



A multi stakeholder coalition on Health-Related Quality of Life for people with HIV, co-chaired by representatives of National Institute of Communicable Diseases “Prof. Dr. Matei Bals”



CONTEXT (2016)

- ❖ **HIV epidemic has changed**, as a result of **advances in antiretroviral therapy (ART)**
- ❖ **UNAIDS 90-90-90 targets** – an end goal in itself, while **loosening policies on controlling HIV**
- ❖ Policies not adapted to **increased life expectancy for people with HIV**

HIV OUTCOMES- a beyond viral suppression approach

- ❖ **2016: HIV Outcomes brings together HIV relevant actors with a beyond biomedical approach, to create public policy and clinical change**
HIV infection is a long-term condition, with specific health and well-being challenges:
 - **increased risk of developing comorbidities**
 - **reduced quality of life**
 - **stigma and discrimination**, both within the health system and outside of it
- ❖ **2017: recommendations on well being for people with HIV- European Parliament**, to be road-tested in Italy, Sweden, Germany, **Romania**, Spain



VISION

A world in which people living with HIV enjoy the highest possible health-related quality of life (HRQoL).

Mission

HIV Outcomes seeks to build **political support and policy measures** to deliver integrated person-centered healthcare and **clinical changes** that deliver **improved HRQoL of all people living with HIV across Europe** – and thereby improve the sustainability of European healthcare systems – by sharing **evidence-based best practices and innovative approaches to care.**

What is 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.**

Co-Sponsors



President



John Bowis

Ambassador



**Vytenis
Andriukaitis**

Co-Chairs



Jeffrey Lazarus



Jane Anderson



Nikos Dedes

Steering Group Members



+20 General Members

Observers

-  **EACS**
European AIDS Clinical Society
-  **ecdc**
EUROPEAN CENTRE FOR DISEASE PREVENTION AND CONTROL
European Center for Disease Prevention and Control
-  **FAST-TRACK CITIES**
-  **UNAIDS**
-  **UNITA**
Global Parliamentarians Network

Policy priorities

- Comorbidity (prevention, treatment, management including mental health)
- Ageing with HIV
- Measurement of patient-reported outcomes and monitoring of HRQoL
- Stigma & discrimination

Working with leading HIV stakeholders, KOLs, patient groups and European agencies/ institutions

Observers



Steering Group Members



HIV Outcomes- achievements

- **European Care Strategy** recognises quality of life as the end-goal of long-term care.
- **Contribution to the Journal of the International AIDS Society.**
- **European Parliament study on the quality of life** launched.
- **Extended ECDC** adds efforts against HIV and not just future against future viral diseases.
- Held a **Focus Group Discussion** (2020) with **WHO** and **UNAIDS** to better define and reference HRQoL
- **UNAIDS Global AIDS Strategy (2021-2026)** references QoL.
- **United Nations Secretary-General Report** differentiated care models to improve QoL.
- **Policy Asks on healthy aging with HIV** supported by the EU Health Commissioner, in the European Parliament.



HIV Outcomes Romania



CONTEXT

- An unique opportunity to create **change, by road-testing HIV Outcomes' approach**- Romanian cohort of **10.000 children** with HIV

POLICY ENVIRONMENT

- HIV biannual **National Plans**
- An **HIV Strategy** not in place since 2007
- **INBI “Matei Bals”** coordinates national data on HIV; reports to ECDC Stockholm
- HIV infection assimilated to **disability**



HIV Outcomes Romania Mission

- Deepen research to understand **what quality of life means**
- Advocate for **HRQoL measurement (PROMs), combatting stigma and discrimination, patient-centred healthcare** delivery
- Complement existing work in HIV by developing **sustainable approaches** – including improved prevention, screening and diagnosis of **comorbidities**

HIV Outcomes Romania governance replicates HIV Outcomes Europe governance

Co-Chair



Prof. Dr. Adrian Streinu-Cercel

- Romanian Parliament, Health Committee Chair
- Leading KOL (clinician and academic)

Co-Chair



Dr. Mariana Mărdărescu

- National Coordinator of HIV data – reports Romanian progress to ECDC Dublin declaration
- Leading KOL

Steering Group Members



- **The Steering Group is the driving force of the initiative and takes strategic decisions**
- Co-Chairs :
 - act as HIV Outcomes promoters
 - facilitate the process of realizing the initiative's objectives
 - ensure progress is made according to initiative's work plan

Political and clinical priorities

- HRQoL and use of PROMs
- Comorbidity screening and treatment
- Integrated care
- HIV related stigma & discrimination
- UNAIDS targets – zero new infections

Engaging with leading HIV stakeholders: patient groups, national institutions, academics, NGOs, HIV care network and industry

Steering Group Members



HIV Outcomes Romania supports and advocates for policy and clinical change

- **Partnered with Ministry of Health and Senate's Health Committee** to include HRQoL on 2030 National HIV Strategy
- **Joint Statement on National HIV Strategy** of 70 experts promoting HRQoL, updated UNAIDS targets and healthy aging with HIV in view of shaping 2030 National HIV Strategy
- References on QoL to be included in **National Strategy for Sustainable Development** as Recommended Actions
- Commitment to promote **HIV U=U** as message of national interest to be broadcasted on radio/TV
- Contribution recognized in the **evaluation report of United Nations High Commissioner for Human Rights** to the UN indicators on discrimination based on sexual orientation & gender, as regards to the SDG 3

Objectives

- Engage with HIV care network care- on **HRQoL best practices** and **PROMs**
- Militate with Governments' institutions for **policy and clinical change**
- Promote **study's findings on QoL** in support of advocacy activities
- Advocate for “**Undetectable = Untransmittable**” as **message of national interest**
- Facilitate a better understanding of impact of **national HIV policies** for various stakeholders
- Enhance HIV Outcomes Romania **profile** in Romania

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HIV Outcomes is a European multi-stakeholder initiative advocating for the long-term health, well-being and quality of life of people living with HIV. HIV Outcomes is enabled by sponsorship provided by Gilead Sciences and ViiV Healthcare.