Mario Cascio
CO-CHAIR

STEERING GROUP



STRATEGIC PARTNERS



EACS European AIDS Clinical Society



Global Parliamentarians Network to End Infectious Diseases

NATIONAL INITIATIVES



Italy



United Kingdom



Romania

OBSERVER MEMBERS



FAST-TRACK CITIES



UNAIDS

HIV OUTCOMES

GENERAL MEMBERS 2024

WHO EUROPEAN REGION

We have **48 members**, among which **28 are individuals**. We also have **20 member organisations** who are active on the ground across the WHO European Region

PLWHA Albanian Association

DIA+LOGS

AFEW International

Grupo de Ativistas em Tratamentos (GAT Portugal)

East Europe & Central Asia Union of People Living With HIV (ECUO)

National Union of Organizations of People Affected by HIV/AIDS (UNOPA)

GAMIAN-Europe

Adhara Asociación VIH/SIDA (ADHARA)

AIDS Action Europe

National HIV Nurses Association (NHIVNA)

Correlation – European Harm Reduction Network (C-EHRN)

European Sex Workers' Rights Alliance (ESWA)

Supporting Women with HIV Information Network (SWIFT Network)

Trans United Europe

One Voice Network

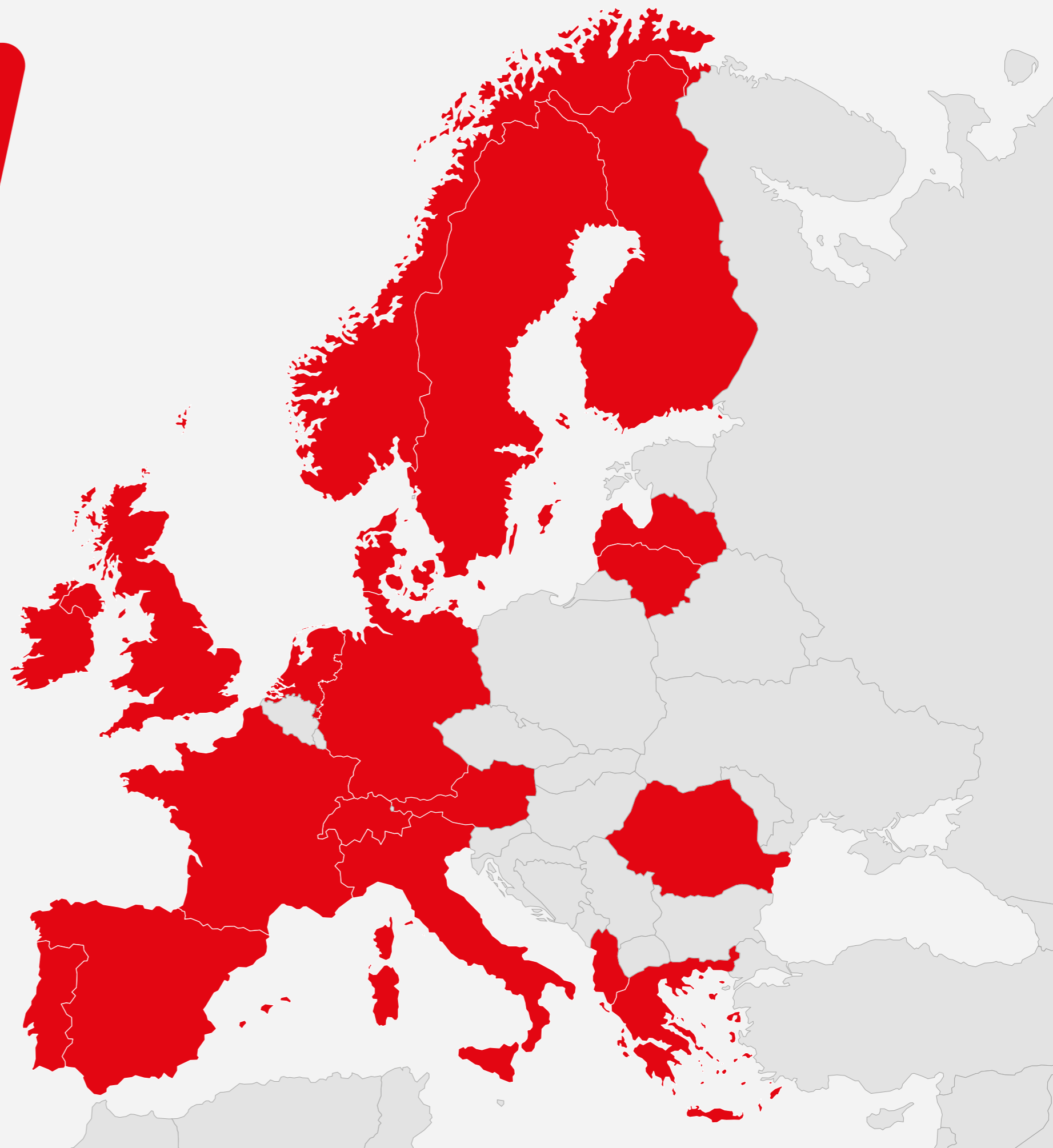
Eurasian Harm Reduction Association

Positively UK

Positiiviset ry, HivFinland

Terrence Higgins Trust (THT)

AIDES & Coalition PLUS



DEVELOP



A credible narrative to raise awareness about the need to ensure a good HRQoL and long-term health outcomes for people living with HIV across Europe.

IMPLEMENT



Evidence-based policy and clinical change at country-level across Europe.

ENGAGE

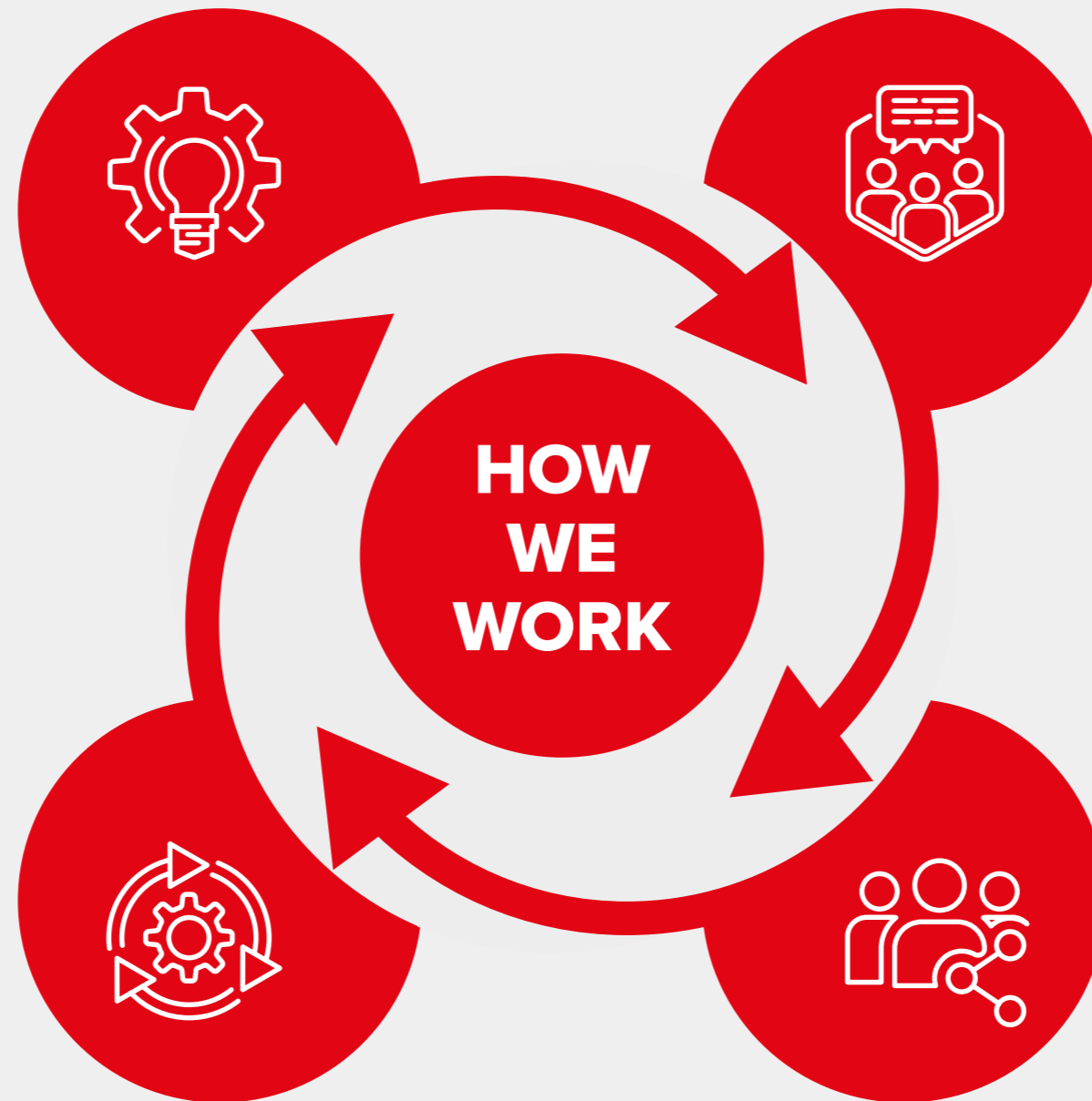


With policymakers and healthcare providers to make today's health and social inclusion issues central to the overall HIV response

SHARE



Evidence-based good practices and innovative approaches to long-term HIV care across Europe.



HIV OUTCOMES STRATEGY

In 2024, the year of the European elections, HIV Outcomes organised its actions around political shifts at both national and European levels. Namely, we worked to ensure that HIV remained on the political agenda amidst these transitions and sought synergies with the EU's new health and equality agendas.

In line with the SDG 3.3 target to end the HIV/AIDS epidemic, we continued our efforts to improve the HRQoL of all people living with HIV by advocating for integrated, person-centred care and the elimination of stigma in healthcare systems. Our efforts included pushing for HRQoL integration into European and national HIV policies, alongside clinical and public health targets.



2024 OBJECTIVES

To advance our 2024 objectives, we developed and disseminated a new HIV Outcomes Call to Action urging the EU to ‘recommit to ending the HIV/AIDS epidemic and to set up a new EU Action Plan on HIV/AIDS, ensuring a strong focus on the long-term health and well-being of people living with HIV. We also established collaborations with newly elected MEPs and strengthened strategic partnerships with key actors at both EU and national levels.

We continued to explore best practices for measuring and improving HRQoL for people living with HIV, focusing on promoting common domains for HRQoL assessment to be adopted across the WHO European region. At the national level, we remained committed to supporting in-country efforts, sharing success stories, and ensuring the ongoing success of these initiatives.



OUR KEY ACHIEVEMENTS

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HIV OUTCOMES ELECTIONS (NEW STEERING GROUP & CO-CHAIRS)

2024 has been a year of renewal and progress for HIV Outcomes, with important developments in our leadership and governance.

Following our internal elections, we welcomed new Co-Chairs and Steering Group members for a two-year mandate, bringing fresh energy and perspectives to the initiative. As the driving force behind HIV Outcomes, the Steering Group plays a crucial role in shaping strategy and direction. With a balanced representation of academics, clinicians, patient representatives, and industry it fosters collaboration and consensus to advance policies that enhance HRQoL for people living with HIV.

A key achievement this year was the expansion of the Steering Group, now ensuring full representation of in-

country initiatives. This significant step strengthens collaboration, ensuring that national priorities are aligned at the European level for greater impact.

This year also marked a transition as we bid farewell to Professor Jane Anderson, one of HIV Outcomes' founders. Her invaluable contributions and inspiring leadership have been instrumental in shaping the initiative and laying a strong foundation for its future progress. We are deeply grateful for her dedication, insights, and unwavering commitment over the past eight years—thank you, Jane!



As we move forward, we are excited about the new leadership's fresh perspectives and their role in driving meaningful progress. To learn more about our leadership and their vision, watch our video on our [YouTube channel](#). Check out a full list of our members on [our website](#).



EXPANSION OF THE GENERAL MEMBERSHIP

This year, we didn't stop at leadership renewal—we listened to our members and took a significant step toward enhancing both expertise and geographical representation. As a result, HIV Outcomes has expanded its General Membership to **48 members**, welcoming **18 new additions**.

Our diverse General Membership now includes patient representatives, clinicians, academics, public health experts, and support services from across Europe and beyond. This expansion strengthens our ability to foster collaboration, integrate a wider

range of perspectives, and drive meaningful change in HRQoL policies for people living with HIV.

With a balance of individuals and organisations, our members bring critical insights from national and European levels, ensuring a comprehensive, inclusive, and representative approach to improving long-term outcomes for all.

This achievement reflects our ongoing commitment to broadening our impact—together, we are shaping the future of HIV care.

HIV OUTCOMES CALL TO ACTION

In 2024, Europe’s commitment to meeting the SDG targets gained fresh momentum, with several European countries endorsing calls to action to end the AIDS epidemic at the WHO, G7 and Council of the European Union.

With the election of new European institutions in 2024, the path to meeting the 2030 target for ending the AIDS epidemic requires renewed leadership. A crucial step forward is the adoption

of a new EU Action Plan on HIV/AIDS, designed to support national efforts in enhancing the long-term health and well-being of people living with HIV.

In July 2024, on the back of recommendations from Romania, Poland and as well as a letter by 30 MEPs to the Commission to propose a new HIV/AIDS action plan, HIV Outcomes published a Call to Action with three central aims:



Reaffirming the EU’s political commitment to ending the HIV/AIDS epidemic by 2030



Improving rapid access to HIV prevention and treatment options



Enhancing efforts to strengthen the long-term health and well-being of people living with HIV

As the core mission of HIV Outcomes focuses on the third of these aims, our priority proposals for a new EU Action Plan focuses principally on that aim.



Enhancing HIV initiatives and best-practice sharing within the Public Health Expert Group (PHEG)



Funding pilot studies on long-term care for people living with HIV



Improving EU-wide data collection, including on HRQoL



Combating stigma & discrimination affecting people living with HIV



Funding programmes that support person-reported outcome measurements (PROMs)



Engaging civil society and community organisations



The Call to Action was widely disseminated on our website and social media channels, presented to the HIV community at a number of key conferences, and formed the basis of our ongoing advocacy with the EU institutions. To further amplify our message, we have also developed a [video](#) showcasing the Call to Action, ensuring broader engagement and awareness.

Letters to President von der Leyen and the former EU Health Commissioner **URGING CONTINUED COMMITMENT TO ENDING HIV/AIDS AND A RENEWED EU ACTION PLAN ON HIV/AIDS.**

G7 reaffirms its commitment to ending the HIV, tuberculosis and malaria epidemics.

Throughout the year, HIV Outcomes issued several communications to the European Commission, urging continued commitment to ending the epidemic and a renewed EU Action Plan on HIV/AIDS.

After the European elections in June, the HIV Outcomes Steering Group sent a letter to Commission President von der Leyen, congratulating her on her second mandate, and to outgoing EU Health Commissioner Stella Kyriakides, calling for the prioritisation of HIV in the new EU mandate. In October, a second letter was sent urging the Commission to bring HIV forward as one of the key themes of the G7 Health Summit.

Both letters were answered by the Commission, which reasserted its dedication to addressing HIV across its different policy, research and funding bodies.

Following the G7 Health Ministers' meeting, the G7's commitment to ending HIV, tuberculosis, and malaria as public health threats by 2030 was reaffirmed in a **communication**. The European Commissioner for Health, alongside health ministers from observing countries, also reiterated this

commitment, emphasising the need to focus on vulnerable populations and secure adequate financial resources to achieve this global goal. This collective recommitment highlights the importance of collaborative efforts and sustained funding to end the HIV/AIDS epidemic by 2030.



To:
Ms. Ursula von der Leyen
President of the European Commission
Rue de la Loi 200
1049 Brussels

Copy to:
Ms. Stella Kyriakides
Commissioner for Health and Food Safety

Ms. Ilze Juhansone
Secretary-General of the European Commission

Brussels, 15 April 2024

Call to Prioritise ending the HIV epidemic in Europe on the next Commission's public health Agenda, 6 years away from the 2030 UNAIDS goals deadline

Dear Madam President,

As Members of the European Parliament, our dedication to advancing public health is unwavering, with a vision to secure a healthy existence for every citizen across the European Union. The COVID-19 pandemic has underscored the critical need not only to combat emergent health threats but also to persistently address enduring ones. HIV/AIDS is a prime example, affecting approximately 780,000 individuals within the EU/EEA and continuing to pose a significant global health challenge.

With the 2030 deadline looming—a mere six years away—we are compelled to urge the Commission to steadfastly maintain its commitment to eradicating the HIV/AIDS epidemic, aligning with the United Nations Sustainable Development Goals, specifically target 3.3.

Recent findings from the European Centre for Disease Control (ECDC) indicate partial progress toward the UNAIDS 95-95-95 targets within the EU/EEA. However, the achievement of these targets is uneven, with only two countries meeting the criterion for diagnosis, and a substantial fraction of one in four HIV-positive individuals not achieving viral suppression. Moreover, preventive measures - such as pre-exposure prophylaxis (PrEP), use of condoms and treatment as prevention (TasP) - are not being adequately scaled, and stigma continues to undermine HIV prevention, testing, and treatment efforts.

NEW CHAMPIONS

After the European Parliament elections in June, HIV Outcomes strengthened its collaboration efforts with the new policymakers, bolstered by the arrival of two Members of the European Parliament as champions of the initiative. Both were instrumental in hosting an MEP Breakfast Discussion in Strasbourg in December and will continue to push for the prioritisation of HIV on the agenda of the new, fully-fledged public health (SANT) committee in 2025.

Dr. Vytenis Andriukaitis is the WHO Special Envoy for the European Region. He practiced as a cardiac surgeon for 20 years and was a member (and Deputy Speaker) of the Lithuanian Parliament for six terms. Dr. Andriukaitis was Minister for Health in Lithuania for two years and then became European Commissioner for Health and Food Safety in 2014 until 2019. He is a former HIV Outcomes Ambassador, now continuing leadership on the HIV cause from the European Parliament.

Tomislav Sokol became a HIV Outcomes MEP Champion in 2024. He is a health law expert, lecturer and former Deputy Minister of Science and Education in Croatia, where he also served as a Member of Parliament. Mr Sokol was elected to the European Parliament in 2019, where he became a leading voice for cross-border European healthcare policies and led negotiations on the European Health Data Space.



Dr. Vytenis Andriukaitis
PROGRESSIVE ALLIANCE OF
SOCIALISTS & DEMOCRATS, LITHUANIA



Tomislav Sokol
EUROPEAN PEOPLE'S
PARTY, CROATIA

LETTER TO THE EUROPEAN COMMISSION ENDORSED BY 30 MEPS

In May, with the support of HIV Outcomes, a letter urging the European Commission to prioritise ending the HIV epidemic in Europe by 2030 was signed by the former Vice-President of the European Parliament, Frédérique Ries, and 30 other cross-party MEPs. The letter, addressed to Commission President Ursula von der Leyen, also urged the President to develop a new Action Plan on HIV with clear goals, targets and timelines, and to address persistent stigma and discrimination including by joining the Global Partnership for Action to Eliminate all Forms of HIV-related Stigma and Discrimination.



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We commend the Commission for its proactive strategies to combat the HIV epidemic, including the implementation of action plans spanning from 2009 to 2016, integrating HIV/AIDS into cancer prevention under the EU Beating Cancer Plan, funding projects for early diagnosis and treatment access, and establishing an Expert Group on Public Health in 2022 to address communicable diseases like HIV.

However, we believe the 2024-2029 mandate represents a critical juncture. This period is possibly our final opportunity to honour our commitment to end the HIV epidemic in Europe by 2030.

Accordingly, we call upon the Commission to consider the following policy requests:

1) Prioritise HIV in the Upcoming European Commission Mandate

To achieve the 2030 goal, HIV must remain a paramount concern for the next European Commission. We advocate for the creation of a dedicated HIV/AIDS working group within the Expert Group on Public Health to facilitate the exchange of best practices in HIV care among Member States, including efforts to improve the health-related quality of life of people living with HIV.

Additionally, we suggest incorporating specific HIV prevention, testing, and treatment targets into the Commission's strategic public health objectives.

Prioritising HIV at the institutional level will ensure sustained attention and action towards achieving the 2030 goal of ending the HIV/AIDS epidemic.

2) Develop a new action plan on HIV

We urge the Commission to devise a comprehensive, ambitious HIV action plan for the 2024-2029 term, leveraging the insights and successes of previous initiatives. This plan should emphasise combination prevention programs, enhance HIV screening, testing and treatment linkages, and confront HIV-related stigma and discrimination. A clear set of objectives, targets, and timelines will guide Member States and complement national efforts toward the 2030 target.

Clear goals, targets, and timelines, should provide a roadmap for Member States to work towards achieving the 2030 target and complement national efforts with EU direct actions.

INFOGRAPHIC TO SUPPORT THE EUROPEAN PARLIAMENT'S STUDY ON HRQOL

Following the development and presentation of the European Centre for Disease Prevention and Control (ECDC) study on HRQoL for people living with HIV, commissioned by the European Parliament in 2022, HIV Outcomes has created an infographic to effectively capture the key findings from the study.

Titled "Navigating HIV," this infographic provides a visual representation of the study's insights, highlighting the progress and ongoing challenges in improving the HRQoL of people living with HIV in the WHO European Region.

It emphasises the complexities of managing HIV as a chronic condition, including the need for long-term care and the impacts of co-morbidities, stigma, and discrimination.

This infographic aims to build on the evidence commissioned by the Parliament, serving as a valuable resource to support discussions about the identified gaps and challenges related to HRQoL, ultimately driving action to improve the lives of people living with HIV. The infographic is available on our website [here](#).



Insights from study demonstrate that only **13 countries in the WHO Europe Region assess HRQoL as part of national monitoring** of people of living with HIV. Few of these countries collect data on stigma and discrimination faced by people living with HIV, and even fewer compare the QoL of people living with HIV and the general population, highlighting a gap in understanding of the broader impact of HIV on overall wellbeing.

MEP BREAKFAST DISCUSSION IN STRASBOURG



On 17 December, in collaboration with our **MEP Champions Vytenis Andriukaitis (S&D, Lithuania)** and **Tomislav Sokol (EPP, Croatia)**, as well as the European AIDS Clinicians Society (EACS) and UNITE Parliamentarians Network for Global Health, a breakfast discussion was held at the European Parliament in Strasbourg. The discussion followed the European Parliament elections in May, drawing from HIV Outcomes' Call to Action for an EU Action Plan for HIV/AIDS, and galvanising political momentum in the European Parliament to meet SDG 3.3 by 2030.

MEP Vytenis Andriukaitis welcomed HIV Outcomes' Call to Action on achieving SDG 3.3 but stressed that

the EU is in its final countdown to meet these targets by 2030. Alongside **MEPs Krzysztof Śmiszek (S&D, Poland)**, he called for HIV policies to be matched by funding to address gaps in HIV care and for the EU to replenish collaborative funding initiatives between EU member states.

The discussion touched heavily on improving the HRQoL of people living with HIV. **MEP András Kulja (EPP, Hungary)** echoed calls from EACS representatives **Miłosz Parczewski** and **Christoph Boesecke** for more standardised HIV care across Europe, highlighting the prevalence of comorbidities amongst people living with HIV.



Marc Angel (S&D, Luxembourg) and **Tilly Metz (Greens/EFA, Luxembourg)** stressed the importance of tackling discrimination and stigma, which continue to hinder treatment and quality of life for 1/3 of Europeans living with HIV, and devised several strategies to

combat discrimination, such as training for healthcare professionals, the revision of national laws, and awareness campaigns like “Undetectable = Untransmittable (U=U)” to improve understanding of HIV and thereby reduce stigma and discrimination.

Key outcomes



MEPs from 3 political groups threw their weight behind our call for an EU Action Plan on HIV/AIDS and promised to take forward this work in their parliamentary terms.



The event received strong engagement on [LinkedIn](#) and [X](#), with MEPs at the event enthusiastically snapping pictures with posters and picture frames with our key messages.



The breakfast discussion was picked up on in major media platform DODS.

HIV OUTCOMES LISTED AS AN EXTERNAL REVIEWER OF THE SPANISH EU PRESIDENCY REPORT

Entering 2024 marked the conclusion of the Spanish EU Presidency, which had prioritised HIV throughout the second half of 2023. As a key outcome of this focus, the Spanish Presidency published a policy brief titled “HIV-related Stigma and Discrimination: The Challenge.” HIV Outcomes was credited as an external reviewer of the report, having worked closely with the Spanish Ministry of Health during the Presidency.

In addition to the policy brief, an [article](#) was also published in the Spanish Journal of Public Health, further advancing the dialogue on HIV-related stigma and discrimination.

“Addressing HIV stigma and discrimination,” the report posits, “will not only benefit people with HIV, though that is reason enough, and the main reason, to act.” It is “neither a luxury or a distraction, but integral to all the SDGs.”

HIV INCLUDED IN THE EU HEALTH MINISTERS’ MEETING IN THE COUNCIL OF THE EU

Romanian Minister of Health called on the Polish delegation to prioritise HIV on the agenda during its Presidency

In June, EU countries took a significant step by urging the European Commission to prioritise ending the HIV epidemic in Europe and putting HIV in the political agenda.

At a meeting of EU health ministers in the Council, the Romanian, Polish and Spanish delegations tabled a call for action at the EU and national level to prioritise efforts and investment towards ending HIV epidemic in Europe until 2030.

EU health ministers discussed how to implement political actions over the next six crucial years as the 2030 SDG elimination deadline approaches. Additionally, they urged the European Commission to include HIV in its public health priorities and define a concrete action plan to support Member States in ending the HIV epidemic in Europe.

The initiative, particularly led by Romania, was the result of months of sustained and productive collaboration between the Romanian Health Ministry and HIV Outcomes Romania, with support from the European initiative. Looking ahead to the upcoming EU Presidency, the Romanian delegation also called for the Polish EU Presidency (taking place from January to July 2025) to prioritise HIV-related policies.

This effort marked a hugely important step forward in getting to an EU-wide approach to ending the HIV/AIDS epidemic and setting joint actions, funding and strategies to achieve this milestone.



HIV OUTCOMES ON THE GROUND

In 2024, HIV Outcomes reinforced its presence on the ground by participating in key conferences across Europe, sharing our message on HRQoL for people living with HIV and strengthening connections with experts and the community.

At AIDS 2024, we officially launched our Call to Action during a multi-stakeholder roundtable in the Silver Zone. The session, “Fostering Change in Policy and Clinical Practice in Europe,” featured contributions from several Steering Group members, Prof. Jane Anderson (HIV Outcomes’ former Co-Chair and founder), and UK Member of Parliament David Mundell.

Reflecting on our Call to Action, speakers explored strategies to advance policy and clinical practice across Europe, urging EU policymakers to prioritise HRQoL and recommit to ending the HIV epidemic in line with SDG target 3.3 by 2030.

Key takeaways:



Keeping HIV as a priority on the political agenda, competing effectively with other health issues and policy priorities.



Strengthening community involvement for effective HIV management and achieving tangible outcomes.



Tackling stigma and discrimination against people living with HIV, as it significantly affects mental health and service accessibility.



Ensuring sustainable funding and partnerships between governments and HIV communities to address structural issues and improve service delivery.



Investing in integrated healthcare services to address comorbidities and improve long-term outcomes.



Tailoring approaches to diverse community needs, with a focus on addressing data gaps, especially for women.

HIV OUTCOMES ON THE GROUND: AIDS 2024



As a final message, sustainable, multidisciplinary solutions are needed to replicate successes across the region, ensuring incremental gains are achieved everywhere and over time.

AIDS 2024 provided a valuable opportunity to exchange perspectives with the community, build connections with key stakeholders, and reaffirm our commitment to improving the long-term care and well-being of people living with HIV.

HIV OUTCOMES ON THE GROUND: HIV GLASGOW

HIV Outcomes had a strong presence at the HIV Glasgow Conference, hosting a booth that sparked insightful discussions and showcased some of our advocacy materials. It was a great opportunity to connect with many of our members who stopped by, as well as to meet new experts in the field and introduce them to the work of HIV Outcomes.

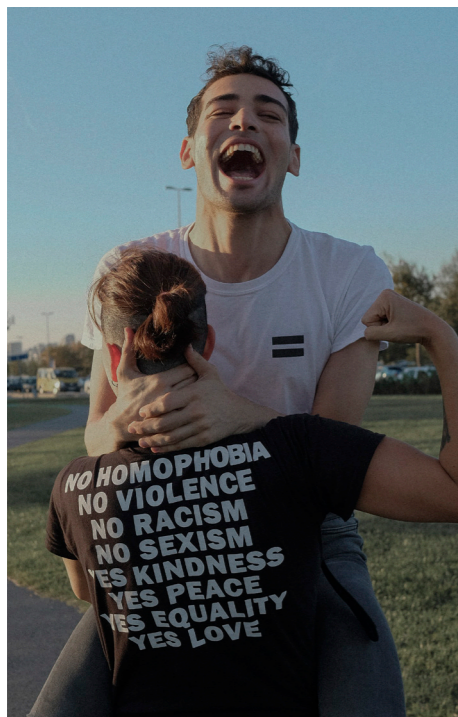
As a key milestone, we held a strategic meeting with representatives from the EACS, the European AIDS Treatment Group (EATG), and the ECDC to explore collaboration opportunities for monitoring HRQoL and the use of patient-reported outcome measures (PROMs) in 2025.



HRQoL SUBGROUP

In 2024, the HRQoL Subgroup continued to build upon the foundational work established in 2023, furthering our objective to improve the understanding of HRQoL measurement of people living with HIV. Chaired by Dr Diana Barger, the Subgroup has effectively harnessed the expertise of both General Members and Steering members to identify and categorise the key domains and subdomains of available HRQoL assessment tools in alignment with the WHO definition of health, encompassing physical, mental, and social well-being.

This year, the Subgroup concentrated on consolidating evidence and refining our research to maximise impact. We engaged in constructive discussions to redefine the categorisation of domains and subdomains essential for HRQoL measurement. Our efforts gained traction through productive meetings with EATG and EACS, both of which are advancing work in the patient-reported outcome measures (PROMs) space, along with the ECDC, which is leading HIV surveillance at the European level. The recognition of our report among these stakeholders underscored the relevance of our work and helped foster a consensus on the need for agreement on what to measure, despite there being no one-size-fits-all tool.



Looking ahead, we are excited to collaborate with key partners such as EACS, EATG, and ECDC to identify synergies in monitoring HRQoL and the use of PROMs. The insights from the HRQoL Subgroup will be instrumental in developing advocacy materials that highlight the importance of HRQoL monitoring among policymakers and the community.

GOOD PRACTICES COLLECTION

Over the past years, HIV Outcomes has been gathering good practices from our members across the WHO European Region, focusing on initiatives that improve the HRQoL and well-being of people living with HIV. This effort led to our [Virtual Good Practice Clinic](#), a compendium of good practices that remains a vital platform for this exchange, first introduced at the European Parliament in 2018.

We believe that sharing best practices has the power to inspire and equip stakeholders to tackle HIV-related challenges in the long term and beyond viral suppression. Following our yearly call for good practices, we are excited that in 2024 we added three, and updated another, good practice to the HIV Outcomes Good Practice Compendium.

3 new good practices:



Unified U=U Education by the Baylor Foundation (Romania): A programme designed to provide consistent, evidence-based counselling sessions for all patients enrolled in care. This initiative enhances patient understanding of the U=U principle while addressing stigma and discrimination.



Chiva's Resources for Schools (UK): A campaign aimed at equipping teachers and schools with accurate information about HIV, ensuring they can educate pupils effectively. It also seeks to foster an inclusive environment where children living with or affected by HIV are treated equally, should they choose to share their status.



Positive Voices Survey (UK): A national survey that gathers population-level data from people living with HIV. The insights help identify key issues affecting their health and wellbeing, supporting the improvement of existing HIV services and policies while informing the development of new services.

HIV Outcomes
BEYOND VIRAL SUPPRESSION



NATIONAL LEVEL WORK



UK



EVIDENCE GENERATION

- o The report '[Beyond the Virus: Prioritising the Mental Health of People Living with HIV in Scotland](#)', providing a framework for integrated HIV and mental health care, was published in November.
- o The report [Living well with HIV in Wales](#) was published together with Fast Track Cymru. It assesses progress and recommends action for the delivery of the Welsh HIV Action Plan.
- o Research on the UK HIV voluntary sector, gathering insights to strengthen support for people living with HIV, has been launched.



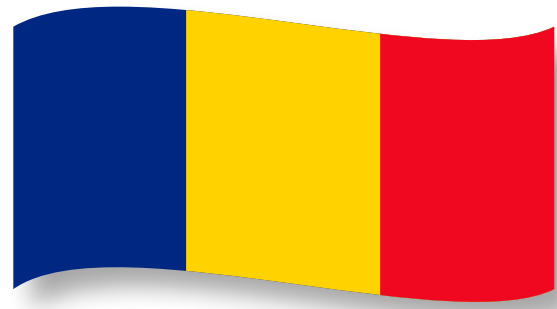
ADVOCACY

- o HIV Outcomes UK engaged parliamentarians and ministers to build support for improving HRQoL for people with HIV.
- o A UK parliamentary event on HIV inequalities was organised with senior government, parliamentarian and UNAIDS speakers, securing support for a stronger HRQoL focus in the next UK Government HIV Action Plan.
- o The initiative hosted the launch event for the [Beyond the Virus report](#) with the Scottish Health Minister and parliamentarians, gaining media coverage and a parliamentary motion urging implementation of recommendations.



MULTIPLIERS

- o HIV Outcomes UK presented at major conferences, including AIDS 2024 and BHIVA, engaging key stakeholders to share our work and build support for our recommendations.
- o The initiative actively participated in conferences and political events, building relationships with decision-makers and advocating for actions to improve the HRQoL of people living with HIV.
- o Several community engagement workshops were organised and hosted, gathering lived-experience insights to inform research and ensure that policies reflect the needs of people living with HIV.



Romania



EVIDENCE GENERATION

- o HIV Outcomes Romania gathered national best practices which were included in the Compendium of Good Practices to combat HIV stigma and discrimination.
- o The Romanian Secretariat continued to monitor the implementation of the National HIV Strategy. Based on the initiative's national study on the QoL of 1,050 people living with HIV, the Steering Group developed and shared tailored evidence with national healthcare and social rights authorities to support the strategy's successful implementation and achieve its 2030 goals.



ADVOCACY

- o HIV Outcomes Romania, in collaboration with the European initiative, launched a joint outreach effort ahead of the EPSCO Health Ministers' meeting, working closely with the Romanian Health Minister to include HIV on the meeting agenda. This resulted in a Call to Action, supported by Poland and Spain, to reaffirm the EU and member states' commitment ending the HIV epidemic by 2030.
- o The initiative launched several joint advocacy actions with HIV community representatives and national key opinion leaders, including 4 Calls to Action on eliminating HIV related stigma, comorbidities treatment and U=U, aiming to improve HRQoL/QoL for people living with HIV by enhancing medical approaches and reshaping policies.



MULTIPLIERS

- o HIV Outcomes Romania partnered with the HIV community and key opinion leaders in several inter/national policy events, showcasing medical practices and policy recommendations on HRQoL.
- o In collaboration with the National Institute for Communicable Diseases, the initiative contributed to a high-level event at the Romanian Parliament to promote its Policy Asks for reaching out the UNAIDS goals. MEP Vytenis Andriukaitis recorded a keynote speech supporting HIV Outcomes Romania's mission.
- o HIV Outcomes Romania's QoL study results were shared at 8 international and national events by the Romanian co-chairs.



Italy



EVIDENCE GENERATION

- o Following the work conducted in 2023, a survey was developed to assess the presence of services for older people with HIV. These results informed the creation of the orientation document [Aging in HIV from a gender perspective](#), which was also translated in English for further dissemination.
- o The survey *Knowledge of HIV Stigma in Hospital Settings* was developed and conducted throughout the year, and will be displayed in a publication in 2025.



ADVOCACY

- o Awareness on HIV was raised at the Italian Parliament through the promotion of a parliamentary question on HIV and aging. HIV Outcomes Italy also engaged with healthcare managers of Italian Federation of Health and Hospital Companies (FIASO) on the topic.
- o 2024 advocacy efforts culminated in a high-level HIV Think Tank event and a press conference held at the Chamber of Deputies.
- o HIV Outcomes Italy participated in fostering institutional dialogue and awareness of HIV, which contributed to securing a €5 million annual fund of the national health budget for HIV, Human papillomavirus (HPV), and sexually-transmitted infections (STI) prevention from 2026.



MULTIPLIERS

- o In October, a meeting was organised on HIV/AIDS related themes in Milan, to disseminate HIV Outcomes initiatives to national stakeholders.
- o In April, HIV Outcomes Italy organised a webinar for 30 General and Health Directorates belonging to FIASO to address the strong training needs of hospital healthcare workers. The recording of the meeting was then posted on the FIASO website and made available to all its members.
- o An HIV Outcomes brochure was disseminated at key events in Italy and internationally, including at the Italian Society of Infectious Diseases and [ICAR Conferences](#).

2024 SOCIAL MEDIA IMPACT

In 2024, HIV Outcomes continued to grow its online presence, using LinkedIn and X (formerly Twitter) as well as our quarterly newsletter and content dissemination through EU-based platforms and media outlets.

HIV Outcomes produced quarterly newsletters to communicate relevant policy updates, events and achievements from across our European and national initiatives. The newsletters were shared with an audience of approximately 500 people, including EU policymakers.



LinkedIn



Total Impressions:
33,925



New Followers:
197



Profile Visits:
589



Number of posts:
55



Reactions:
1,310

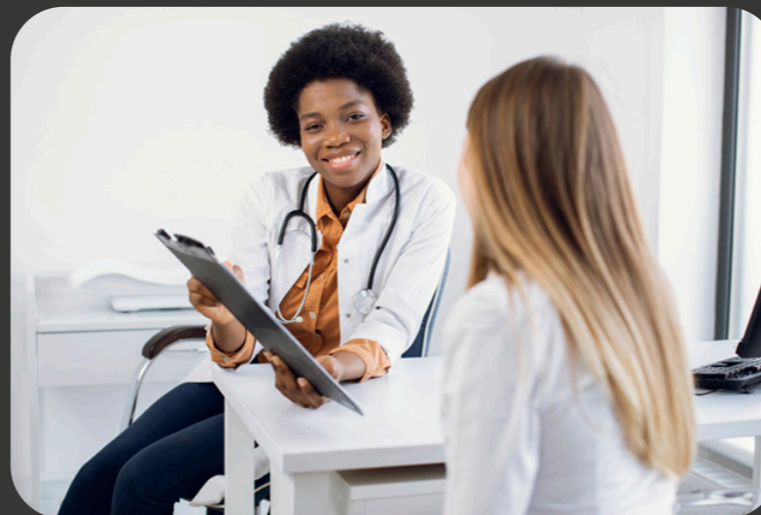
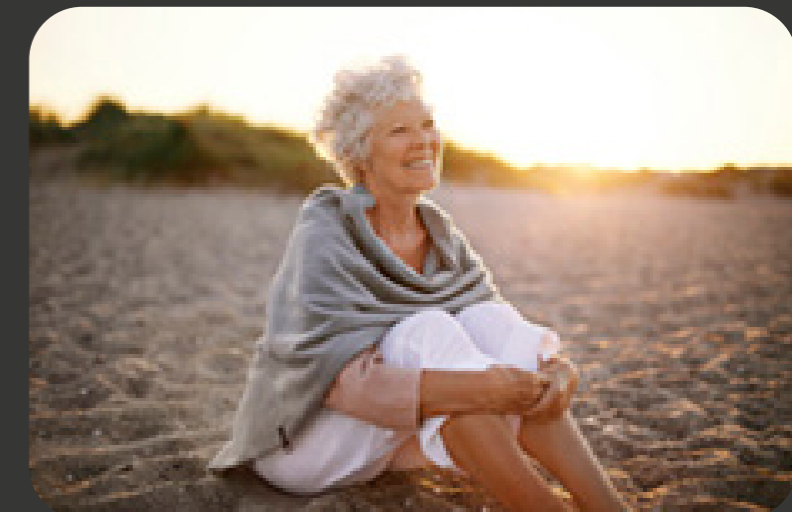


OUR VISION FOR 2029

With only 5 more years before the 2030 milestone, HIV Outcomes has developed a 5-year strategy running from 2025 to 2029 thus aligning with the timeline of the new EU mandate. The strategy maps the key directions for the initiative to take in order to ensure the long-term health and well-being of people living with HIV through continued political commitment to deliver person-centred health policies and improve quality of life for all.

Over the next 5 years, HIV Outcomes aims to grow momentum at EU level and beyond to reaffirm commitment to SDG 3.3, targeting the end of the HIV/AIDS epidemic. This will include calling for the creation of a new EU Action Plan on HIV/AIDS and contributing to the upcoming UNAIDS Global AIDS Strategy to ensure a better focus long-term health and wellbeing. Efforts will also be made to advocate close to policymakers, clinicians, public health institutions, and the HIV community recognise the importance of HRQoL domains for people living with HIV, and to prioritise measurement and monitoring of these outcomes.

We will continue to foster HIV Outcomes' multi-level actions, as the initiative spans advocacy efforts at both national and European levels. At the national level, we will drive the adoption of policies promoting person-centred and integrated care, showcasing best practice examples beyond their borders. Additionally, we will ensure that the EU continues its commitment to combating HIV/AIDS across the WHO Europe Region, including in the context of EU enlargement, to ensure vulnerable and underserved populations are not left behind.





5 YEAR PLAN [2024-2029]

2025 is set to be an important year, with the new EU political leadership fully in place and growing political momentum on HIV. Building on the milestones of 2024 and the upcoming UNAIDS Global AIDS Strategy, new opportunities are on the horizon. Despite a challenging political environment with competing priorities, HIV Outcomes will continue to push for the prioritisation of HIV and advocate for its place at the forefront of the EU agenda.

We will continue our steadfast work to improve the long-term health and well-being of all people living with HIV. This is the final push toward ending the HIV epidemic, and complacency is not an option—no one can be left behind.

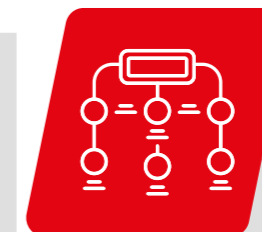
IN 2025 OUR PRIORITIES WILL CONCENTRATE ON:

- 1 Comorbidity prevention, treatment and management
- 2 Mental health
- 3 Supporting healthy ageing
- 4 Measurement of patient-reported outcomes (PROMs) and monitoring of HRQoL
- 5 Addressing inequalities in outcomes
- 6 Supporting and incorporating the U=U message into EU and national policies to address stigma and discrimination

2025 Objectives



Keep HIV high on the political agenda by sustaining political focus on HIV and integrating pandemic lessons into HIV and wider health policies at EU level.



Support the development of HRQoL framework by producing work on PROMs for clinical and surveillance purposes together with HIV Outcomes national initiatives, EATG PROMise, EACS and ECDC.



Advocate for HIV funding at EU level in programs including Horizon Europe and EU4Health.



Strengthen HIV Outcomes membership, strategic partners/ networks and national initiatives.

2024

ANNUAL REVIEW

IN CONCLUSION

Amidst the political shifts of 2024, HIV Outcomes has been able to maintain and strengthen its presence at EU and national levels by engaging with newly appointed EU officials and other global leaders. The support we have gathered includes the endorsement of 30 cross-party MEPs who signed our call to the European Commission to recommit to SDG 3.3 during its new mandate and an official statement of G7 ministers of health putting HIV on their common health agenda. The successes of the year were well illustrated in HIV Outcome's December event, a breakfast discussion at the European Parliament organised with the participation of 5 MEPs who committed to champion the long-term health of people living with HIV. Throughout the year, our actions have been amplified to reach a greater audience through our strategic use of social media and other external communications.

Entering 2025, HIV Outcomes continues to gather momentum around HIV and to advocate for a holistic understanding of SDG 3.3 in which HRQoL must be a guiding principle for actions to end the HIV/AIDS epidemic.

USEFUL LINKS



Call to Action



Policy Asks



Report 'The impact of COVID-19 on HIV in Europe'



Advocacy Toolbox



Mapping on the use of HRQoL in Health Policy & Practice



Website



X



LinkedIn



Contact