

HIV Outcomes

BEYOND VIRAL SUPPRESSION



2023

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 participate fully in society.



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FOREWORDS



John Bowis
President

As a new year begins, it offers us an opportunity to reflect upon the progress made, the multiple challenges faced in the ongoing battle against HIV/AIDS in the European Region, and how to do better. As we look back on our achievements throughout the year, this Annual Review should also serve as a roadmap for the path that lies ahead.

As 2023 came to an end, there was increased pressure to keep up with the UNAIDS call for countries to end AIDS as a public health threat by 2030. Only 8% of countries in the WHO European Region (53% of all EU/EEA countries) have met or exceeded the UNAIDS Fast Track targets, showing the need for a more united front in co-creating policies, practices and actions to fight HIV.

From the beginning of the HIV epidemic, we have witnessed a pernicious dimension to the impact of this virus:

stigma and discrimination. This year saw the launch of mental health policies acknowledging that people living with HIV are more vulnerable to, and experience higher levels of, stigma and discrimination. Research has found that people with HIV are twice as likely as the general population to experience feelings of depression or anxiety. Recognition of this in mental health policies is a step forward and presents opportunities for progress.

As we celebrate the accomplishments of last year, including HIV Outcomes' contributions to mental health policies, we must also acknowledge that there is still much to be done. We hope that this Annual Review can be an incentive to keep working and amplifying our impact.



Ambassador Dr Vytenis Andriukaitis
WHO Special Envoy for the European Region & former EU Health Commissioner

The year 2023 has undoubtedly been a year of reflection, adaptation, and resilience. As the global landscape was still affected by the COVID-19 pandemic, the commitment of the HIV Outcomes community to advancing the fight against HIV/AIDS was unwavering.

The journey within these pages represents the critical importance of a multistakeholder approach. HIV Outcomes exemplifies this ethos, and this collaborative spirit is not merely symbolic: it is the foundation upon which progress in policy and practice is built.

The HIV/AIDS landscape is evolving, and so must our response. With fewer lives being claimed by AIDS and more individuals learning to live with the virus, the imperative to provide comprehensive care becomes increasingly apparent.

This demands a comprehensive approach to healthcare that accounts for the needs of an ageing population with HIV.

The upcoming European elections will be crucial to build on the work we have done to advance the rights and health-related quality of life (HRQoL) of people living with HIV. This will present challenges but also opportunities in various policy areas, such as person-centred HIV care, ageing with HIV, and stigma and discrimination. **Together, we can, we will and we must make a difference in the lives of those affected by HIV/AIDS.**

BEYOND VIRAL SUPPRESSION

Advancing the Health-Related Quality of Life of people living with HIV



Prof Jane Anderson

HIV Outcomes Co-Chair and Consultant Physician at Homerton Healthcare NHS Foundation Trust, UK



Nikos Dedes

HIV Outcomes Co-Chair and Positive Voice President, Greece



Prof Jeffrey Lazarus

HIV Outcomes Co-Chair and Associate Research Professor at the Barcelona Institute for Global Health (ISGlobal), Spain

This report is testament to HIV Outcomes ambition to go beyond viral suppression and through the promotion of best practice, enhance the Health related quality of life (HRQoL) of people living with HIV.

This review sets out our work during 2023 and the topics that will be our continuing focus in 2024. HIV Outcomes realises its ambition through collective action across organisational, disciplinary and national boundaries, We work to reach consensus on the complex issues that impact HIV related HRQoL, bringing together experiential, clinical and academic expertise.

During 2023 HIV Outcomes' worked at a pan European and at national

"HIV Outcomes champions a world in which people living with HIV can live their best lives. The Initiative brings together the knowledge, skills, and advocacy of people with lived experience, clinicians, academics, and industry representatives, collaborating across nations and disciplines, to make the difference we need to see."

– Jane Anderson

"HIV Outcomes must be proud of 2023's achievements, a year that showcased once again how this initiative works with the crucial support and involvement of people with HIV. "Nothing about us without us" – and so it was, with this initiative bringing lived-experience to the core of its goals and actions."

– Nikos Dedes

"Following up on the work carried out by the European institutions, we must keep working towards active collaboration between HIV health experts and public health policy-makers when it comes to HIV-related initiatives. Research and policy must walk in the same direction with a common goal: people-centred care and the improvement of the health-related quality of life of people living with HIV."

– Jeffrey V. Lazarus

levels, disseminating best practices and advocating for comprehensive HIV responses to remain high on the political agenda.

We thank the multiple contributors, partners, and individuals who have dedicated their time and expertise to HIV Outcomes, shaping our collective efforts throughout the year.

In the spirit of cooperation, let us move ahead. Together, we have the power to transform the landscape of HIV and AIDS, ensuring a future in which people living with HIV are able to live a healthy, fulfilling life, free from stigma, discrimination and prejudice.

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 central role in long-term well-being.

Nevertheless, challenges persist. The principle of HRQoL as a policy

goal and measurement tool remain 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.

HIV has a history of having 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. Advances in this area promise to drive change in HIV policy and beyond.

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

“ ‘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 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 healthy, lives.

By raising awareness around the value of HRQoL for people living with HIV, we seek to have appropriate metrics and indicators featured more prominently in HIV policy. We work 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 30 organisations and individuals active in the HIV space. Our Steering, General and Observer Members include patient advocates, healthcare professionals, academics, public institutions, HIV organisations and industry. At the national level, we were present in 2023 in Germany, Italy, Romania, Spain and the United Kingdom.

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OUR MEMBERS



Dr. Vytenis Andriukaitis
AMBASSADOR



John Bowis
PRESIDENT



Prof. Jane Anderson
CO-CHAIR



Prof. Jeffrey Lazarus
CO-CHAIR



Nikos Dedes
CO-CHAIR

STEERING GROUP



GENERAL MEMBERS



NATIONAL INITIATIVES



Germany



Italy



Romania



Spain



United Kingdom

OBSERVER MEMBERS



DEVELOP



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

ENGAGE



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

IMPLEMENT

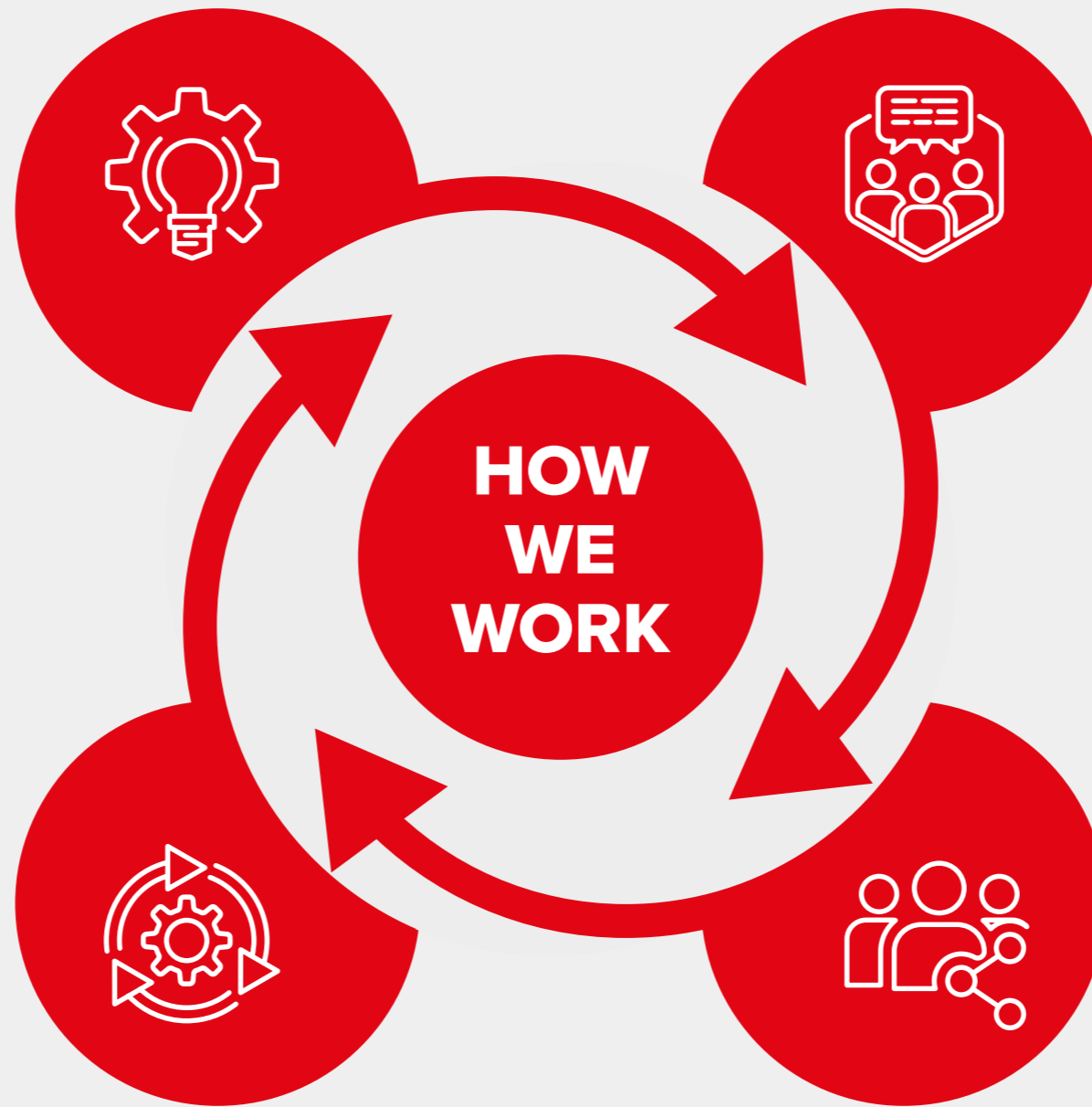


Evidence-based policy and clinical change at country-level across Europe.

SHARE



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



HIV OUTCOMES STRATEGY 2022-2026

In 2022, we set out our long-term strategy running from 2022 to 2026, aiming at transitioning from a policy commitment to the principles of HRQoL to its operationalisation, adoption and use within European health systems.

We are dedicated to advancing the monitoring and assessment of HRQoL by 2030 to provide integrated, person-centred care and eliminate stigma in healthcare systems. Our focus includes advocating for HRQoL integration in European and national HIV policies, alongside clinical and public health targets. We will identify best practices for HRQoL measurement in national health systems and collaborate with the European Centre for Disease Prevention and Control (ECDC) to enhance HIV data monitoring. Nationally, we will support the development of HIV-specific Patient Reported Outcome Measures (PROMs) to assess HRQoL outside clinical settings.

2023 OBJECTIVES

To advance our long-term strategy, in 2023 we focused on leveraging the HIV Outcomes Policy Asks and contributing to European policy to improve the HRQoL of people living with HIV, with a focus on stigma and discrimination, mental health, and the needs of people ageing with HIV.

Additionally, we explored overarching domains for measuring and monitoring HRQoL to inform and strengthen HIV Outcomes' position, and identify areas where action is needed but currently lacking.

At the national level, we remained committed to strengthening our collaboration, ensuring the continued success of in-country work, and sharing success stories.



OUR KEY ACHIEVEMENTS

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WORLD AIDS DAY

29 NOVEMBER 2023

On 29 November, in collaboration with Members of European Parliament (MEPs) Frédérique Ries, Sara Cerdas and Sirpa Pietikäinen, stakeholders gathered in the European Parliament in Brussels for a discussion focused on driving meaningful political change and strengthening HIV policies in the context of the upcoming 2024 European elections. The event reflected on policy actions that can help to advance towards the shared goal of ending HIV in Europe by 2030, while emphasising the importance of sustained action and addressing the evolving needs of people living with HIV.



EU Health Commissioner Stella Kyriakides commended HIV Outcomes for organising the event and emphasised the ongoing global challenge of HIV. Commissioner Kyriakides highlighted the necessity for increased investments to combat stigma and enhance equity, underscoring the importance of maintaining HIV as a priority in 2024 for the European Health Union.

KEY TAKEAWAYS



Magdalena Bartnik from EATG underscored the vital roles of communities, governments, and institutions in fostering non-judgmental approaches to drug prevention policies, emphasising the necessity of government accountability. **Prof Oana Sandulescu** highlighted the significance of integrating (PROMs) into healthcare settings, advocating for their standardised measurement at the European level. **Dr Nicoletta Policek** discussed the rising lifespan of individuals with HIV and the consequent increase in comorbidities, stressing the importance of comprehensive care integration, anti-stigma initiatives and community engagement to address underlying social issues.



EU Equality Commissioner Helena Dalli emphasised the imperative to combat stigma in healthcare settings, particularly for vulnerable populations in need of HIV care. She stressed the need for enhanced education and awareness in this regard.



UNAIDS Executive Director Christine Stegling applauded the progress made by some countries towards achieving the 2030 targets and called for comprehensive approaches to address HIV globally. She underscored the role of communities and the importance of ensuring that no one is left behind in prevention strategies.

OUTCOMES



1. Over 50 people attended the event, and many others followed the web stream through **HIV Outcomes' YouTube channel**, the streaming page dedicated to the event, and the Parliament's website.



2. The event gathered substantial attention on the HIV Outcomes social media platforms **X and LinkedIn**, notably including engagements with the DG SANTE official account and several MEPs.

3. The high-level event was covered in media outlets such as DODS.

SPANISH EU PRESIDENCY AND ROUNDTABLE

HIV Stigma and Discrimination: a European Approach

Ahead of the start of the Spanish Presidency of the EU, HIV Outcomes delivered a roundtable within SEISIDA's Scientific Meeting on 17 May, in Madrid, Spain.



MEPs from various political groups supported the event through video interventions and endorsed efforts to reduce HIV stigma and discrimination. HIV Outcomes Champions MEP Frédérique Ries (Renew Europe), MEP Sirpa Pietikäinen (EPP), and MEP Sara Cerdas (S&D), as well as MEP Tilly Metz (Greens/EFA) and MEP Marisa Matias (The Left), joined this statement of support.

The roundtable event featured high-level speakers, including Spanish Health Ministry representative, Dr Julia del Amo, who outlined Spain's priorities for the EU Presidency.

We had the pleasure of having the presence and contributions of Dr Esteban Martínez (President of the European AIDS Clinical Society), Prof Jane Anderson (HIV Outcomes Co-Chair & Consultant

Physician at Homerton Healthcare NHS Foundation Trust), Sini Pasanen (HIV Outcomes Steering Group Member, Steering Committee Member of AIDS Action Europe & Executive Director of Positiiviset ry), Stéphan Vernhes (HIV Outcomes Steering Group Member & Coordinator European Platform AIDES), Prof María José Fuster (HIV Outcomes Spain / SEISIDA) and Prof Jeffrey V. Lazarus (HIV Outcomes Steering Group Member / ISGlobal).

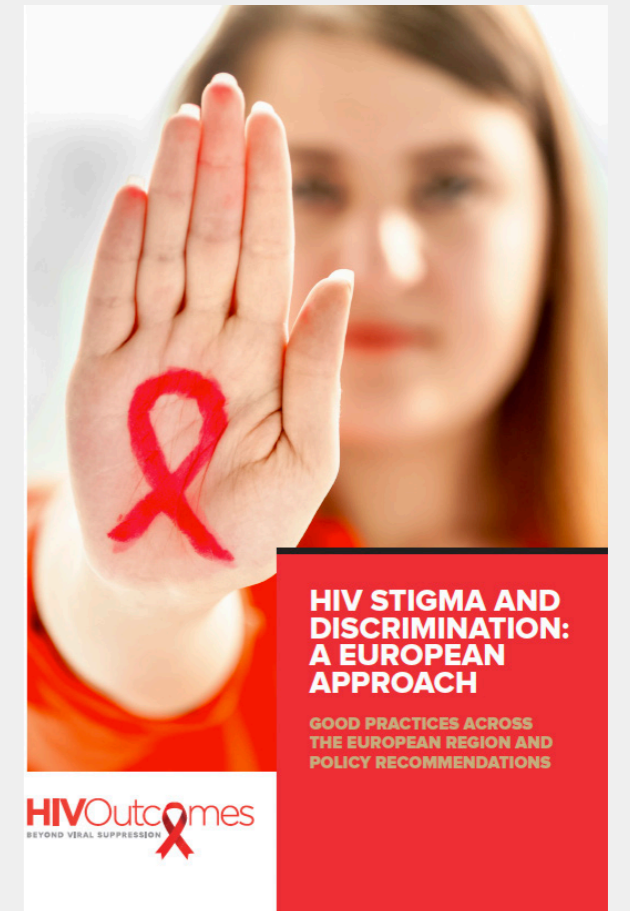
Representatives from all in-country HIV Outcomes initiatives (Germany, Spain, Italy, Romania, and the UK) joined us in Madrid to attend this roundtable. The event attracted strong interest, with approximately 200 participants attending in person, and it was followed online by viewers across the world.

Good practices and recommendations on HIV stigma and discrimination

The roundtable provided an opportunity to launch HIV Outcomes' comprehensive paper titled "HIV Stigma and Discrimination: A European Approach". This publication highlights **35 good practices observed across various European countries, accompanied by policy recommendations**. These good practices and policy inputs were **submitted and suggested by our members**, highlighting the need for:

- ! Training & education of healthcare professionals on HIV stigma and discrimination
- ! Financing multidisciplinary care for patients with multimorbidity, including integrated mental health services
- ! Treatment as prevention to ensure swift access to innovative care
- ! Monitoring & tracking stigma and discrimination and adapting policies accordingly
- ! Legal protections to tackle discrimination and support those affected
- ! Quality of life monitoring every two years across Europe
- ! Digitalisation & health data space to empower and protect the privacy of citizens
- ! Involvement of people with HIV at every stage of policy and care

By consolidating successful strategies and offering actionable recommendations, the ultimate objective of the paper is to contribute collectively towards achieving the ambitious HIV elimination targets.





ENGAGING WITH THE SPANISH EU PRESIDENCY AND CONTRIBUTING TO THE POLITICAL DECLARATION

Ahead of the roundtable, **we also contributed to the draft policy brief on HIV stigma and discrimination** developed by the Spanish EU Presidency. This key document served as a reference for stakeholders and policymakers in the ongoing battle against HIV stigma and discrimination. In addition, the **good practices paper presented at the roundtable was also shared with Spanish health authorities** to inform their political declaration “HIV and Human Rights: political action to achieve ZERO stigma”, and their overall work on HIV stigma and discrimination.

During the Spanish Presidency, **HIV Outcomes Co-Chair Nikos Dedes and Steering Group Member Sini Pasanen attended the Spanish EU Presidency high-level meeting in person in Sevilla** which focused on discussing the political declaration.



EUROPEAN PARLIAMENT

Recognition of HIV by the European Parliament

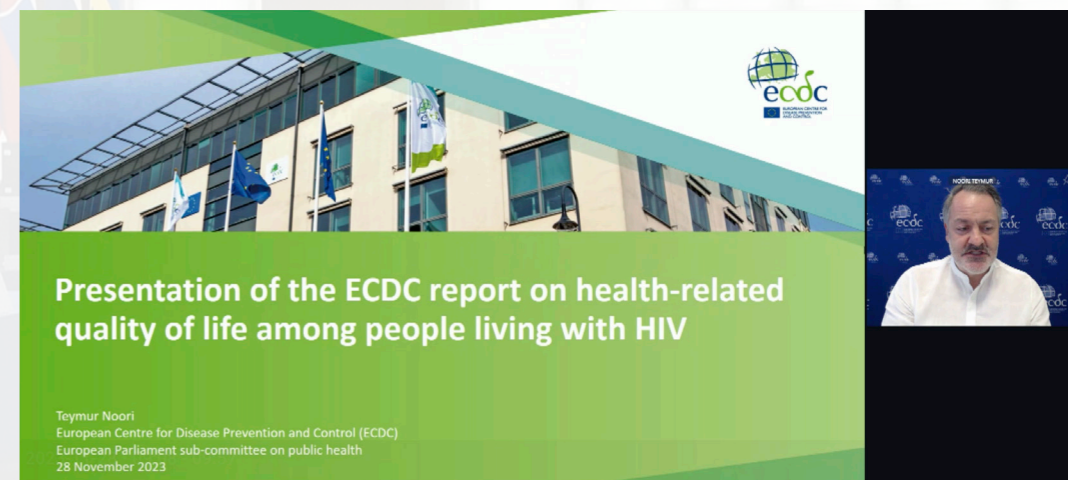
In December, the European Centre for Disease Prevention and Control (ECDC) presented the study on the HRQoL of people living with HIV during a public hearing at the European Parliament Subcommittee on Public Health (SANT). Commissioned by MEP Frédérique Ries with cross-party support from the European Parliament ENVI committee in 2022, this study marked a significant step forward in addressing critical issues surrounding HIV.

The ECDC study presentation was delivered by Teymur Noori, highlighting data from the ECDC/WHO Europe's 2023 report on HIV/AIDS surveillance and monitoring data.

During the MEPs' reaction to the ECDC study, MEP Sara Cerdas, a dedicated champion of HIV Outcomes, emphasised the importance of access to specialised mental health services for those living with HIV.

This study and the inclusion of HIV in the policy agenda represents a significant milestone in our collective efforts to advocate for the well-being and HRQoL of people living with HIV.

KEY POINTS FROM THE PRESENTATION OF THE ECDC STUDY



- 1 Disparities in reaching the 95-95-95 targets by 2025, with Western countries performing well and Central/Eastern countries facing challenges, especially in treatment.
- 2 Missing data in relation to stigma and quality of life may affect capacity to meet the UNAIDS targets for 2025.
- 3 Persistence of stigma and discrimination, emphasising the critical role of mental health services, given their impact on overall well-being.
- 4 There is a strong need to consider how HRQoL data collection can be standardised across the European region, to allow comparison of data between countries.
- 5 Concerns of people living with HIV about being treated differently. This can affect people's willingness to share their HIV status with family, friends, and/or sexual partners, and influence health-seeking behaviour.

Exchange between MEP Ries and EU Health Commissioner Stella Kyriakides

MEP Frédérique Ries, Champion MEP of HIV Outcomes, submitted a question to EU Health Commissioner Stella Kyriakides regarding the **need for renewed commitment from the EU in the fight against HIV**. This question was co-signed and supported by other MEPs across four different political groups, namely MEP Susana Solís Pérez, MEP Katalin Cseh, MEP Sirpa Pietikäinen and MEP Sara Cerdas.

This question presented a great opportunity for interinstitutional engagement by:

- reminding the European Commission about the closing of the Civil Society

Forum on HIV in 2019

- asking about the Commission's future work to promote HIV-related policies
- encouraging Member States to fight to end the epidemic in Europe.

Following this question, Commissioner Stella Kyriakides replied to MEP Frédérique Ries, **underlining the renewed EU commitment against HIV, as well as highlighting the extension of the Public Health Expert Group to communicable diseases** – an initiative which HIV Outcomes has been strongly advocating for.

European Commission reply to Ambassador Dr Andriukaitis letter reiterating its commitment to ending HIV/AIDS

At the end of 2022, HIV Outcomes sent a letter to Commissioner Schinas and Commissioner Kyriakides on behalf of Ambassador Dr Andriukaitis. This letter emphasised the need for the European Commission to support people living with HIV who fled Ukraine, particularly regarding the need for:

- Health services specialised in HIV
- Coordinated approaches
- Humanitarian assistance platform
- ECDC initiatives
- Thematic networks on continuity of care and HRQoL
- Expert group covering HIV

At the beginning of 2023, we received a reply on behalf to Commissioners Schinas and Kyriakides by **Sandra Gallina, Director General for Health and Food Safety**.

DG SANTE Director General Gallina **thanked HIV Outcomes for the support and stressed the European Commission's commitment to reaching the UN Sustainable Development Goals for HIV by 2030 and accelerating its progress**.

This was another stepping stone in the engagement between the initiative and the European Commission, which continued throughout the year.

INCLUSION OF HIV AS A PRIORITY OF THE EUROPEAN COMMISSION PUBLIC HEALTH EXPERT GROUP



The European Commission Public Health Expert Group (PHEG), which replaced the former Steering Group on Health Promotion, Disease Prevention, and Management of Non-Communicable Diseases, has included HIV/AIDS, tuberculosis and hepatitis as a priority for the Group in 2025. This achievement stands out as a positive result of our advocacy efforts, ongoing since the expansion of the Group's mandate to include communicable diseases in 2022." to "HIV Outcomes was one of the organisations advocating for this, since the expansion of the Group's mandate to include communicable diseases in 2022.

The Expert Group, which brings together Member States, provides an ideal platform for sharing best practices in promoting well-being and accelerating the elimination of communicable diseases, including HIV. It represents a unique opportunity to champion the discussion around the HRQoL of people living with HIV, marking a substantial milestone for HIV in the policy agenda.

MENTAL HEALTH POLICY CONTRIBUTIONS

European Commission's comprehensive approach to mental health

This year was marked by an unprecedented initiative as mental health was recognised as one of the priorities of the European Commission, according to Commission President, Ursula von der Leyen. A novel **comprehensive approach to mental health** was then announced in June 2023, and a call for evidence was opened.

We have contributed to this call for evidence, providing data, good practices and evidence to support the need for an HIV-informed angle to be considered. The comprehensive approach to mental health was adopted on 9 June, with **many of the HIV Outcomes asks featuring in the published strategy:**

- Monitoring of HRQoL of people living with mental health disorders, with a particular focus on addressing stigma.
- Expanding access to mental health support to those who experience stigma and discrimination and promote good practice sharing on mental health promotion, prevention, early detection and intervention.
- Training healthcare professionals to deliver integrated and person-centred care and reduce stigma and discrimination.
- Funding to support research and innovation projects on mental health.

Acknowledgement that determinants of mental health interact with existing inequalities in society, putting stigmatised groups in a particularly vulnerable position regarding mental health – in line with the LGBTIQ equality strategy 2020-2025.

Building on our contribution to the call for evidence, HIV Outcomes was recognised as a valuable stakeholder by the European Commission and invited to submit a **poster on how to “Support Member States in expanding access to mental health services”**. The poster was shortlisted by the Commission and presented during an online webinar which took place in April, providing us with a valuable opportunity to showcase our insights and initiatives in support of mental health expansion efforts.

European Parliament's SANT subcommittee report

Following the lead of the European Commission's initiative, the European Parliament's Subcommittee for Public Health (SANT) announced its own **report, with a focus on mental health in the EU**, particularly considering the aftermath of the COVID-19 pandemic.

HIV Outcomes contributed with evidence and amendments to the report, led by MEP Sara Cerdas. As the report calls on Member States to prioritise and improve access to mental health services for vulnerable groups, **multiple consolidated compromise amendments concerning HIV were successfully adopted**, namely:

- The recognition of the importance of integrating psychosocial interventions to support patients with psychological consequences of HIV and supporting HIV services in line with WHO recommendations.
- The recommendation to further integrate mental health concerns in other programmes recommended by the UN such as HIV.
- The acknowledgement that communicable diseases such as HIV are often the cause of stigmatisation and mental health impairment for individuals.

This report received support from across political groups and was debated in the SANT subcommittee, bringing another opportunity for engagement and advocacy.

PRESENTATION OF HIV OUTCOMES VIEWPOINT AT THE IAS CONFERENCE

During the prestigious **12th Conference of the International AIDS Society (IAS) in Australia**, our Co-Chair Jeffrey Lazarus presented a perspective derived from the HIV Outcomes Policy Asks.

Lazarus JV et al. Journal of the International AIDS Society 2023; 26(11):e26117
<https://onlinelibrary.wiley.com/doi/10.1002/jia2.26117> | <https://doi.org/10.1002/jia2.26117>



VIEWPOINT

A person-centred approach to enhance the long-term health and wellbeing of people living with HIV in Europe

Jeffrey V. Lazarus^{1,2,3,4}, Mario Cascio⁴, Jane Anderson⁵, Sini Pasanen⁶ and Richard Harding⁷

¹Corresponding author: Jeffrey V. Lazarus, Calle del Rosellón, 171, ENT-2, Barcelona ES-08036, Spain. Tel: +34 608 70 35 73. (jeffrey.lazarus@iph.cuny.edu)

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Person-centred care is a critical attribute of high-quality healthcare, promoting quality of life, improving an individual's interaction with the health system and valuing people's social networks [1]. Lifesaving antiretroviral therapy is now increasingly widely available around the world, although not all countries have reached their coverage targets related to prevention, diagnosis and linkage to care. As a consequence of the enormous progress made, most people living with HIV are able to grow older rather than dying prematurely [2]. Therefore, it is essential that health systems respond to the changing needs of an ageing population living with HIV, who have comparatively higher multimorbidity (both physical and mental) and experience persistent stigma [3, 4].

To achieve this, person-centred care services for people living with HIV must focus on long-term wellbeing by monitoring and managing multimorbidity, health-related quality of life (HRQoL), stigma and discrimination [5]. In line with WHO's global strategy on HIV for 2022–2030 [2] and UNAIDS targets set in 2021 [6], a person-centred approach is essential to allow for this transformation of health systems. Health services must offer an integrated response to the evolving health needs and choices of people living with HIV—and this is still not the case in most settings, including high-income countries in Europe [7].

The crisis with health systems during 2020 and the worsening of health outcomes during the COVID-19 pandemic [8] demonstrated the importance of coordination among European countries to protect population health across national borders, especially among the most vulnerable. Against the backdrop of the pandemic, in 2020, the European Union put forward a proposal for a European Health Union [9]. Ambitious policy opportunities were identified, from a proposal for a European Health Data Space, to reinforcing the European Centre for Disease Prevention and Control mandate and pushing forward the European Care Strategy [10]. Person-centricity is at the core of these health system initiatives, paving the way for personalized healthcare delivery. These initiatives are of particular relevance for people living with HIV and their healthcare services given their multidimensional health and social care needs.

A person-centred health system is organized around what is important to people living with HIV, their needs and choices, rather than focusing on individual diseases [5, 11]; it "consciously adopts the perspectives of individuals, families and communities (...), sees them as participants and beneficiaries of trusted health systems that respond (...) in humane and holistic ways" and "acknowledges the experiences and perspectives of health-care providers that may enable or prevent the delivery of [these health services]" [12]. In the context of HIV, people living with HIV must be empowered and supported to make decisions about the degree of self-management that they are capable of and willing to assume in line with their age, gender, socio-economic status and support network.


A key objective of a person-centred approach is to ensure that the views, needs and wellbeing of people living with HIV are represented in policy initiatives by prioritizing the enhancement of their long-term health, HRQoL and overall wellbeing, from diagnosis until the end of life [5]. With this goal in mind, in 2021 and 2022, over 60 multidisciplinary HIV organizations and experts from the HIV Outcomes initiative co-developed a set of 27 policy asks and recommendations for European health systems and authorities [13]. Qualitative input was collected with a representation of people living with HIV, clinicians, academics, public health professionals, policymakers and industry representatives. Expert interviews were conducted via a questionnaire and at seven workshops. Entitled "Enhancing long-term health and wellbeing among people living with HIV," the policy asks were grouped into four areas where policy action is most urgent to improve wellbeing: (1) comorbidity prevention, treatment and management-including mental health; (2) ageing with HIV; (3) patient-reported outcomes measures and national monitoring of HRQoL; and (4) combatting stigma and discrimination. For each area, specific, implementable and translatable recommendations were made for HIV clinics/care providers, national and regional authorities and European Union health policymakers. Priority recommendations are highlighted in Table 1 [13].

Although focusing on monitoring HRQoL may be challenging for countries or health systems with fewer resources available, people living with HIV experience a greater overall burden of multimorbidity in comparison with the general population and reduced HRQoL across all domains. Therefore, actions that can benefit both individual wellbeing and health

- The ViewPoint focused on **“A people-centred approach to enhance the long-term health and well-being of people living with HIV in Europe”**, which was published in the Journal of IAS in 2022.
- This piece, co-authored by several of our members, emphasised putting people at the centre of clinical approaches, recognising the need to look beyond suppression and survival, but working to improve the long-term health and well-being of people living with HIV in Europe.

ENGAGEMENT AND COLLABORATION WITH KEY STAKEHOLDERS

HIV Outcomes endorsed a letter from the International Association of Providers of AIDS Care (IAPAC) urging Health Commissioner Stella Kyriakides to introduce a new EU Action Plan, specifically addressing HIV and viral hepatitis, and the effective involvement of people living with HIV in decision-making. In acknowledging the alignment between IAPAC's letter and HIV Outcomes' advocacy goals, our endorsement marks a significant step forward in our shared goals, highlighting collaborative efforts among stakeholders.



Call for a Renewal of an EU Action Plan on HIV and the Effective Involvement of People Living with HIV in Decision-Making

Dear Commissioner Stella Kyriakides,

The International Association of Providers of AIDS Care (IAPAC) is a not-for-profit association with more than 30,000 members worldwide whose mission is to expand access to and improve the quality of prevention, care, and treatment services provided to people affected by and living with HIV.

In partnership with the other co-signatories of this letter, IAPAC urges the European Commission to action the following requests within the construct of the health-related initiatives that will be developed during the upcoming 2024–2029 mandate for European Union (EU) Member-States.

As you are aware, the HIV pandemic has had a devastating effect on our world, claiming over 40 million lives since its start in the mid-1980s. Despite an overall decline in new diagnoses in the last decade, according to the European Centre for Disease Control (ECDC), nearly 107,000 people were diagnosed with HIV in 2021 in the EU/EEA. In Europe, the burden of HIV disproportionately falls on socially marginalized and/or vulnerable populations, such as people who inject drugs, LGBTI individuals, sex workers, and migrants. This is why the involvement of these populations is key to ensure the planning and implementation of an effective response to HIV.

With only 7 years left to achieve the [2030 Joint United Nations Programme on HIV/AIDS \(UNAIDS\) Targets](#), most European countries are currently not on track to achieve these milestones, as is reflected in the ECDC's [progress report dated September 2023](#). The report shows that Europe-wide only 83% of all people living with HIV (PLHIV) know their status, 85% of people who know their status are on HIV treatment, and 93% of people on treatment have achieved viral suppression. Moreover, the pace of scale-up for pre-exposure prophylaxis (PrEP), an important adjunct to HIV treatment that together comprise combination HIV prevention, is less than optimal, with [68 089 oral PrEP initiations in 2020](#). Here, too, the EU faces a deficit in relation to the UNAIDS goal that 95% of people who are clinically eligible should be using combination HIV prevention, including PrEP. The targets are within reach. However, they cannot be achieved without sustained commitment and focused actions.

In this context, the need to enhance the HIV response in Europe stands out as a key pending task for the EU as a whole and its Member-States. This enhancement should be part of Europe's efforts to get back on track to reach the health-related Sustainable Development Goals (SDGs), specifically SDG3.3, which seeks to end the epidemics of HIV, tuberculosis (TB), malaria and neglected tropical diseases by 2030 and combat hepatitis, water-borne diseases, and other communicable diseases. Data-informed, equity-based efforts to achieve SDG 3.3 should be made reality through a targets-driven EU Plan of Action, guided by existing international frameworks, such as the UNAIDS Global AIDS Strategy, the Stop TB Partnership and UNOPS' [Global Plan to End TB](#), and the WHO's [Global Health Sector Strategy](#) for hepatitis and STIs.

As important, and in line with the UNAIDS focus on the greater involvement of people living with HIV (GIPA), the involvement of socially marginalized and vulnerable populations is key to ensure the planning

HEALTH-RELATED QUALITY OF LIFE SUBGROUP

In 2023, a dedicated HIV Outcomes Subgroup, comprising experts including academics, clinicians and individuals living with HIV, undertook a significant initiative aimed at advancing the understanding of HRQoL measurement for people living with HIV. Led by our Co-Chair Jeffrey Lazarus and Dr Diana Barger, a researcher at the University of Bordeaux, this effort aimed to investigate common elements among various HRQoL assessment resources, categorise them and determine which elements should be incorporated into a European framework for a shared understanding. This framework should guide the assessment of HRQoL, streamlining essential elements for evaluating patient experiences and outcomes in the context of patient-centred HIV services.

Additionally, we compared our assessment with the OECD PaRIS Survey, which collects data on PROMs from people with chronic conditions. This comparison aimed to potentially inform the OECD PaRIS Survey to include elements specific to HIV, representing a significant step forward in ensuring that the experiences of people living with HIV are accurately represented and addressed in broader health surveys and assessments.

The findings were consolidated into a comprehensive report, including recommendations aimed at optimising the assessment of HRQoL, leading to better-informed interventions and support strategies for individuals living with HIV. The report is planned for publication and dissemination in 2024, furthering our commitment to advancing and contributing to the monitoring of HRQoL for people living with HIV.

HIVOutcomes
BEYOND VIRAL SUPPRESSION 

NATIONAL LEVEL WORK



Germany



EVIDENCE GENERATION

- HIV Outcomes Germany has collected national best practices in the Compendium of Good Practices to fight HIV stigma and discrimination.
- The German secretariat monitored the status of the mid-term review of the national HIV strategy. The members collected ideas to improve the strategy's measures to reach its goals for 2030.



ADVOCACY

- HIV Outcomes Germany launched an outreach effort, in anticipation of the Spanish EU Presidency, targeting German MEPs, specifically those involved in health policy. The primary focus of this outreach was to address issues related to discrimination and stigmatisation within the context of preparations for the Spanish EU Presidency.



MULTIPLIERS

- The German HIV Outcomes secretariat attended a working meeting in Brussels where, together with the other country secretariats, it prepared the roundtable event in Madrid on the topic of stigma and discrimination.
- HIV Outcomes Germany attended the roundtable in Madrid ("HIV Stigma and Discrimination: A European Approach") which aimed to impact the declaration on HIV and stigma of the Spanish EU Presidency.



Italy



EVIDENCE GENERATION

- A proposal was developed to highlight gender dimensions to be considered in the context of the ageing in HIV, aiming to shape the definition of diagnostic and therapeutic pathways.
- A survey conducted in 2022 on the stigma faced by people living with HIV in Italian hospitals was accepted as a poster presentation at the European AIDS Clinical Society (EACS) Conference. The poster was also accepted as an oral presentation at the Italian Conference on AIDS and antiviral Research (ICAR), where it was awarded 1st prize for 'Best abstract on social sciences'.



ADVOCACY

- Informative materials were disseminated among the main Italian institutional stakeholders, such as the Ministry of Health and members of the Technical Health Committee.
- Monitoring activities were initiated in preparation for the upcoming EU elections 2024.



MULTIPLIERS

- In June 2023, HIV Outcomes Italy held a lunch session at the International Conference on AIDS and Antiviral Research (ICAR).
- HIV Outcomes Italy, together with the Istituto Superiore di Sanità (ISS), held a training event dedicated to key Italian institutional stakeholders.
- HIV Outcomes brochures were disseminated at key events in Italy and internationally, including at the Italian Society of Infectious Diseases and ICAR Conferences.



Romania



EVIDENCE GENERATION

- HIV Outcomes Romania developed a set of policy recommendations based on its national study on what quality of life means for 11050 people living with HIV in Romania.
- Visual materials with adapted key messages for various stakeholders were developed to support the initiative's views on the implementation of Romania's HIV Strategy.
- The Romanian version of the HIV Outcomes Policy Asks developed at European level was developed and disseminated.



ADVOCACY

- HIV Outcomes Romania engaged with the Minister of Health, Minister of Labour, the Presidency, the Prime Minister and Parliament on enhancing the HRQoL/QoL of those with HIV by amending social and healthcare policies and legislation. Its engagement was supported via the initiative's online channels, by its members, and by media outlets.
- The initiative developed and promoted two joint statements on the implementation of Romania's national HIV strategy and on social legislation, together with KOLs and the community.
- Four quarterly newsletters were developed and launched to leverage the initiative's advocacy on HRQoL.



MULTIPLIERS

- In collaboration with Prof Dr Matei Bals of the National Institute for Communicable Diseases, HIV Outcomes Romania co-organised a high-level event at the Romanian Parliament to promote its policy recommendations on Enhancing QoL. HIV Outcomes Ambassador Dr Vytenis Andriukaitis showed his support to the event in a recorded keynote speech.
- The initiative's study results on QoL were shared by the Romanian co-chair Dr Mariana Mardarescu, at the EACS 2023 conference.
- Multiple international and national policy events were co-organised with KOLs and the HIV community, presenting HIV Outcomes Romania's policy recommendations on HRQoL, HIV prevention (including PrEP), and multidisciplinary approaches of HIV care.



Spain



EVIDENCE GENERATION

- HIV Outcomes Spain, alongside SEISIDA and the HIV Legal Clinic of the University of Alcalá, has developed the “Structural Stigma Project” where it analysed regulations and legislation, and reviewed the Global AIDS Monitoring indicators.
- The Spanish Secretariat has developed the “Comorbidity Surveillance Project”, a study that included focus groups with public health authorities, surveillance professionals and HIV clinicians from different regions in Spain. The first analysis was conducted to identify barriers and facilitators.



ADVOCACY

- HIV Outcomes Spain conducted engagement meetings with representatives from different Spanish regions to discuss the Comorbidities Surveillance Project.
- Engagement with UNAIDS to discuss their updated indicators on structural discrimination.
- HIV Outcomes Spain was involved in the organisation of activities carried out within the Spanish Presidency of the Council of the European Union.



MULTIPLIERS

- The Spanish secretariat was part of the organising committee of SEISIDA’s meeting: Make Visible the Invisible (Hacer Visible lo invisible), which took place in Madrid, Spain, in May 2023. The Spanish team collaborated with the European initiative to host a roundtable on HIV stigma and discrimination at the SEISIDA meeting.
- HIV Outcomes Spain, alongside SEISIDA, created and disseminated informative videos on the Policy Asks.



UK



EVIDENCE GENERATION

- A Vision Document was published presenting how HIV Outcomes UK will ensure that HIV is embedded as an equal outcome in clinical, academic and policy decision-making across the UK.
- A briefing was published exploring synergies between the HIV response and Core20PLUS5, the National Health Service’s approach to addressing health inequalities in England. The briefing highlighted measures to re-engage people in HIV care, prevent late HIV diagnosis and support people’s mental health needs.



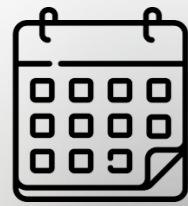
ADVOCACY

- HIV Outcomes UK Steering Group members partnered with the National Health Service to develop an e-learning module on HIV for mental health practitioners.
- HIV Outcomes UK Steering Group members successfully campaigned for the expansion of opt-out HIV testing in Emergency Departments to all high HIV prevalence areas in England.
- Following the publication of the briefing on health inequalities, local health system leaders consulted with HIV Outcomes UK on their HIV strategies in line with its recommendations.



MULTIPLIERS

- HIV Outcomes UK’s briefing on health inequalities was disseminated at events around World AIDS Day, including at the British HIV Association Conference and National AIDS Trust & One Voice Network’s roundtable with the UNAIDS Executive Director.
- HIV Outcomes UK presented at a meeting with health system leaders working on HIV in Scotland, and participated in several national and international conferences.
- HIV Outcomes UK Co-Chair Dr Nicoletta Policek contributed to HIV Outcomes’ World AIDS Day event in the European Parliament.



2023 SOCIAL MEDIA IMPACT

During 2023, HIV Outcomes continued to grow its online presence, not only on social media (on Twitter/X, LinkedIn and YouTube), but also through its quarterly newsletter and content dissemination through EU-based platforms and media outlets.



HIV Outcomes produced quarterly newsletters in 2023 to communicate relevant policy updates, events and achievements. The newsletters were shared with an audience of approximately 500 people.





LOOKING AHEAD – HIV OUTCOMES 2024 WORK PLAN

LOOKING AHEAD – HIV OUTCOMES 2024 WORK PLAN

2024 is set to be an important year of transition marked by the upcoming EU elections. While new configurations within the European Commission and the European Parliament will arise, **HIV Outcomes remains committed to fostering relationships and collaborations to ensure continued attention to HIV.**

Our focus will be on:

- 1** Comorbidity prevention, treatment and management – including mental health
- 2** Ageing with HIV
- 3** Measurement of PROMs and monitoring of HRQoL
- 4** Combatting stigma and discrimination
- 5** Support and incorporate the concept of Undetectable = Untransmittable into EU and national policies to test, screen, prevent and treat HIV

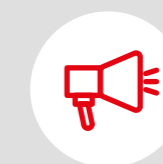
2024 Objectives



Develop a Call to Action for policymakers, incorporating concrete and measurable actions emerging from the Policy Asks, on how the EU could lead the way in ending HIV by 2030



Engage EU Presidencies, advocating leadership in advancing HIV Outcomes' agenda



Promote and disseminate common domains in HRQoL PROMs for country adoption



Expand HIV Outcomes into the Netherlands and identify other target countries to drive policy change

IN CONCLUSION

Our efforts throughout 2023 have marked important milestones, underscoring our commitment to addressing the global challenge of HIV/AIDS.

We have maintained collaborations with key MEPs and the European Commission to keep the momentum and the Union's commitment in the fight against the HIV/AIDS epidemic. On World AIDS Day, we gathered in Brussels to discuss the diverse needs of people living with HIV with key stakeholders from the European Commission, European Parliament and UNAIDS. We have kept the spotlight on the HRQoL of people living with HIV in various forums, including the EU Spanish Presidency and the IAS Conference. At national level, our cross-border initiatives across the EU region demonstrate our commitment to driving change.

Our strategic use of social media and external communications has effectively amplified our message. As we look ahead to 2024, we remain committed to our goal of ending HIV by 2030, advocating for integrated person-centred care, and improving the HRQoL of people living with HIV.

USEFUL LINKS



Policy Asks



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



Advocacy Toolbox



Mapping on the use of HRQoL in Health Policy & Practice



Consensus Statement



Website



Twitter



LinkedIn



Contact