

2021 Annual
Review

HIVOutcomes
BEYOND VIRAL SUPPRESSION

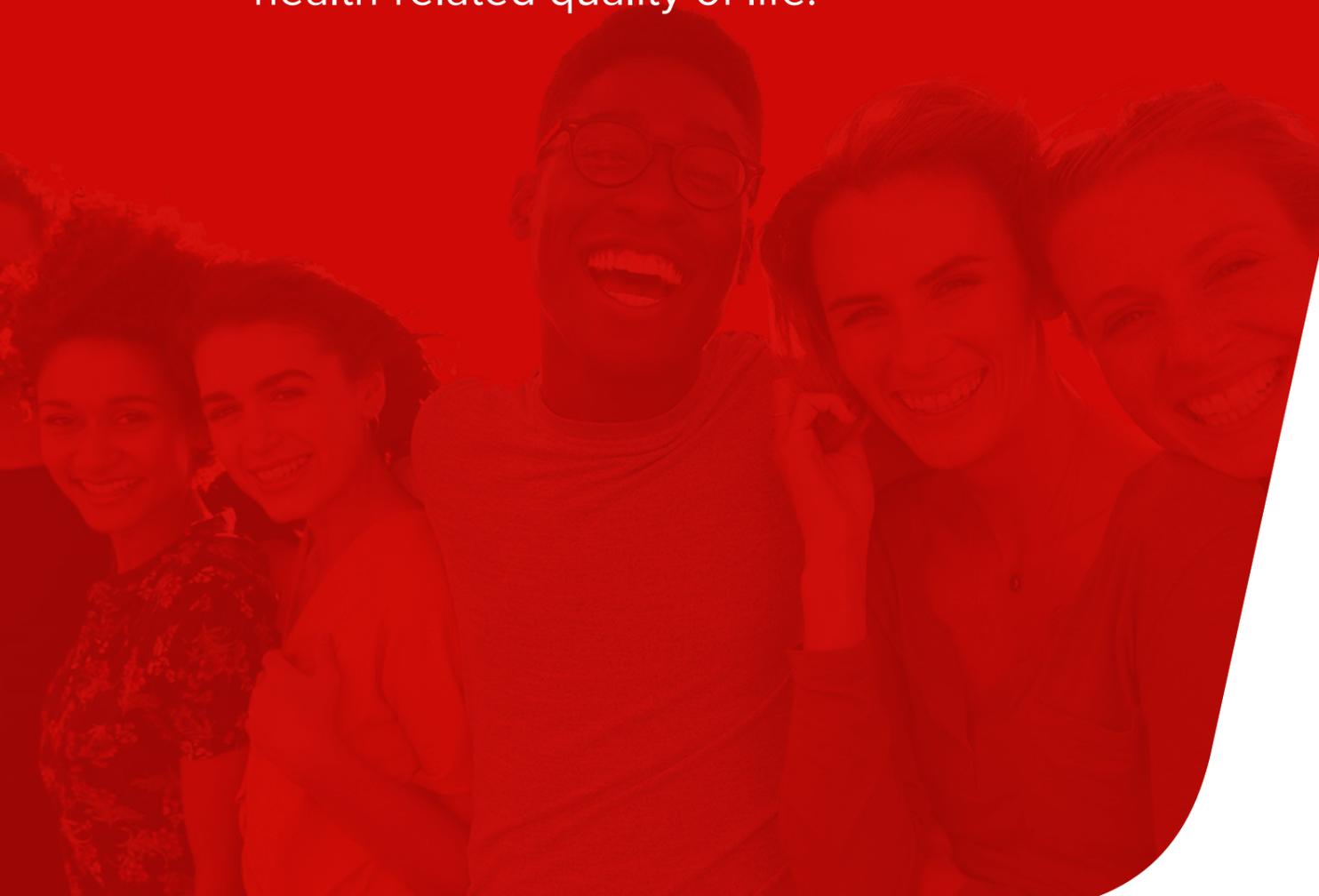




HIV Outcomes began its journey in 2016 by bringing together patients, healthcare professionals, academics, public institutions, and industry to align on a new agenda to address the unmet health needs of people living with HIV, to ensure that they can maximise their health-related quality of life.

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Health-Related Quality of Life

Despite the historic breakthroughs in treatment and prevention, the health-related quality of life (HRQoL) of people living with HIV is not comparable to that of the rest of the population. But what do we mean by HRQoL? Why does it matter and how do we measure it?

HIV Outcomes works to define HRQoL as a construct that captures an individual's perceptions of his or her well-being in health-related aspects of life, with the concept of health understood to encompass physical, mental, and social dimensions.

Across Europe, we are witnessing how HRQoL becomes a guiding light when seeking to address the long-term well-being of people living with HIV. With this in mind, it is notable that even if only 5 out of 48 countries in Europe currently include HRQoL in their HIV monitoring, HRQoL has consistently 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.

HIV-related stigma remains pervasive across Europe and can lead to the under-utilisation of health services by people living with HIV and ultimately to poorer health outcomes. A 2016 survey conducted in 48 countries by the European Centre for Disease Prevention and Control (ECDC) highlighted stigma and discrimination among health workers as common barriers to the uptake of HIV services. Moreover, HIV-related stigma is associated with lower adherence to antiretroviral therapy (ART) and greater incidence of depression and mental distress. For this reason UNAIDS has included a new 2025 target: less than 10% of

people living with HIV should experience stigma and discrimination, with sub-targets addressing internalized stigma and experiences in health settings or with law enforcement.

The significant increase in life expectancy for people living with HIV across Europe has often failed to be matched by needed legal change. So, whilst most countries have repealed laws barring employment or travel entry based on HIV status, many discriminatory laws persist. Moreover, discrimination in healthcare settings is routinely reported, with approximately 1 in 8 people living with HIV estimated to have

been denied healthcare. Episodes of forced disclosure of HIV status or restricted or limited access to financial services also continue to be reported. Therefore, UNAIDS has included targets on punitive laws and policies among its 2025 AIDS Targets. By 2025, less than 10% of countries should be criminalizing sex work, same-sexual behaviour, HIV transmission, etc.

Despite being virally suppressed, people living with HIV are at higher risk of comorbidities and often have multimorbidity at younger ages than those without HIV. Some comorbidities are generally monitored, like tuberculosis and

“ We need to respond and address inequalities, including those that exist for people living with HIV in regard to HRQoL ”

EU Health Commissioner
Stella Kyriakides



FOREWORD



John Bowis
Co-President,
HIV Outcomes

2021: a historic year for the fight against HIV.

In 2021, the world commemorated 40 years of HIV fight. HIV Outcomes and its members took the occasion to celebrate the great progress to date and consider the changing needs of the HIV population four decades later. The achievements of the past should push us forward, not make us complacent.



Thanks to treatment advances, life expectancy has significantly increased for people living with HIV. Unfortunately, those living with the disease face continuing stigma and discrimination alongside having to deal with significant comorbidities and the impact of ageing. These affect their well-being and impede a full HRQoL comparable to that of the general population.

For the past years, we have campaigned for a natural continuation of HIV policy into issues beyond viral suppression, so people living with HIV can also live long and healthy lives. The exclusive focus on treatment is a two-edged sword having on the one hand led to game changing breakthroughs in treatment, whilst on the other neglecting aspects of the care process such that the HIV population will not reap the full benefits of treatment advances. Four decades on, it is time we end the health inequalities that persist between the general and the HIV population.

COVID-19 has only made the continuation into issues beyond viral suppression more urgent. We are beginning

to learn how the pandemic has made life harder for people living with HIV. For example, evidence across Europe shows a worsening of the already fragile mental health of this population, with many reporting a doubling in levels of stigma, anxiety, and depression. Unless policies targeting HRQoL are introduced swiftly, the well-being of people living with HIV will continue to lag.

In 2021, HIV Outcomes engaged with stakeholders at national- and EU-level for HRQoL to feature more prominently in the policy agenda. To inform these discussions, we made use of our new Advocacy Toolbox – which explains in simple terms what HRQoL is and what its main challenges are – and a Consensus Statement lead authored by our Co-Chairs and signed by over 90 individuals and organisations, which highlighted the role of health systems in improving HRQoL.

Thanks to collaborations such as these, the well-being and HRQoL of people living with HIV were anchored in relevant EU efforts. I am particularly delighted that a study on how health systems are meeting the long-term needs of people living with HIV has been requested by the European Parliament. As no systematic attention has been paid to the well-being of the HIV population, a robust evidence base will be an essential platform for decision-makers to cover the unmet needs of those living with HIV in Europe.

This year, we also strengthened our partnership with global actors such as UNAIDS and WHO. As many people living with HIV in Europe are virally suppressed, we were invited to contribute to the UNAIDS Global AIDS Strategy for 2021-2026 and the WHO Global Health Sector Strategy on HIV for 2022-2030, for these to protect and improve well-being for the HIV population.

I am very proud of the work carried out in 2021 to build momentum around HRQoL together with our national and global partners. The year 2022 is an opportunity to capitalise on our previous efforts and deliver positive and meaningful change for the HIV population. The well-being of people living with HIV matters!

FOREWORD



Dr. Jane Anderson
Consultant physician in
HIV medicine, Homerton
University Hospital NHS
Foundation Trust, United
Kingdom



Nikos Dedes
President Positive
Voice, Greece



Dr. Jeffrey Lazarus
Head of Health
Systems Research
Group at ISGLOBAL,
Spain

A new chapter is unfolding in which there is a strong push for the well-being of people living with HIV to be prioritised.

2021 marked forty years since the first cases of AIDS were reported. On this symbolic anniversary, many across Europe learned that whilst important battles have been won HIV is far from over. It is entering a crucial new stage that requires a focus on well-being and HRQoL. With a significant increase in life expectancy, more attention is required on well-being and issues that go beyond the current focus on viral suppression. Whilst this trend must continue and even accelerate, the reality is that most decisionmakers in Europe still associate the HIV end-game as only suppressing the virus.

This is why HIV Outcomes advocacy has been to anchor HIV policies in the concept HRQoL – an umbrella term



that captures the many issues that compromise the well-being of all people living with HIV. The last year has highlighted that the concept is well-known in clinical and academic settings but only now beginning to enter the health policy landscape. It was gratifying to see HRQoL gaining prominence in the field of oncology, and the momentum generated needs to take the agenda into other disease areas including HIV.

The future looks promising and, more than ever, we are convinced of the need to raise awareness of the value of HRQoL across the HIV response.

From the perspective of people living with HIV, HRQoL needs to be given the prominence it deserves in the policy process. The shift towards HRQoL is welcome

news for those living with a condition that too often damages lives with its high psychosocial and physical burden. HRQoL is a tool that can facilitate both long and healthy lives for people living with HIV. As highlighted by Health Commissioner Stella Kyriakides at our World AIDS Day event, the focus must shift from the virus to the people living with the virus and their long-term unmet needs.

From a clinician perspective, the widespread use of HRQoL in clinical settings across Europe can facilitate a shift to truly person-centred care. Our compendium of best-practices demonstrates that when HRQoL is included long-term interventions are better able to deliver high quality HIV-related care. HRQoL is particularly helpful in the identification and measurement of the multidimensional challenges to the wellbeing of people living with HIV and ultimately in addressing them. This enables the appropriate level of care across all health dimensions: physical, mental and social.

From an academic standpoint, HRQoL offers those teaching and researching in the field of HIV a powerful construct that allows for the well-being of people living with HIV to be studied and advanced by encompassing the physical, mental and social dimensions of health. Whilst consensus on a working definition is only beginning to emerge, HIV Outcomes provides scholars an opportunity to discuss, refine and disseminate the concept, facilitating its adoption across academic, policy and clinical settings.

As 2021 closes we are delighted that the efforts of the HIV Outcomes Initiative on HRQoL are bearing fruit. As we enter 2022, we look forward to building on this foundation to translate knowledge into action and see HRQoL become a new benchmark in assessing progress in the global ambition to end the threat of HIV by 2030.

“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 the HIV population, it is imperative that we move beyond the traditional focus on viral suppression to ensure that the HIV population not only live long but also healthy lives.

Our mission is to raise awareness around the value of HRQoL for people living with HIV, so that it is featured more prominently in HIV policy. This way, we ensure that policymakers pay due attention and address the issues challenging 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 bring in and 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 present in Germany, Italy, Romania, Spain, and the United Kingdom.

HIVOutcomes
BEYOND VIRAL SUPPRESSION 

HOW WE WORK

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.

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.

IMPLEMENT



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

OUR INITIATIVE



OUR OBJECTIVES FOR 2021

In 2021, our priority was to articulate and define good long-term health outcomes and quality of life beyond viral suppression, to incorporate co-infections and comorbidities, discrimination and prejudice. To that end, we focused our efforts in promoting the prioritization of these aims in the UNAIDS Strategy, the wider policy debates on HIV at the European level, as well as in related HIV Plans and Strategies.

At the national level, we have worked with our in-country initiatives in Germany, Romania, and Italy to align national and European advocacy as well as build new engagement plans in England and Spain.

debate around long-neglected themes in HIV, such as the importance of healthcare services reconfiguration, the potential impact of COVID on access to care, and the impact of comorbidities, including long COVID-19.

COVID-19 has given us the opportunity to upscale our advocacy and launch a fruitful



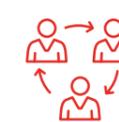
OUR 2021 WORK PLAN



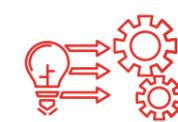
Advocate at European level to keep HIV on the policy agenda and encourage the prioritization of long-term outcomes and HRQoL of people living with HIV.



Increase global level engagement to advocate for the next phase of the HIV response.



Draw together available evidence on good long-term health outcomes and HRQoL for people living with HIV in support of advocacy activities.



Identify and exploit synergies across similar communicable disease areas.



Align activities to health policy priorities including mental health and healthy ageing.



WHAT WE ACHIEVED IN 2021

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SATELLITE SYMPOSIUM AT IAS CONFERENCE 2021 ON THE IMPACT OF COVID-19 ON HIV

IAS 2021
18-21 July




The COVID-19 pandemic poses a significant challenge to the well-being and HRQoL of people living with HIV. In July, HIV Outcomes Europe and HIV Outcomes Germany co-hosted at the IAS Conference 2021 the satellite symposium 'Supporting health-related quality of life for people living with HIV: Lessons and learnings from the COVID-19 pandemic'. Attended by over 140 people and moderated by HIV Outcomes Co-President John Bowis, the purpose was to learn how COVID-19 can greatly amplify the challenges to the HRQoL of people living with HIV. The IAS Conference is one of the world's most influential meetings on HIV research and its applications and is attended by world-class scientists and national and EU-level policymakers interested in the latest breakthroughs in HIV and their potential application in science and policy.



A major conclusion emanating from the Conference was that the HRQoL framework can be used to identify and address the issues affecting people living with HIV who are experiencing short- and long-term COVID symptoms. HRQoL can also be used to measure and address the impact of COVID-related disruptions on the mental health and co-morbidity management of those who have (or not) had COVID.

For example, there has been a dramatic increase in the incidence of mental health issues among people living with HIV with reports of double-stigma resulting from being HIV and COVID-19 positive. To date health systems have often proved ill-equipped to meet these challenges holistically, resulting in the well-being of the HIV population continuing to be negatively impacted.

For healthcare systems to protect and improve the well-being of people living with HIV in COVID times, we must gradually move towards long-term models of care, where an orientation towards HRQoL can facilitate holistic and person-centred care.

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

In December 2021, the European Parliament Committee on the Environment, Public Health and Food Safety (ENVI) approved the request by MEP Frédérique Ries (Renew Europe Vice-President, Belgium) for a study on the long-term needs of people living with HIV. Endorsed by the main political groups at the European Parliament, the breakthrough study is expected to begin in early 2022.

In the past decades, life expectancy has greatly increased for people living with HIV across Europe. This creates complex care needs coming from a growing number of people living with HIV, whose HRQoL is lower than the general population principally as a result of stigma, discrimination and a higher risk of comorbidities.

In light of this, the study aims to build a robust evidence base to support and guide healthcare systems in addressing such issues and improving the HRQoL and overall well-being of people living with HIV.

The study will look at the current status in each of the EU27 Member States, providing an overview of the utilization of QoL and HRQoL measures as well as the range of services available for people living with HIV.

Resolution on “Accelerating progress and tackling inequalities towards ending AIDS as a public health threat by 2030”

In May 2021, the European Parliament approved a Resolution outlining concrete actions to end AIDS in Europe through a multi-sectorial approach and multi-level cooperation. Supported by the efforts by HIV Outcomes, the Resolution recognised the need to advance the quality of life and well-being of people living with HIV throughout the lifespan. The Resolution also prioritised the fight against stigma and discrimination, which are key determinants to the HRQoL of people living with HIV.

MEP Frédérique Ries Op-ed at the Parliament Magazine

THE PARLIAMENT
 POLITICS, POLICY AND PEOPLE **MAGAZINE**

OPINION | MEP AWARDS | INTERVIEWS | PM+ | POLICY | MAGAZINE | EVENTS

The revolution in HIV demands an EU response, explains Frédérique Ries

We should celebrate the stunning progress in HIV survival rates, while putting health-related quality of life at the centre of policy, says Belgian Renew Europe Group MEP

Further to her request, MEP Frédérique Ries wrote an article in The Parliament Magazine, entitled ‘The revolution in HIV demands an EU response’. MEP Ries argued that the study is pertinent, in view of the growing demand for a better HIV response at the national and European level, with a focus on the long-term needs and well-being of people living with HIV, as well as concrete steps for policy-makers on how to end stigma and discrimination. “By working with people living with HIV, by sharing best practices and by collecting data on health-related quality of life, we can build on the tremendous progress we have witnessed since the first AIDS cases were reported,” MEP Ries concluded.

 The Parliament Magazine
 @Parlimag

Belgian @RenewEurope MEP @Frederiquerries on why her proposal for an in-depth study on effective #HIV practices will help in highlighting #EU & Member State policy gaps & assist in putting people at the centre of policymaking. bit.ly/3peTU1L
 @EP_Environment @HIVOutcomes



WORLD AIDS DAY 1 DECEMBER 2021

WITH THE PARTICIPATION OF
Stella Kyriakides
European Commissioner for
Health and Food Safety

HIV 40 YEARS ON
*Time to focus now on
health-related quality of life!*

H I G H - L E V E L C O N F E R E N C E

HOSTED BY

FRÉDÉRIQUE RIES
Member of the European
Parliament, Renew
Europe Vice-President,
Belgium

CYRUS ENGERER
Member of the European
Parliament, Progressive
Alliance of Socialists and
Democrats (S&D), Malta

FRANCES FITZGERALD
Member of the European
Parliament, European
People's Party (EPP), Ireland

World AIDS Day
1 December 2021
10:00-12:00 CET

AIDS ACTION EUROPE **NATIONAL AIDS TRUST**
CHIVA **AIDES**
EA TG **European AIDS Treatment Group** **GILEAD** **Viiv Healthcare**

This initiative is enabled by sponsorships provided by Gilead Sciences and Viiv Healthcare

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HIV 40 YEARS ON: TIME TO FOCUS ON HEALTH-RELATED QUALITY OF LIFE

2021 marked the 40th anniversary since the first cases of AIDS were reported. HIV is no longer necessarily a death sentence and substantial progress has been made since 1981. However, people living with HIV still do not enjoy the same HRQoL as the rest of the population. On World AIDS Day 2021, we convened a high-level conference to explore the policy actions needed to enable greater emphasis on HRQoL to deliver tangible value to people living with HIV.

Key takeaways:

- The EU Health Commissioner gave her support to the concept of HRQoL for people living with HIV and there was a discussion relating to potential value of adding Communicable Diseases to the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases.
- MEP Frédérique Ries (Renew Europe, Belgium) announced that the European Parliament's Health Committee will be requesting a study on the HRQoL of people living with HIV. This follows 2019 HIV Outcomes Call to Action which was calling on MEPs to commission a study from the Parliament's Research Services to understand the evolution of HIV as a long-term condition.

Outcome

- The event benefited from the participation of several high-level speakers (EU Health Commissioner, UNAIDS Special Adviser, cross-party support from Members of the European Parliament).
- Over 130 people attended the event which was web streamed on four platforms (Zoom, HIV Outcomes website, HIV Outcomes LinkedIn and HIV Outcomes YouTube)
- The event generated significant engagement on social media with (27,000 organic impressions, 113 registration clicks, 68 profile visits, 251 likes and 120 retweets)
- Health Commissioner Kyriakides, the DG SANTE official account and several MEPs tweeted or retweeted HIV Outcomes posts.
- The high-level conference was covered in the institutional press release of the European Commission.

#WorldAIDSday2021 HIVOutcomes

"Too often, we focus on the disease, and not on the person behind the disease. That needs to change. We need to put fundamental human rights first, so that we can end stigma and discrimination. This means making HIV services easily accessible and to tailor health services to the needs of patients. We also need new approaches to prevention, treatment and care. Thanks to treatment advances, life expectancy has already significantly increased for people living with HIV and the HIV population is larger than ever. But we can and must do more."

Stella Kyriakides, EU Health Commissioner

#WorldAIDSday2021 HIVOutcomes

"It is time for a paradigm shift beyond viral suppression. For 40 years, the HIV population has waited policy action on the issues affecting their health-related quality of life."

MEP Frances Fitzgerald,
European People's Party (EPP),
Ireland

#WorldAIDSday2021 HIVOutcomes

"Four decades on we now have effective prevention and treatment for people living with HIV. But stigma, discrimination and mental health challenges still exist and my study commissioned by the Parliament will assess and help develop policies to remedy them. People living with HIV deserve a better quality of life, and it's time to deliver."

Frédérique Ries, MEP and
Renew Europe Vice-President,
Belgium

#WorldAIDSday2021 HIVOutcomes

"We should try our best to draw on the many lessons learned from the COVID-19 pandemic. We must adapt to meet the emerging needs of people living with long-term conditions such as HIV."

Vinay P. Saldanha,
UNAIDS Special Adviser to the
Executive Director

#WorldAIDSday2021 HIVOutcomes

"We have tools to improve the health-related quality of life of people living with HIV. Let's build on the good practices collected over the years. Let's secure the political commitment!"

MEP Cyrus Engerer,
Socialists & Democrats in Europe
(S&D), Malta

EU POLICY ADVOCACY

MEETING WITH EUROPEAN COMMISSION DG SANTE

In September, HIV Outcomes met with the European Commission, Directorate General for Health (DG SANTE) to discuss the potential extension into Communicable Diseases (CD) of the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases, to facilitate the uptake of best practices on HRQoL for people living with HIV across Europe.

This Steering Group was set up for DG SANTE to select and share with Member States good practices in the Non-Communicable Diseases area towards meeting the UN targets and supporting their implementation. DG SANTE acknowledged the work done and the best practices on HRQoL collected by HIV Outcomes over the years and noted that there will be a place for their submission into the Steering Group should it be extended to include communicable diseases. The value of the concept of HRQoL for policymaking was also discussed and DG SANTE committed to exploring how best to capitalise on the expertise of HIV Outcomes.



MEETING WITH EU HEALTH COMMISSIONER KYRIAKIDES

In November, HIV Outcomes met virtually with the EU Health Commissioner Stella Kyriakides. The invitation followed the recognition of our work and expertise in the HRQoL space. At the meeting, the Commissioner expressed her commitment to addressing the inequalities that exist regarding HRQoL for people living with HIV across Europe. We were delighted to hear from the Commissioner about the proposed extension into communicable diseases of the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases – an extension strongly supported by HIV Outcomes and its partners as it may facilitate the uptake of best-practices on HRQoL for people living with HIV across Europe. The Commissioner was concerned about the impact of COVID-19 on people living with HIV and HIV services and asked HIV Outcomes to brief her on this topic at a second meeting in 2022.



ECDC MANDATE EXTENSION

The ECDC is the EU health agency in charge of the monitoring and surveillance of viral diseases. Given the lessons of the COVID-19 pandemic, the European Commission decided to expand the resources and capacities of the ECDC, to improve the agency's data collection to prevent major outbreaks from future viral diseases.

For HIV Outcomes, such extension presented with the opportunity to also expand data collection on HIV, especially around HRQoL, with the Initiative putting forward the case for the 'reinforced' capacities to target not only future viral threats but also prevalent diseases such as HIV. We are pleased that the European Parliament and the Council of the European Union have responded positively to the case we made and factored in our concerns and the mandate extension – that will go into force in 2022 – will significantly expand data collection around HIV.



ECDC – Input to Dublin Questionnaire

The ECDC invited HIV Outcomes to review and input on the questions on Quality of Life in the ECDC's new Dublin Questionnaire. HIV Outcomes suggested that mental health be featured more prominently, requested more clarity on the use of HRQoL across Europe, as well as calling for further consideration of the role of polypharmacy, which is often relevant for people living with HIV who suffer from a higher risk of comorbidities. Since 2019, the ECDC has monitored the HIV response of EU/EEA countries annually with the Dublin Questionnaire following UNAIDS' pledge to report annually on the progress against HIV response in Europe.



European Parliament's report on 'The situation of sexual and reproductive health and rights in the EU, in the frame of women's health'



In June, a long-awaited report on Sexual and Reproductive Health was approved and published by the European Parliament Committee on Women's Rights and Gender Equality following a yearlong of work.

In line with our suggestions, the Report factored in the need to consider the impact of COVID on HIV testing and called on Member States to ensure that people living with HIV can also enjoy their sexual and reproductive health rights. HIV Outcomes had previously emphasised that HIV-related stigma and discrimination often bar the HIV population from adequate sexual and reproductive care.

- Elimination of HIV-related stigma and discrimination to ensure people living with HIV and/or STIs can receive adequate care and enjoy their sexual and reproductive health rights.
- Better health literacy on HIV and other STIs to end discriminative practices and tackle stigma in both social and healthcare settings.
- Integrated systems of care and targeted screening protocols to improve the quality of life and long-term health outcomes of people living with HIV and other STIs.
- Action to address the disruptions in the provision of HIV and STIs services caused by the COVID-19 pandemic.



European Commission's Green Paper on Ageing

The European Commission's Green Paper on Ageing is a non-legislative initiative to assess if European social protection and healthcare systems can deal with the challenges created by Europe's population ageing. HIV Outcomes responded to the consultation call on the Green Paper with a set of recommendations, which were factored in by the Commission, on the need to consider the specific long-term needs of population groups and the importance of addressing discrimination and tackling loneliness and social isolation, which are key determinants to the HRQoL of people living with HIV. These recommendations were published in a report that has been shared with Member States.



The European Commission's Green Paper on Ageing is a non-legislative initiative that aims to launch a debate on the long-term impact of population ageing in Europe and to assess whether European social protection and healthcare systems are fit to deal with the needs of an ageing population. The initiative – which includes a public consultation – is part of a wider pillar of work that aims to support the European Union through its demographic transition.

As part of this work strand, the Commission published a Report on 'The Impact of Demographic Change', to feed into the Green Paper and the wider debate on ageing.

HIV Outcomes submitted its considerations on the Commission's Report on 'The Impact of Demographic Change', to emphasise the specific needs of people ageing with HIV – and chronic conditions more generally – and highlight the need to support the shift to more integrated systems of care, with the ultimate

Our advocacy efforts were greatly reflected in the text of the Green Paper on Ageing, which highlights the need to:

- Develop strong long-term care systems to improve access to affordable and quality long-term care
- Support integration of care through close cooperation between professionals, patients and their carers.

goal of improving quality of life and health outcomes. In January 2021 the Commission published the Green Paper on Ageing, factoring most of the HIV Outcomes recommendations on meeting the health and long-term care needs of an ageing population.

ADVOCACY TOOLBOX ON THE HRQoL OF PEOPLE LIVING WITH HIV

HIV Outcomes developed an Advocacy Toolbox that aims to support our advocacy efforts when engaging with policymakers. The Toolbox introduces the concept of HRQoL and some of its key determinants with four factsheets focusing on HRQoL, stigma, discrimination, and comorbidities.



HRQoL

HRQoL is a construct that reflects an individual's perceptions of his or her well-being in health-related aspects of life, with the concept of health understood to encompass physical, mental and social dimensions. The role of HRQoL in clinical and policy settings should

be highlighted and its potential value assessed as it provides insight into how well people respond to the challenges associated with complex long-term health conditions.



Stigma

HIV-related stigma remains pervasive in Europe and can lead to the under-utilisation of health and social services and ultimately poorer health outcomes. Policymakers should support national and international efforts, including for the UNAIDS 2025 targets, to

monitor HIV-related stigma and stigma against key populations among the general population.



Discrimination

Structural factors, such as criminalisation and human rights infringements targeting key populations can undermine the HRQoL of people living with HIV. Discrimination can be legislated against by reviewing and reforming existing laws that reference HIV status.

No European country should have any law in place that discriminates based on HIV status or that discriminates or criminalises key populations.



Comorbidities

Despite viral suppression, people living with HIV often have multimorbidity at younger ages than those without HIV due in part to chronic inflammation of the immune system and other social, behavioural and environmental determinants. People-centred or integrated

care approaches can allow individuals to discuss and address issues that concern them beyond viral suppression which may be more relevant to them, particularly as they age and their own needs change.

Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV

In July 2021, HIV Outcomes gathered a multidisciplinary panel of 44 HIV experts to develop a common understanding of the role of health systems in advancing the long-term well-being of people living with HIV. The process led to the development of 31 consensus points which were set out in the "Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV".

The purpose of the Consensus Statement is to guide stakeholders at all levels of governance in improving health system responses to achieve the best possible HRQoL and long-term health outcomes for people living with HIV in the key domains of multimorbidity, HRQoL, and stigma and discrimination, as well as addressing psychosocial needs associated with these issues.

Dr Jeffrey V. Lazarus, our Co-Chair, led the project, which was co-chaired by a number of our Steering Group and General members, as well as other experts with diverse disciplinary and geographical perspectives and wide - ranging lived experience.

More than 86 organizations and individuals that advocate for people living with HIV have endorsed the Consensus Statement with the ability for further signatories remaining.

PERSPECTIVE

<https://doi.org/10.1038/s41467-021-24673-w> OPEN

Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV

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COLLABORATION WITH WHO AND UNAIDS

WHO consultation on HIV, Hepatitis and Sexual Health



In the context of the update to the WHO Global Health Sector Strategy on HIV, HIV Outcomes was invited by WHO to contribute to the discussion regarding which aspects of the HIV Strategy should be prioritised in 2022-2030.

A draft version shared in late 2021 demonstrated that our observations were taken into account, particularly on the need to pay attention to the well-being of those living with HIV, eliminate stigma and discrimination in health care settings and gradually move towards long-term and person-centred models of care able to meet the needs of people living with HIV holistically. The finalised Strategy is expected to be published in early-mid 2022.

Participation at High-Level Experts Meeting on Quality Care organised by WHO



At the high-level Experts Meeting on Quality of Care in the WHO European Region in the post-COVID era entitled “Meeting of Minds”, HIV Outcomes with its Steering Group Member Mario Cascio (Programme Chair, Quality of Care Programme, EATG) set out good practice on the quality of older adults living with HIV.

Mario shared the Italian experience of the Ageing Clinics which provide a multi-disciplinary health service with a mission of addressing comorbidities and complications associated with HIV.

Workshop with UNAIDS: How to define HRQoL for people living with HIV in view of the UNAIDS 2021-2026 Strategy?



In February, HIV Outcomes co-hosted with UNAIDS a workshop to input on the UNAIDS Global Strategy devising a working definition for HRQoL and agreeing associated metrics to assess it.

The workshop was attended by more than 50 participants – including WHO and UNAIDS representatives – who agreed on the need to reach consensus on definitions, to support action to address the impact of discrimination, stigma and comorbidities on the long-term well-being of people living with HIV. The meeting followed an earlier event that took place in 2020 at which six recommendations were agreed to prioritise HRQoL in the UNAIDS Strategy. In the end, the UNAIDS Global AIDS Strategy (2021-2026) referenced quality of life, and the United Nations Secretary-General Report captured the importance of adopting differentiated care (which were called for in the HIV Outcomes supported workshops).

NATIONAL-LEVEL WORK

EVIDENCE GENERATION

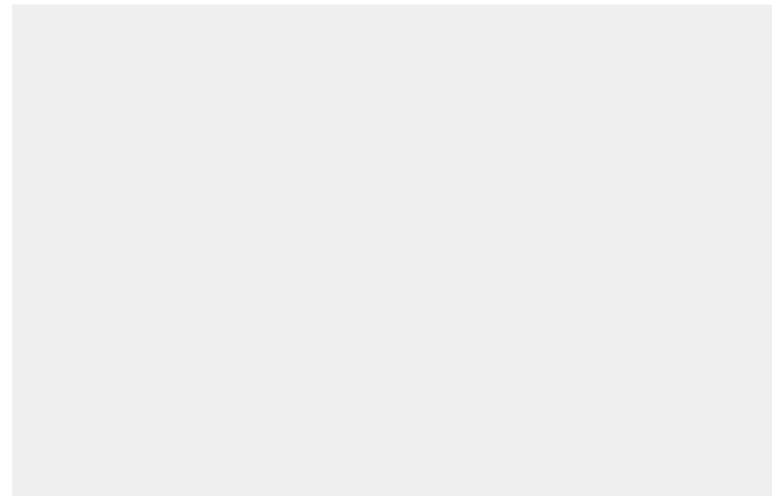


Romania

- To facilitate the prioritisation of HRQoL in Romania, a breakthrough study was launched on Quality of Life, the long-term needs and challenges for the HIV population. The results of the study will be published in a series of dossiers/reports and presented at a high level public event to facilitate discussions with policymakers.
- To improve HIV Outcomes Romania's visibility and credibility, briefing notes presenting HIV Outcomes Romania were shared at key meetings as well as sent to the Ministry of Health, the General Secretariat of Romanian Government, Members of the Parliament, people living with HIV, key NGOs, patient associations, clinicians, etc.



Spain

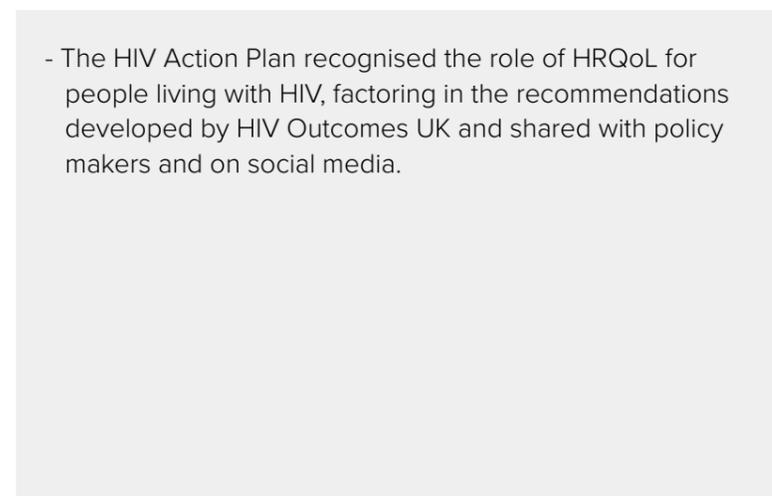
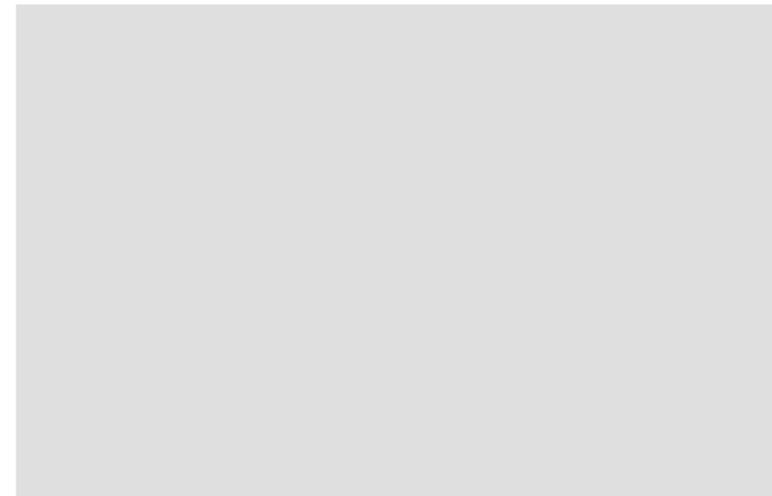


United Kingdom

- As the UK HIV Action Plan offered a unique opportunity to address the HRQoL of people living with HIV, key UK HIV stakeholders (clinicians, patient representative and researchers) were convened by Co-Chair Prof Anderson. The group co-developed a series of high-level of recommendations to achieve parity for quality of life for people living with HIV in England and to mitigate and eradicate the stigma and discrimination faced by people living with HIV.

ADVOCACY

- The final draft of the Action Plan for the Romanian 2030 National Strategy for Sustainable Development included the need to consider the HRQoL of people living with HIV, to fight discrimination and stigma. This initiative also gave input and stressed the importance for discrimination and stigma to be included in all GRE strategic documents and of meeting the UNAIDS targets.
- HIV Outcomes Romania also engaged with Parliamentarians for Romania to change the current legislation on HIV and public health to enable responsible monitoring of HIV, in line with Romania's commitments to the EU, UNAIDS and WHO.



MULTIPLIERS

- To disseminate its narrative, HIV Outcomes Romania shared its perspective on HRQoL at high-level events such as one stigma and discrimination and a virtual roundtable on the involvement of people living with HIV in the development of public policy.

- HIV Outcomes Spain organised seven virtual meetings on how to improve the HRQoL of people living with HIV with regional experts and authorities in Catalonia, Basque Country, Madrid, Valencia, Aragon, Galicia and Andalusia. At the meetings, mental health and the attitude of health workers towards people living with HIV emerged as key determinants.
- Over 200 participants attended an online Symposium which included the participation of high-level health authorities, clinicians, and researchers.

- HIV Outcomes UK convened two roundtable discussions on HRQoL with high-level local stakeholders. At the first roundtable, participants committed to act on the HRQoL of people living with HIV in the UK. Building on the lessons of this first meeting, a second roundtable discussion was organised to jointly develop an impactful narrative to try and ensure that HRQoL featured prominently in the HIV Action Plan.

NATIONAL-LEVEL WORK



Germany

EVIDENCE GENERATION

- To structure the discussion with policymakers, a dossier capturing HIV Outcomes Germany's key five demands was developed, highlighting the need to prioritise the HRQoL of people living with HIV, to end discrimination and stigma, and to address the impact of comorbidities, among others.

ADVOCACY

- Several discussions were organised with high-level parliamentarians, including MP Prof. Dr. Andrew Ullmann (Liberals) and MP Kordula Schulz-Asche (Greens).

MULTIPLIERS

- HIV Outcomes Germany presented its goals to an expert audience at the 2021 German-Austrian AIDS Congress and co-hosted with HIV Outcomes Europe a joint IAS Satellite Symposium on "Supporting health-related quality of life for people living with HIV. Lessons and learnings from the COVID-19 Pandemic". Participants included high-level academics, clinicians and parliamentarians, including Prof. Georg Behrens, Prof. Dr. Hendrik Streeck and MP Prof. Andrew Ullmann. A member of the German Steering Committee also participated at the World AIDS Day 2021 event hosted by HIV Outcomes Europe, stressing the important role of communities and the need for bottom-up participation.



Italy

- The Secretariat launched a project using the Delphi methodology to maximise the consensus in Italy around the need to prioritise HRQoL for people living with HIV among community and clinicians.
- The results were published in the dossier 'Proposals for an integrated approach to health for people living with HIV' which strongly advocated for the prioritisation of HRQoL and was informed by open and closed questionnaires as well as expert interviews.

- The dossier informed the discussions between HIV Outcomes Italy and policymakers and was shared with the Italian Health Ministry's Technical Health Committee for the fight against HIV.

- On 2 December 2021, commitment on the need to act on the HRQoL of people living with HIV in Italy emerged at a meeting involving the Interparliamentary Group "Italy stops AIDS", European Parliamentarians Alessandro Panza and Pierfrancesco Majorino and HIV Outcomes Italy. Parliamentarians pledged to share the dossier with their colleagues as well as participate in future events, to familiarize on the long-term needs of people living with HIV.

2021 SOCIAL MEDIA IMPACT

The online presence of HIV Outcomes has grown significantly

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



+210 posts
a 110% increase in 2021

almost 20,000
profile visits
a 769% increase in 2021

+339 followers
a 119% increase in 2021

256,000
impressions
a 177% increase in 2021



55 posts

11,000
impressions

400
profile visits

130
followers



LOOKING FORWARD

— OUR 2022 WORK PLAN

For the first time since its foundation, HIV Outcomes is opting for a four-year strategy (2022-2026) to allow for a stepwise transition from policy commitments to HRQoL to the operationalisation, adoption and use of HRQoL at European health systems. In this way, we expect that HRQoL will be fully integrated and delivering positive benefit for people living with HIV by 2030. In 2022, we will redouble our advocacy efforts at national and EU-level for HRQoL to be linked to clinical and public health targets.



- 1** Achievement of a high level of HRQoL for people living with HIV embedded as an aim in National and European Health Polices.
- 2** HRQoL of people living with HIV systematically, comprehensively, and regularly assessed in clinical settings.
- 3** HRQoL of people living with HIV subject to regular monitoring, reporting and review at operational and policy levels.
- 4** Results used to shape integrated person-centred care and reduce stigma and discrimination in healthcare settings.
- 5** Results additionally used to inform National and European HIV policy development.

USEFUL LINKS



**Advocacy
Toolbox**



**Consensus
Statement**



Call to Action



Recommendations



Website



Twitter



LinkedIn



Contact

2021 Annual Review

HIVOutcomes
BEYOND VIRAL SUPPRESSION

