



HIVOutcomes
BEYOND VIRAL SUPPRESSION



2022

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

After a year of many battles, let's keep up the fight against HIV



John Bowis
President

2022 presented many challenges that have inevitably impacted the health of millions: the COVID-19 pandemic, the war in Ukraine and other regions of the world, and the global outbreak of mpox are just a few of the health emergencies we were faced with last year.

That is why this year's message is clearer than ever: people living with HIV cannot be left behind. While those with HIV are living longer, they are often at higher risk of developing a range of other physical and mental health conditions.

At the beginning of 2022, despite earlier optimism that the war on COVID-19 had already been won, we endured a particularly challenging new wave of infections, and a rapid increase in cases and deaths. For HIV services and communities, the impact throughout Europe was significant, resulting in the disruption of HIV care, testing and treatment.

The burden of the pandemic and other health threats on the mental health of people

living with HIV cannot be overlooked. The prevalence of stigma during the COVID-19 pandemic and the mpox outbreak prompted social distancing and saw an increase in discrimination against people living with HIV. Together with HIV communities, HIV Outcomes will work to ensure that they will not be misrepresented in the upcoming European Union (EU) Mental Health Strategy.

With significant challenges come even greater opportunities. Since the launch of the HIV Outcomes recommendations in 2017, we have worked intensively to convert them into new policy asks that reflect the ongoing challenges and gaps in care for people with HIV.

HIV Outcomes is committed to driving these actions forward. We will continue to engage policymakers to improve the health-related quality of life (HRQoL) of all people living with HIV.



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

While 2022 was another atypical year with the start of the war in Ukraine, it served as a reminder that people living with HIV are still in need of support across Europe. The prevalence of HIV in Ukraine is among the highest in Europe. An estimated 10% of Ukraine's total HIV population need HIV services in refugee hosting countries.

The coordinated efforts of receiving countries, as well as the cooperation between the EU and Member States, have been outstanding. To support this vital work, HIV Outcomes cooperated with its national initiative in Romania to gather insights on the specific needs of Ukrainian refugees living with HIV and shared insights with the EU Health Commissioner and the European Commission's Civil Protection mechanism.

We must pave the way for our healthcare systems to ensure the highest standards of prevention, treatment, care and information to avoid widening health inequalities and prevent a spike in HIV incidence, mortality and morbidity. This can only be done by sharing best practices among clinicians as

well as community members to improve integrated, holistic care for people living with HIV.

Over the past year, the HIV Outcomes advocacy efforts have built on work initiated during my time as Health Commissioner and successfully led to the creation of the new Member States Expert Group to exchange best practices on communicable diseases, including HIV, and foster their implementation across the EU. Let us not forget that long-term interventions can better deliver high quality HIV-related care, address the multidimensional challenges to the wellbeing of people living with HIV, and ultimately improve their HRQoL.

The Ukraine crisis and the COVID-19 pandemic show how much progress can be achieved against viral diseases when we act in coordination and solidarity. As HIV Outcomes Ambassador, I commend all the ongoing joint efforts and am proud to support the initiative's mission of improving the HRQoL of all people with HIV.

Beyond Viral Suppression

Advancing the HRQoL 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)

HIV is no longer a death sentence. However, as more people live longer lives with HIV, added complications emerge, bringing HRQoL into the spotlight. Long-term viral suppression is a crucial target for HIV treatment, but health systems must also address the wider health and well-being complexities associated with HIV.

In the past year, HIV Outcomes has worked hard to develop the recently launched Policy Asks document calling for an integrated, person-centred approach to HIV care. The initiative continues to advocate for the implementation of clear policy recommendations at local, national and European levels.

HIV remains one of the most stigmatised diseases worldwide. Stigma and discrimination within health systems impacts throughout the HIV continuum of care – from diagnosis to viral suppression and comorbidity management. It is imperative that health systems now monitor HRQoL and address the challenges posed by living with HIV in the long term.

Action must be taken by HIV clinical services and care providers to implement patient-reported outcomes measurements (PROMs) and to use the data generated to monitor health outcomes at local, national and European levels.

'It is urgent that PROMs are fully integrated

into clinical practice and used to support shared decision-making with those living with HIV. Our Policy Asks address how to advance the integration of PROMs into routine HIV care provision.'

– Prof Jeffrey Lazarus

Poor mental health among people with HIV is almost double that of the general population. This means that mental health services must consider the specific needs of people living with HIV, which are often closely related to the experience of stigma and discrimination.

'Mental health remains a significant challenge for people with HIV, in part due to the effects of stigma and discrimination, leading to poorer HRQoL. I welcome HIV Outcomes Policy Asks document which calls for an integrated, person-centred approach to HIV care.'

– Prof Jane Anderson

As we reflect on 2022, we are delighted by the successes achieved by the HIV Outcomes Initiative. From the inclusion of HRQoL in guidance reports for the first time, the recognition of quality of life as the end-goal of long-term care in the EU, to the launch of the Policy Asks. We now proudly move forward to build on these achievements and make 2023 the year in which we see real improvements in the HRQoL of 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.

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 for people living with HIV.

While HRQoL plays an important role in addressing the long-term well-being of people living with HIV, only five out of 48 European countries currently include it in their HIV monitoring.

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.



“

'HIV Outcomes has a simple but powerful vision – one that I think we could all adopt: A world in which people living with HIV enjoy the highest possible HRQoL. In this future, we focus on the person and not the disease. In this future, it is not enough that people with AIDS live long lives; they should also live healthy and fulfilling lives, free from stigma and discrimination.'

”

– Health Commissioner
Stella Kyriakides

at the HIV Outcomes World AIDS Day 2022 event

“ ‘Our vision is a world in which people living with HIV enjoy the highest possible HRQoL’ ”

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.

Our mission is to build political support and policy measures to deliver integrated person-centered 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 with HIV in the long term, including stigma, discrimination, and a higher risk of comorbidities.

HIV Outcomes is proud to partner with over 30 like-minded 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 are working in Germany, Italy, Romania, Spain and the United Kingdom.

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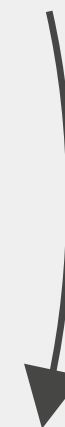
1 DEVELOP

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.



2 ENGAGE

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



4 IMPLEMENT

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



3 SHARE

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

OUR INITIATIVE



John Bowis
PRESIDENT



Dr. Vytenis Andriukaitis
AMBASSADOR



Prof. Jane Anderson
CO-CHAIR



Nikos Dedes
CO-CHAIR



Prof. Jeffrey Lazarus
CO-CHAIR

STEERING GROUP



GENERAL MEMBERS



NATIONAL INITIATIVES



Germany



Italy



Romania



Spain



United Kingdom

OBSERVER MEMBERS



HIV OUTCOMES STRATEGY 2022-2026

In 2022, we laid down our long-term strategy for the period 2022 – 2026, aiming at transitioning from a policy commitment to the principle of HRQoL to its operationalisation, adoption and use within European health systems. To that end, we focused our efforts on advancing towards effectively monitoring and assessing HRQoL by 2030, as the basis for delivering integrated person-centred care and eliminating stigma and discrimination in healthcare settings.

In order to achieve this ambitious goal, we will continue to advocate for integrating HRQoL in European and national HIV-related policies, to be linked to clinical and public health targets. In addition, we aim to assess and identify best practices in the use of HRQoL tools/measures in national health system settings. In parallel, we will be engaging with the European Centre for Disease Prevention and Control (ECDC) to assess data

monitoring on HIV and identify gaps (following the Dublin Declaration).

At national level, in-country initiatives will explore and support the development of HIV specific patient-reported outcome measurements (PROMs) which fully account for HRQoL in order to leverage parallel methods to assess HRQoL outside clinical settings.



HIV Outcomes will advocate for Member States to **systematically monitor and assess the HRQoL of people living with HIV as the basis for delivering integrated person-centred care.**



Achieve a high level of HRQoL for people living with HIV embedded as an aim in national and European health policies.



HRQoL of people living with HIV to be systematically assessed in clinical settings using PROMs.



Results used to shape integrated person-centred care and reduce stigma and discrimination in healthcare settings.



Results additionally used to inform national and European HIV policy development.

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WHAT WE ACHIEVED IN 2022

WORLD AIDS DAY

1 DECEMBER 2022

‘Enhancing long-term health and well-being among people living with HIV – Launch of HIV Outcomes Policy Asks’

For the first time since the start of the COVID-19 pandemic, we convened an in-person high-level event on **World AIDS Day 2022** at the European Parliament in Brussels. The event raised awareness of measures to improve well-being for people living with HIV and the importance of measuring the HRQoL. It also saw the launch of the HIV Outcomes Policy Asks, the result of a year-long collaboration between over 60 experts and organisations with the ambition to guide policy actions that European and national level policymakers can take to improve the long-term health and wellbeing of people living with HIV.



Stéphan Vernhes, HIV Outcomes Steering Group Member and Coordinator of the European Platform AIDES, provided a personal experience of living with HIV, highlighting the impact of stigma on mental health and psychological well-being. A minute's silence was then observed to remember all those that have died from AIDS.



Key takeaways:

The EU Health Commissioner Stella Kyriakides commended the ‘simple but powerful vision’ of the World AIDS Day event: ‘that all people living with HIV should enjoy the highest possible quality of life’. Commissioner Kyriakides praised the Policy Asks as an important step towards this shared vision. She confirmed that the establishment of the new EU Expert Group on Public Health will cover communicable diseases including HIV, in line with our advocacy efforts.

MEP Frédérique Ries (Renew Europe Vice-President, Belgium) championed the work of HIV Outcomes and welcomed the new report by the ECDC, commissioned by the European Parliament committee responsible for public health (ENVI).

The Policy Asks were launched and presented by HIV Outcomes Co-Chairs and Steering Group Members (Prof Jane Anderson, Prof Giovanni Guaraldi, Prof Jeffrey Lazarus, as well as Mario Cascio and Anton Basenko of the European AIDS Treatment Group (EATG)). The Policy Asks highlight the need for actions by HIV clinics/care providers, regional and national health authorities, and the EU.

HIV Outcomes Ambassador and World Health Organization (WHO) Special Envoy for Europe Dr. Vytenis Andriukaitis, commended HIV Outcomes for its work and called for best practices sharing among clinicians and community members to improve integrated, holistic care for people with HIV.



Outcome:

The event benefited from the participation of several high-level speakers (EU Health Commissioner, ECDC Principal Expert in Infectious Diseases, WHO Special Envoy for the European Region and cross-party Members of the European Parliament).

Over 60 people attended the event, and many others followed the web stream through HIV Outcomes' YouTube channel and the Parliament's website.

The event generated significant engagement on social media (19,400 organic impressions, 190 total clicks, 60 profile visits, 403 likes and 130 retweets) including reactions from the DG SANTE official account and several MEPs.

The high-level event was covered in DODS, POLITICO and the Health Policy Platform of the European Commission.

HIV OUTCOMES POLICY ASKS

This year saw the launch of the HIV Outcomes Policy Asks at our World AIDS Day high-level event at the European Parliament. This policy paper has been developed through collaboration among HIV Outcomes members across Europe, thereby ensuring multi-disciplinary expertise and balanced participation from organisations representing people with HIV, clinicians, academics, public health professionals and industry.

Even when HIV is effectively treated, people living with HIV remain at higher risk than the general population of developing a range of other serious health conditions (i.e. co-morbidities or multimorbidities). These include cancer, cardiovascular disease, and other physical disabilities, as well as depression and anxiety. The HIV Outcomes Policy Asks focus on tackling challenges and gaps in care for people with HIV and identifies areas of action for HIV clinics, care providers, national and sub-national health authorities, and the EU. The document touches upon four key areas where action is needed to improve health and well-being among people with HIV:



Comorbidity
prevention,
treatment and
management



Ageing
with HIV



Measurement
of PROMs and
monitoring of
HRQoL



Combatting
stigma and
discrimination

The recommendations in this policy paper aim to complement other initiatives that focus on HIV prevention, testing, universal access to treatment and care (including for migrants, refugees and internally displaced people), and 'getting to zero' – zero new infections, zero AIDS-related deaths, and zero discrimination – where significant efforts are still needed in many European countries.

JIAS
JOURNAL OF THE
INTERNATIONAL AIDS SOCIETY

**JOURNAL OF THE
INTERNATIONAL
AIDS SOCIETY (JIAS)**

Stemming from the Policy Asks document, our Co-Chairs and some of our Steering Group Members (Prof. Jeffrey Lazarus, Prof. Jane Anderson, Prof. Richard Harding, Mario Cascio, and Sini Pasanen) presented an abstract for the Journal of the International AIDS Society (JIAS) Supplement: "Person-centred approaches to address the health needs of people living with HIV and co-infections and co-morbidities". Our abstract was one of the 15 selected from over 50 submitted abstracts and the final paper entitled "Enhancing long-term health and well-being among people living with HIV" will be published in July 2023.

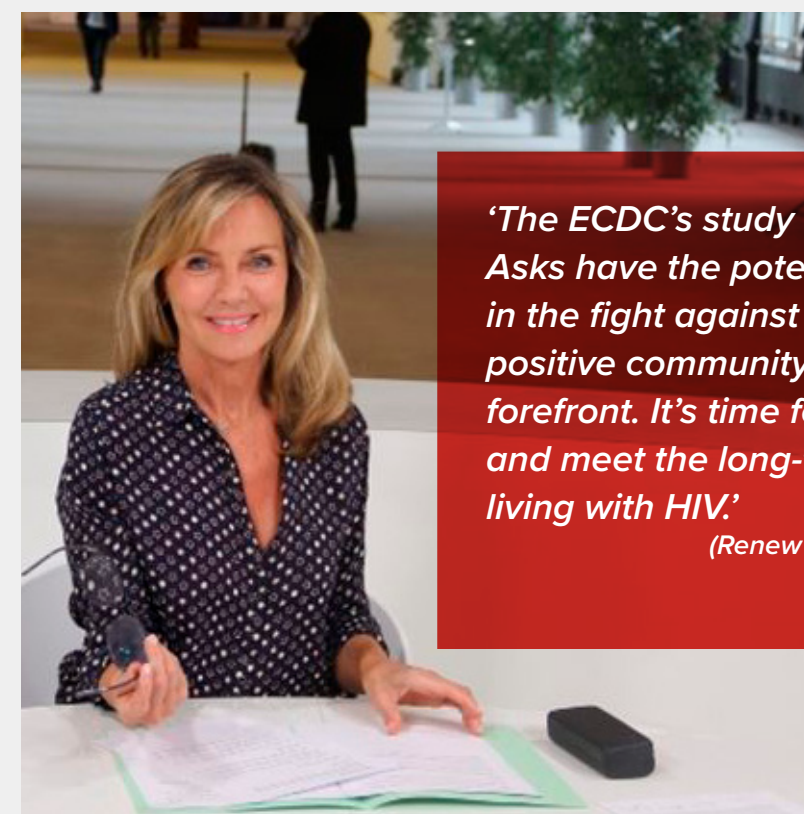
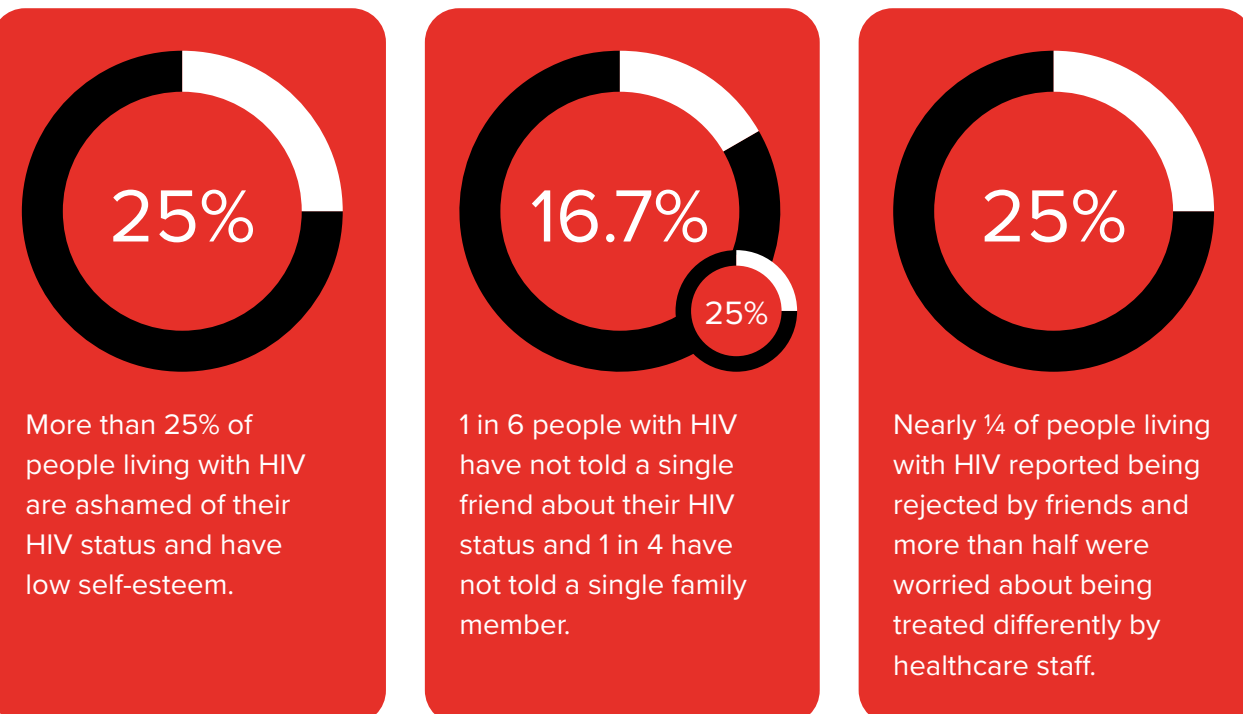
EUROPEAN PARLIAMENT STUDY ON THE LONG-TERM NEEDS OF PEOPLE LIVING WITH HIV

At the World AIDS Day event, the new ECDC report on the HRQoL of people living with HIV was launched. The study was commissioned by MEP Frédérique Ries with cross-party support from the European Parliament ENVI committee.

This paper aims to help policymakers and other stakeholders to get a better picture of the current situation in relation to people living with HIV in the EU, including HIV-related stigma and issues which impact on their HRQoL. The background paper aims to support discussion and to inform EU and national policy options to improve the HRQoL.

The main findings were presented by Dr Anastasia Pharris, Principal Expert on Infectious Diseases at the ECDC.

While the UNAIDS has a new target that less than 10% of people living with HIV and key populations should experience stigma, there is currently a lack of tools to measure stigma across countries.



'The ECDC's study and HIV Outcomes Policy Asks have the potential to open a new chapter in the fight against HIV by putting the HIV positive community and its well-being at the forefront. It's time for our policies to evolve and meet the long-term needs of people living with HIV.' – **MEP Frédérique Ries**
 (Renew Europe Vice-President, Belgium)



The ECDC report also highlights additional challenges to the health and well-being of individuals living with HIV, such as a higher incidence of co-infections like tuberculosis, hepatitis B and C, and comorbidities, including non-communicable diseases and mental health conditions. Furthermore, the report points to legal restrictions faced by people living with HIV in 48 countries worldwide.

Accelerated action in the following areas is suggested in order to reduce HIV incidence and to improve HRQoL for people living with HIV in the European Region:

- 1** Developing integrated, patient-centred, patient-involved services and approaches.
- 2** Improving measurement and expanding monitoring of HRQoL, including PROMs.
- 3** Monitoring and addressing HIV-related stigma, particularly in healthcare systems.
- 4** Assessing the impact of the COVID-19 pandemic on people living with HIV and on HIV services.

ROUNDTABLE EVENT

Delivering on political commitments to tackle HIV in France

While France seems to be on the right track to eliminate HIV by 2030, much remains to be done. Beyond the virus itself, the QoL of people living with HIV in France is a blind spot where French public policies are concerned. The HIV positive population does not enjoy the same QoL as the general population.

In this context, and for the first time, HIV Outcomes held a virtual roundtable event in France, bringing together key stakeholders in the fight against HIV to discuss concrete actions that French policymakers could take together to ensure that tackling the HIV epidemic remained a priority in France and Europe. The event took place in March during the French Presidency of the Council of the European Union and was attended by around 50 participants.



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@hivoutcomes
hivoutcomes.eu

**DELIVERING ON POLITICAL COMMITMENTS
TO TACKLE HIV IN FRANCE**
Roundtable discussion on the health-related quality of life of people living with HIV

**TENIR LES ENGAGEMENTS POLITIQUES
POUR LUTTER CONTRE LE VIH EN FRANCE**
Table ronde sur la qualité de vie liée à la santé des personnes vivant avec le VIH

This initiative is enabled by sponsorship provided by Gilead Sciences and ViiV Healthcare

Logos: AIDS ACTION EUROPE, NATIONAL AIDS TRUST, CHIVA, EA TG, AIDES, GILEAD, ViiV



#ZeroDiscriminationDay


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"This event comes at an important time as the French Presidency wants to prioritise well-being, health promotion and prevention. This gives the necessary impetus to put the quality of life and well-being of people living with HIV on the political agenda in France and in Europe. Nothing about us without us."

Stéphan Vernhes,
Coordinator European Platform AIDES &
HIV Outcomes Steering Group Member

Key recommendations emerging from the roundtable:



Need for a tool to measure the QoL of people living with HIV that can be used widely across Europe to facilitate comparisons between countries, regions and even hospitals;



The indicator for measuring HRQoL of people living with HIV should include physical, mental and social dimensions. Questionnaires assessing HRQoL should be short and used in healthcare settings on a regular basis;



Finance a health mediator role to facilitate contact and the exchange of information. Health mediators could serve as a bridge between the clinical health approach and the lived experience of people with HIV;



Mental health screening to be made mandatory for people living with HIV;



Strengthen the role of advocacy and support groups, which have been forward-thinking and proactive in their proposals for disease management;



Address stigma by making undetectability a national communication priority.

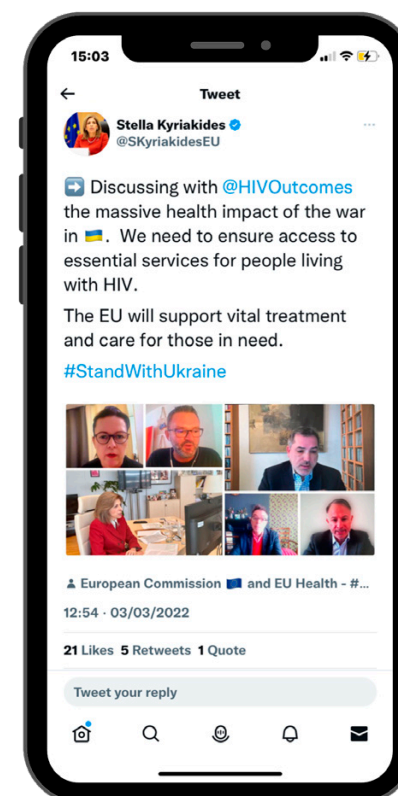
ADDRESSING THE NEEDS OF PEOPLE LIVING WITH HIV FLEEING UKRAINE

With the start of the war in Ukraine at the beginning of 2022, HIV Outcomes has extended its efforts to support the European Commission in addressing the needs of Ukrainian refugees living with HIV.



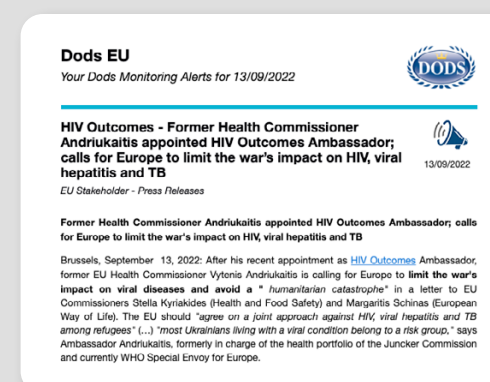
Meeting with EU Health Commissioner Kyriakides

In March, HIV Outcomes met with EU Health Commissioner Stella Kyriakides to discuss the effects of the war in Ukraine on people living with HIV and ways in which the Commission could further aid work related to HRQoL. The Commissioner acknowledged the importance of HIV Outcomes' work as a valuable source of information and support for addressing the health needs of the HIV community affected by the war in Ukraine.



We were delighted to hear from the Commissioner the value of the data points collected by HIV Outcomes on the impact of COVID on HIV care and services as a model of good practice and a significant support to her work. Additionally, the Commissioner reiterated her support for HIV Outcomes' agenda on HRQoL as the foundation for how health systems should be structured in the future.

Following the meeting with the Commissioner, we have cooperated with the national initiative in Romania to gather insights on the specific needs of Ukrainian refugees living with HIV. The collected input was then shared with the European Commission's Health Security Committee, in charge of providing guidance to Member States in their support of refugees fleeing Ukraine.



Letter to Commissioners and press release

Dr Vytenis Andriukaitis, former EU Health Commissioner and WHO Special Envoy for the European Region, joined HIV Outcomes as the Initiative's Ambassador in April.

To support our work around the needs of people living with HIV fleeing from Ukraine, Dr Andriukaitis sent a letter addressed to EU Commissioners Stella Kyriakides (Health and Food Safety) and Margaritis Schinas (European Way of Life), with the ambition of ensuring high care standards and well-being for refugees living with a viral condition.

The Ambassador also called for the mandate of the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases (SGPP), initiated during his tenure as Health Commissioner, to be extended to communicable diseases.

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POLICY ADVOCACY

POLICY ADVOCACY EU



ECDC Mandate Extension

In October, the European Parliament adopted the extension of the mandate of the ECDC. We have long advocated for the ECDC's extended capacities and resources to cover not only emerging viral threats, but also existing communicable diseases such as HIV.

Several of our suggestions were included in the final text, including the monitoring of existing prevalent communicable diseases such as HIV, and not just future viral threats. Additionally, our input was also included regarding guidance on enhancing national health systems' capacity for treating communicable diseases, testing and treatment surveillance, and data collection from vulnerable populations.

POLICY ADVOCACY EU



European Care Strategy and Council Recommendation on long-term care

In September, the European Commission presented the European Care Strategy, a comprehensive plan to improve the accessibility, affordability, and quality of care. A proposal for a Council Recommendation on affordable high-quality long-term care accompanies this strategy.

HIV Outcomes input was reflected in the final documents and was listed as one of the stakeholders who co-developed the Strategy. It is a major accomplishment that the Council adopted the Recommendation by the end of 2022 signalling a significant step forward in ensuring that individuals living with HIV have access to the care they need.

POLICY ADVOCACY EU



European Health Data Space

In May, the European Commission proposed a Regulation for a European Health Data Space, a health-specific framework for electronic health data sharing. The proposal aims to give individuals better access and control over their personal health data and allow for its secondary use in research and policymaking.

HIV Outcomes called for improvements in integrated care for people living with HIV and for stronger data security and privacy measures to prevent discrimination. Our vision is a proposal that goes beyond data collection and includes provisions for quality and value-based healthcare and a focus on quality of life.

POLICY ADVOCACY EU



New Member States Expert Group

In December, DG SANTE announced the establishment of a new Member States Expert Group to replace the current SGPP.

As a result of our advocacy efforts, the new group will cover communicable diseases, including HIV/AIDS, tuberculosis, and hepatitis. Notably, it was a key topic addressed in the letter sent by our Ambassador Dr Andriukaitis to EU Commissioners and in meetings with EU Health Commissioner Stella Kyriakides.

The new Expert Group, which brings together Member States, is an ideal forum for discussing best practices for promoting well-being and accelerating viral disease elimination, such as HIV. This represents a unique opportunity for the inclusion of the HRQoL of people living with HIV in the discussion.

POLICY ADVOCACY EU



Thematic Networks

HIV Outcomes supported the proposal, presented by the EU Civil Society Forum and coordinated by the EATG, for a Thematic Network on “HIV, Tuberculosis, viral hepatitis and Sexually Transmitted Infections”. A Thematic Network is a multi-actor project organised by the European Commission which collects existing knowledge and best practices on a given theme.

This Thematic Network will examine outstanding challenges through online workshops and will nurture collaboration among stakeholders to ensure continuity of prevention, treatment, care, and better quality of life for all people living with or most affected by HIV/AIDS and other infectious diseases, including an adapted response for migrant populations.

We are thrilled to support the EU Civil Society Forum in developing a Joint Statement that might be further supported and promoted by the Commission in policy papers and programmes.

POLICY ADVOCACY WHO European Region



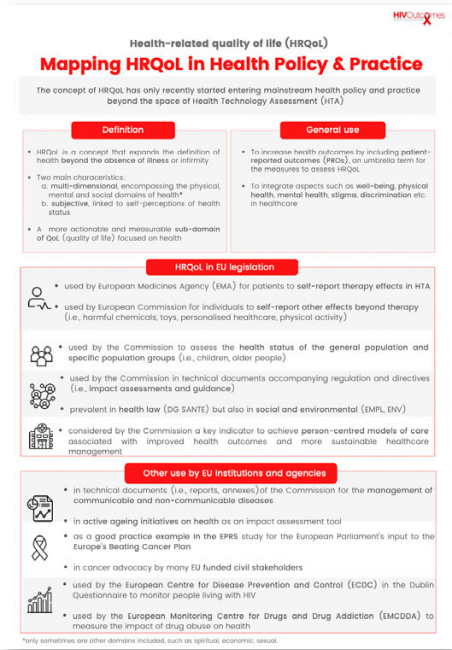
WHO Global Health Sector Strategies for HIV, Viral Hepatitis and Sexually Transmitted Infections for 2022-2030

In June, the WHO published the Global Health Sector Strategies for HIV, Viral Hepatitis, and Sexually Transmitted Infections (GHSS) for 2022-2030. This new strategy, approved at the 75th World Health Assembly, sets out a common vision to put an end to the HIV, Viral Hepatitis, and STIs epidemics, while also taking an individualised approach to each disease area.

Our input has been instrumental in shaping the GHSS, as we have successfully advocated for the inclusion of a new key outcome for health service delivery: HRQoL. This is a historic first for HIV Outcomes and marks a significant step forward in our efforts to improve the lives of people living with HIV.

The inclusion of HRQoL in the GHSS is not only a great achievement for HIV Outcomes but also represents a step forward in monitoring the health and well-being of people living with HIV.

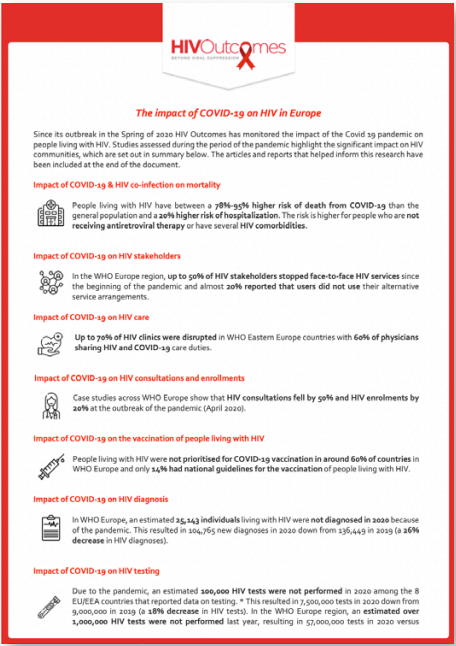
EVIDENCE GENERATION



HRQoL Mapping

We have mapped the use of HRQoL in the European Union institutions and agencies, as well as in global health organisations present in the WHO European Region, spanning the last 20 years. This exercise follows the recommendation of the European Commission DG SANTE which encouraged us to map the concept and use the assessment to educate European policymakers.

The concept of HRQoL can be traced back to the 1970s but has recently been adopted in health policy and practice beyond clinical trials. It is widely used in EU legislation and in non-legislative documents in health technology assessment. The concept has been expanded for self-reported health outcomes, and aligns with the WHO's 1948 definition of health, recognising its subjective and multi-disciplinary nature. HRQoL is well-established beyond the EU in the context of the OECD and is gaining traction in the WHO's work.



Report on the impact of COVID-19 on HIV services

Since the outbreak of the COVID-19 pandemic, HIV Outcomes has monitored the impact of this health crisis on people living with HIV, their health services and the civil organisations supporting them.

At the EU Health Commissioner's request, we have produced a short report highlighting the impact of COVID-19 on HIV services and care in Europe.



Animated video

We developed an animated video highlighting the impact of comorbidities on the HRQoL of people living with HIV to encourage EU policymakers to address the problems faced by those ageing with HIV. The video tells the story of Alex, a person living with HIV who is virally suppressed but still has many comorbidities, such as cancer, sleep disorders, mental health issues, and other non-communicable diseases. The video was disseminated on HIV Outcomes social media and website, as well as displayed at the World AIDS Day event, in the European Parliament.

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NATIONAL LEVEL WORK

NATIONAL LEVEL WORK



Germany



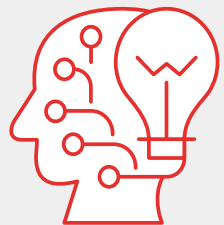
EVIDENCE GENERATION

- Informative materials were produced and disseminated on the importance for HIV care and prevention in Germany.
- Ideas were disseminated for improving the availability of pre-exposure prophylaxis (PrEP), focusing on extended extra-budgetary remuneration, availability in rural areas, and extended outreach to key groups.
- A plea was sent to political and civic actors on World AIDS Day, requesting year-round attention to the fight against HIV and AIDS.



ADVOCACY

- The German HIV Outcomes team met with newly-elected MP Tessa Ganserer (German Green Party, the first trans woman in the German federal parliament) and discussed stigma and discrimination, PrEP availability, health communication, and global cooperation.



MULTIPLIERS

- HIV Outcomes Germany attended the Munich AIDS and COVID Days, a medical conference where the initiative, its members and policy proposals were presented.



Italy



EVIDENCE GENERATION

- Informative materials about the initiative were produced and disseminated.
- An advocacy toolbox on the HRQoL of people living with HIV was developed and included six Italian good practices.
- Two large-scale surveys were conducted, addressing stigma faced by people living with HIV in Italian residential care homes and hospitals.



ADVOCACY

- Informative materials were disseminated among the main Italian institutional stakeholders, such as the Ministry of Health and members of the Technical Health Committee.
- HIV Outcomes Italy achieved Italian institutional stakeholders' support for the extension of the mandate of the European Commission SGPP, and the need for long-term care of people living with HIV in the European Care Strategy.
- A new institutional framework and mapping of new policymakers was developed.



MULTIPLIERS

- HIV Outcomes Italy participated in the 14th Italian Conference on AIDS and Antiviral Research and the 21st National Congress of the Italian Society of Infectious and Tropical Diseases. The role of communities and the need for bottom-up participation was highlighted.

NATIONAL LEVEL WORK



Romania



EVIDENCE GENERATION

- A Joint Statement was developed following a high-level roundtable convened by Prof Dr Adrian Streinu Cerel (Chair of the Senate's Health Committee). The roundtable brought together over 70 national experts on the need to address the HRQoL of people with HIV in Romania.
- A joint letter on the importance of swiftly adopting a National HIV Strategy focusing on HRQoL was drafted together with patient organisations (UNOPA), NGOs and other HIV stakeholders.
- Policy recommendations on the HRQoL of people living with HIV were produced, as well as informative materials, both in English and Romanian.



ADVOCACY

- The Independent Expert of the United Nations High Commissioner for Human Rights recognised HIV Outcomes Romania's contribution to the evaluation report on sexual and gender discrimination.
- Following various advocacy campaigns, HRQoL measurement was included in the Romanian National HIV Care Plans 2022-2024, in the National Healthcare Strategy 2022-2030, and in the Action Plan of the National Strategy for Sustainable Development 2030.
- The initiative presented its main policy asks to the Romanian Presidency, the General Secretariat of the Government, the Ministers of Health and Labour, as well as the Parliament Health Committee's Chairs and MPs.



MULTIPLIERS

- HIV Outcomes Romania participated in the high-level roundtable on "HIV Infection – Where to? The New HIV National Strategy 2022-2030", co-organised with the Senate's Chair of the Health Committee and the Health Minister.
- HIV Outcomes Romania successfully raised awareness on the relevance of HRQoL in eight high-level policy events led by the HIV community, policymakers, industry and key opinion leaders.



Spain



EVIDENCE GENERATION

- The Spanish version of the Policy Asks was developed and disseminated.
- The HIV Outcomes input to the European Care Strategy was translated and adapted for dissemination to Spanish stakeholders.



ADVOCACY

- A meeting was held with experts on comorbidity and discrimination against people living with HIV. Participants included healthcare professionals, regional HIV representatives, the HIV community, and NGOs.
- Spanish Ministries received the HIV Outcomes input to the European Care Strategy.



MULTIPLIERS

- HIV Outcomes Spain participated in the XX National Meeting on HIV and STIs, sharing views on the importance of mental health.
- The initiative also took part in the conference "Does Stigma and Discrimination Still Exist?" to present various studies on stigma and discrimination faced by people living with HIV.

2022 SOCIAL MEDIA IMPACT

The online presence of HIV Outcomes has registered steady growth

HIV Outcomes' online presence is a valuable asset as public affairs activities become largely digital



164

posts in 2022

almost

25,000

profile visits in 2022

+222

followers in 2022

80,400

impressions in 2022



123

posts 2022

38,160

impressions 2022

639

profile visits 2022

+216

followers 2022



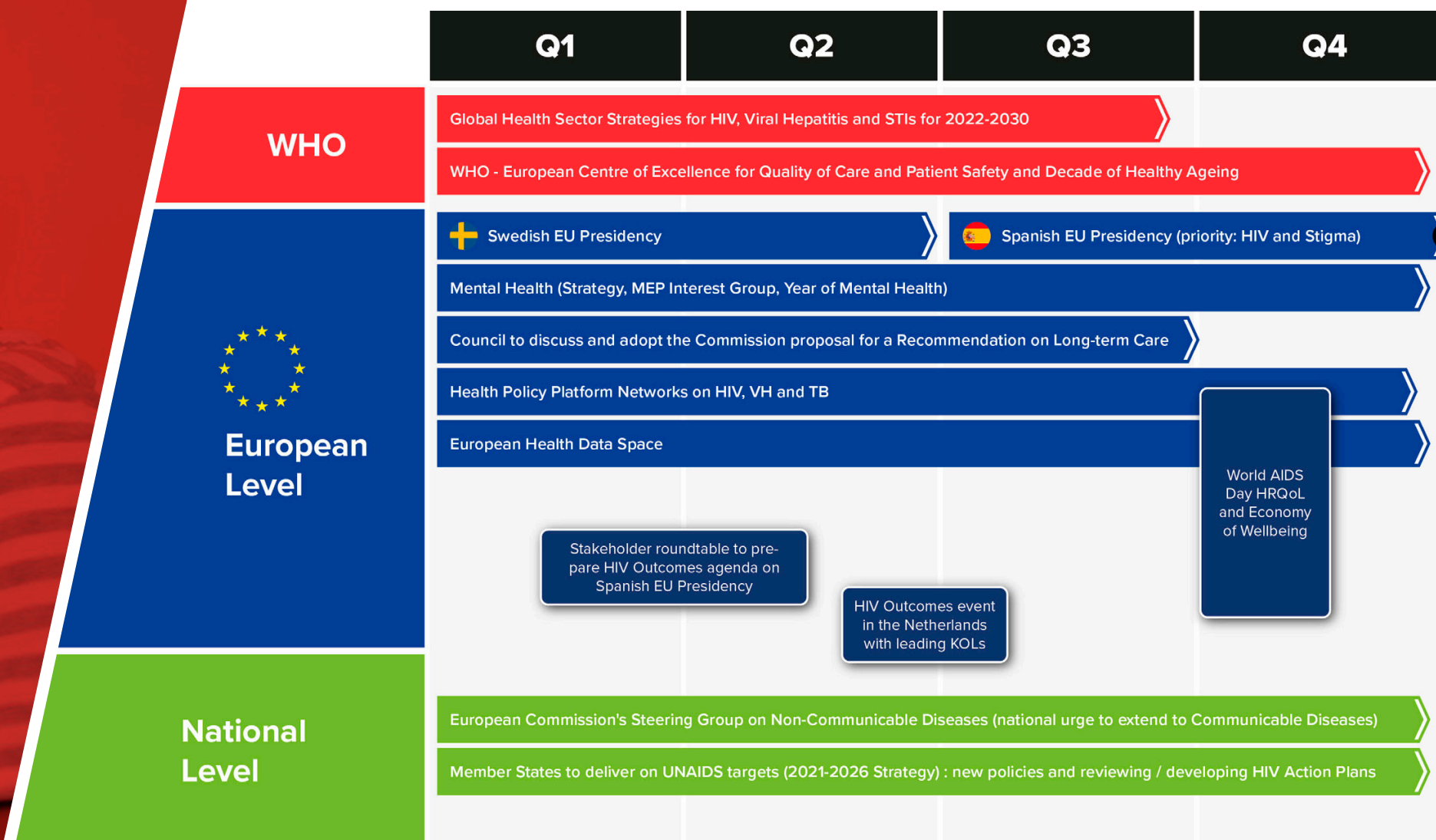
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BEYOND VIRAL SUPPRESSION

LOOKING FORWARD — OUR 2023 WORK PLAN

In 2023, we will continue to build political support and policy measures at national and EU-level to deliver integrated person-centred healthcare and clinical changes.

ADVOCACY OPPORTUNITIES - POLITICAL AND POLICY HOOKS

The timeline is indicative



Strategy priorities

- 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 U=U message into EU and national policies to prevent and treat HIV

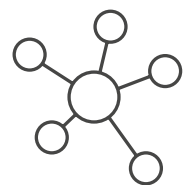
2023 objectives

- 1 Leverage the updated Policy Asks
- 2 Engage EU Presidencies on HIV Outcomes agenda
- 3 Contribute to a common understanding of HRQoL for people living with HIV
- 4 Explore extending HIV Outcomes to the Netherlands

USEFUL LINKS




**Policy
Asks**



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



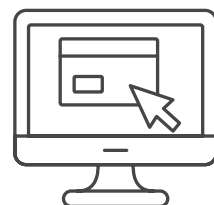
**Advocacy
Toolbox**



**Mapping on the use
of HRQoL in Health
Policy & Practice**



**Consensus
Statement**



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