



HIV STIGMA AND DISCRIMINATION: A EUROPEAN APPROACH

**GOOD PRACTICES ACROSS
THE EUROPEAN REGION AND
POLICY RECOMMENDATIONS**



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INITIATIVE PARTNERS



INTRODUCTION

Life expectancy has increased greatly for people living with HIV, thanks to advances in care. Innovative options in prevention and treatment have led to long-term success in HIV management overall.

This ageing population has higher comorbidity than their HIV-negative peers and faces challenges relating to quality of life. Health systems must adapt to meet the complex needs of growing numbers of people with HIV¹. Patient input can enhance person-centred care in a range of areas, including fighting stigma and discrimination^{2,3}.

Since 2016, HIV Outcomes has tapped into its network of HIV experts, advocates and people living with HIV to advance policy at European and national level. Drawing on insights from the HIV community and good practices by health authorities, non-governmental organisations and service providers, HIV Outcomes is uniquely positioned to highlight challenges, promote debate, and showcase recommendations.

There is growing momentum across the HIV community to develop and implement effective policies that address long-term

health and well-being, taking account of the elevated rates of non-communicable diseases (NCDs) and mental health needs of people living with HIV. In particular, stigma and discrimination have a profound impact on the health-related quality of life of people with HIV. Both HIV Outcomes Policy Asks⁴ and the roundtable event in Madrid on 17 May 2023 reflect this problem. However, evidence-based policy should address stigma wherever it is found – in healthcare settings, in access to innovative options in prevention and treatment, in the workplace, in the legal system and in wider society.

In this paper, HIV Outcomes compiles good practices from European countries (see Annex) and presents concrete recommendations that can be implemented at EU level. Together we can achieve our goal of advancing the health-related quality of life of people living with HIV and reach the HIV elimination targets.

1 Safreed-Harmon et al. (2019). Reorienting health systems to care for people with HIV beyond viral suppression. *The Lancet HIV*, 6(12), e869–e877. [https://doi.org/10.1016/s2352-3018\(19\)30334-0](https://doi.org/10.1016/s2352-3018(19)30334-0)

2 Kall et al. Patient-reported outcomes to enhance person-centred HIV care. *The Lancet HIV*, 7(1), e59–e68. [https://doi.org/10.1016/s2352-3018\(19\)30345-5](https://doi.org/10.1016/s2352-3018(19)30345-5)

3 Andersson et al. Stigma reduction interventions in people living with HIV to improve health-related quality of life. *The Lancet HIV*, 7(2), e129–e140. [https://doi.org/10.1016/s2352-3018\(19\)30343-1](https://doi.org/10.1016/s2352-3018(19)30343-1)

4 HIV Outcomes. (2023, February 14). *HIV Outcomes Policy Asks: Enhancing long-term health and well-being among people living with HIV - HIV Outcomes*. Available at: <https://hivoutcomes.eu/policy-asks/>

OBSERVER MEMBERS

- European Centre for Disease Prevention and Control (ECDC)
- European AIDS Clinical Society (EACS)
- UNITE Global Parliamentarians Network (UNITE)
- Joint United Nations Programme on HIV/AIDS (UNAIDS)
- Fast-track Cities Europe

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KEY THEMES

- **Training & education** of healthcare professionals and raising public awareness.
- **Innovation in prevention and treatment**, particularly pre-exposure prophylaxis (PrEP) and Treatment as Prevention (TasP), to ensure swift access to innovative care, leading to long-term success and reduction of stigma.
- **Legal protections** to tackle discrimination and support those affected.
- **Digitalisation & health data space** to empower and protect the privacy of citizens.
- **Financing multidisciplinary care** for patients with multimorbidity, including integrated mental health services.
- **Monitoring & tracking** stigma and discrimination and adapting policies accordingly.
- **Quality of life** monitoring every two years across Europe.
- **Involvement of people with HIV** at every stage of policy and care.

EUROPEAN CONTEXT: MONITORING IMPLEMENTATION & MEASURING PROGRESS

EU Member States and the countries of Europe and Central Asia have agreed that HIV is a political priority. Through a series of formal Declarations, beginning with the Dublin Declaration in 2004⁵, governments have set out measurable actions to enhance the response to HIV and to build partnerships between political leaders, government agencies, international organisations, civil society and people living with HIV.

- **Dublin Declaration** on Partnership to Fight HIV/AIDS in Europe and Central Asia (2004)⁵: A set of 33 actions agreed by governments, including a call on the EU to monitor progress on implementation. The ECDC has published several progress reports on the Dublin Declaration⁶ and the WHO Regional Office for Europe published a comprehensive review, prepared under the auspices of UNAIDS⁷.
- **Vilnius Declaration** on Measures to Strengthen Responses to HIV/AIDS in the EU and in Neighbouring Countries (2004)⁸: Reaffirmed the Dublin Declaration's

commitments to strengthening the capacity of the EU to fight the spread of HIV/AIDS and expressed support for close monitoring and evaluation of policy implementation.

- **Bremen Declaration** on Responsibility & Partnership – Together Against HIV/AIDS (2007)⁹: Committed to political leadership at national, European and international level, and to be transparent in ensuring accountability for action.
- **Communication from the European Commission** (2009): Combatting HIV/AIDS in the EU and neighbouring countries¹⁰: Aimed to reduce HIV infections, improve access to prevention, treatment, care and support, and improve the quality of life of people living with, affected by, or most vulnerable to HIV. Surveillance, monitoring and evaluation are among the key roles of Member States, with support from ECDC.
- **Lisbon roundtable**: The ECDC published a Special Report on HIV treatment, care and support, focused on the implementation of the Dublin Declaration¹¹. The report was the result of a monitoring and evaluation workshop in Lisbon in 2012.

5 Dublin Declaration on Partnership to fight HIV/AIDS in Europe and Central Asia. (2004). OSCE. Available at: <https://www.osce.org/secretariat/29873>

6 Monitoring implementation of the Dublin Declaration. (2013, June 4). European Centre for Disease Prevention and Control. Available at: <https://www.ecdc.europa.eu/en/infectious-disease-topics/z-disease-list/hiv-infection-and-aids/prevention-and-control/monitoring-0>

7 Srdan et al. (2008). Progress on implementing the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia. World Health Organization. Regional Office for Europe. Available at: <https://apps.who.int/iris/handle/10665/107951>

8 Vilnius Declaration on Measures to Strengthen Responses to HIV/AIDS in the EU and in Neighbouring countries. (2004). European Commission. Available at: https://ec.europa.eu/health/ph_threats/com/aids/docs/ev_20040916_rd03_en.pdf

9 Bremen Declaration on Responsibility & Partnership – Together Against HIV/AIDS. (2007). European Commission. Available at: https://ec.europa.eu/health/ph_threats/com/aids/docs/bremen_declaration_en.pdf

10 European Union: European Commission, *Communication from the Commission to the European Parliament, The Council, The European Economic & Social Committee, and the Committee of the Regions: Combatting HIV/AIDS in the EU & neighbouring countries, 2009-2013*. 26 October 2009, COM(2009)569 final. Available at <https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:52009D0569>

11 European Centre for Disease Prevention and Control. Thematic report: HIV treatment, care and support. Monitoring implantation of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia: 2012 progress report. Stockholm: ECDC, 2013.

INITIATIVE PARTNERS



RECOMMENDATIONS TO FIGHT HIV STIGMA AND DISCRIMINATION AT EU LEVEL

PROFESSIONAL TRAINING ON HIV

- Develop educational material with input from the lived experience of people with HIV.
- Train healthcare professionals to increase awareness of discrimination against people living with HIV and share examples of strategies that prevent internalised stigmatisation.
- Provide healthcare professionals with the tools to identify and address the consequences of stigma on mental health and well-being.
- Ensure training programmes are systematically updated to cover current knowledge about HIV and AIDS, including in doubly stigmatised populations such as the LGBTIQ+ community.
- Adapt training modules to make them relevant in all health and social care settings.
- Ensure that healthcare staff are aware of the confidential nature of people's medical records, including their HIV status.
- Publish a list of healthcare professionals and clinics that have completed training, making it easier for people living with HIV to find a trustworthy practice.

EDUCATION AND AWARENESS

- Educate people living with HIV about U=U as part of the minimum care package, starting from the very beginning of the care process.
- Work to enhance public understanding and social acceptance of HIV: prevent and reduce social stigma and discrimination in education.
- Develop a new online training package, free to access, for all citizens.

LEGAL FRAMEWORK AND PROTECTION

- Establish and enforce a legal framework that defends people living with HIV against discrimination.
- Promote policies to tackle discrimination in the workplace.
- Provide people living with HIV with a way to report stigma and discrimination and offer a clear pathway to seek legal redress.
- Respond firmly to discrimination in any healthcare setting.
- Protect the right to privacy: Abolish the requirement to disclose HIV status in healthcare settings.

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INNOVATION IN PREVENTION, TREATMENT AND CARE

- Contribute to reducing stigma by advancing prevention and improving long-term health outcomes for people with HIV.
- Recognise the importance of combination HIV prevention and support access to innovative HIV prevention options, including PreP, as key tools to end the HIV epidemic in Europe.
- Embrace TasP and Rapid Start approaches, ensuring fast linkage to care, as key tools to driving down stigma and discrimination.
- Ensure people living with HIV, including key populations, can access innovative treatment options that promote adherence, optimal use of healthcare resources, and improved long-term health outcomes.
- Support and fund screening and testing for all in the EU.

MONITORING

- Monitor quality of life of people living with HIV in the EU every two years.
- Introduce common qualitative and quantitative tools to evaluate and monitor stigma and discrimination across the EU.
- Use patient-reported outcomes, including the impact of stigma and discrimination on mental health, and adjust HIV care plans and interventions as needed.
- Conduct regular patient experience surveys across medical departments to assess satisfaction with care and monitor the experience of stigma. Providers should retain documentation of such surveys to ensure regular monitoring is conducted.

ADVISORY SERVICES

- Raise awareness of the rights of people living with HIV and empower them to seek available advice if their rights are violated.
- Provide support to associations which educate people with HIV on how to identify and document discrimination (including the use of a medical healthcare companions), as well as how to seek compensation.
- Provide budgetary support to cover psychological support and legal representation for stigma and discrimination situations.

FINANCING

- Finance access to healthcare, particularly to a multidisciplinary HIV-educated team, including mental health professionals.
- Allocate resources and strategies (such as reimbursement schemes) to facilitate mental health care to people living with HIV.
- Provide support for research and evidence development on stigma in older people living and ageing with HIV, including those with comorbidities.
- Support broader testing/screening programmes and fast linkage to care as part of a population-wide prevention drive.
- Secure appropriate resources to ensure access to innovation in prevention and treatment of HIV, achieving long-term success in HIV care overall and supporting efforts to end the epidemic in Europe.
- Ensure access to innovation in prevention and treatment of HIV to achieve long-term success in HIV care overall and support ending the epidemic in Europe.
- Address health inequities in key populations at risk of HIV in Europe by allocating appropriate healthcare resources.

INITIATIVE PARTNERS



DIGITALISATION AND HEALTH DATA SPACE

- Promote digital solutions within healthcare to fight stigma and discrimination and establish supportive clinical and community relationships to ensure services remain available to key priority groups.
- Use innovative technologies, such as the 'Happi App', to help people with HIV take more control over their health and improve their health outcomes. (See Annex.)
- Ensure data protection and privacy in healthcare-related digital systems and educate healthcare staff regarding data security and confidentiality.
- Prioritise the development of an effective, people-centred model of information sharing with contributions from HIV clinics and from people living with HIV.
- Engage with people with HIV about their information sharing preferences and provide them tools to easy access to their health information.
- Ensure that medical certificates do not disclose serostatus as an indicator of infectious disease.
- Develop guidelines to protect the confidentiality and security of personal health information and assess their implementation in clinics, data repositories and at national level.

ACCESS TO MENTAL HEALTH SERVICES

- Establish and maintain strong pathways between HIV clinics and mental health services to ensure efficient referral and management of people living with HIV.
- Involve HIV clinical nurse specialists in liaising with mental health services.
- Embed psychology services within HIV clinics to provide better access to mental health support for people living with HIV.
- Gather feedback from people living with HIV to assess their satisfaction with mental health services, shape service development and ensure that they are responsive to users' needs.
- Implement a triaging system to identify individuals who could benefit from group counselling and peer support services. This approach has the potential to reduce the demand for more intensive mental health support.

INVOLVEMENT OF PEOPLE LIVING WITH HIV

- Develop patient-reported outcomes in HIV research and clinical management, with input from people living with HIV.
- Promote the empowerment of people living with HIV and value their participation towards people-centred actions and policies.
- Involve citizens and people living with HIV in responses to stigma and discrimination as part of wider inter-institutional, interdisciplinary efforts.
- Work in partnership with the HIV voluntary sector, people living with HIV, the health system, public health organisations, and Fast-Track Cities.
- Harness the potential of advocacy groups in promoting the rights of people living with HIV, including their right to access healthcare without discrimination.
- Engage with communities to expand the reach and impact of anti-HIV stigma tools.
- Include people with HIV in the development of health goals and outcome indicators and improve the delivery of value-based HIV care.

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LOOKING AHEAD: THE KEY ROLE OF THE SPANISH PRESIDENCY OF THE EU



Through this publication and the roundtable event, HIV Outcomes aims to engage with Spanish authorities and inform the work of the Spanish Presidency of the European Union. We congratulate the Spanish Presidency for having the fight against HIV as one of its priorities, and we reiterate HIV Outcomes' availability to collaborate and engage with the Presidency's activities.

We hope that its continuous work, which will officially start on the 1 July, allows the EU to rethink the need of disease-specific policies and alongside with Member States to engage in a renewed commitment to end HIV in Europe, acknowledging the threat that HIV presents to the health and quality of life of millions of Europeans. We highlight that during the Spanish Presidency, HIV Outcomes will organise an event at the European Parliament around World AIDS Day to engage with policymakers.

CONCLUSIONS

Stigma and discrimination are complex challenges. However, through collaboration and peer learning, stakeholders can co-develop solutions that have a meaningful, lasting impact. The experiences of health authorities, NGOs and others can inspire policymakers and the HIV community to drive the changes required.

Europe can be a world leader in addressing the stigma and discrimination faced by people living with HIV. Spain can catalyse the necessary action by embracing innovation in prevention and treatment for long-term success in HIV care and an ambitious approach to delivering legal, data and service-level reforms. HIV Outcomes stands ready to support this work.



INITIATIVE PARTNERS



ANNEX

COMPENDIUM OF GOOD PRACTICES TO FIGHT HIV STIGMA AND DISCRIMINATION

France

A HIV & Refusal of Care: The Other Epidemic?

An article in REMAIDES magazine provides an example of good practice in fighting discrimination in healthcare. It puts the spotlight on discrimination against people with HIV whose care is refused by doctors. France has a Commission that evaluates healthcare professionals who refuse care and issues recommendations to end discriminatory practices.

B AIDES – The right to health and the principle of equality of treatment

Telephone survey carried out in France to several dental and gynaecological clinics to request an appointment. The study concludes that there is a higher rate of refusal of care for people who declare to be HIV-positive than for those who do not disclose their HIV status.

C HIV concerns everyone: protocol for dental surgeons

Protocol to be followed by dentists published by Le Chirurgien-Dentiste, a professional union for dental surgeons. As multiple drugs interact with antiretrovirals, it informs dental healthcare providers of the different treatments that may be taken by people living with HIV.

Germany

A 'Practice Diversity' seal of approval

A certificate of quality awarded by the German AIDS Self-Help Association to health professionals who complete training on HIV-specific practices, engage in respectful communication and are welcoming to everyone, no matter their race, sexuality, HIV status or culture.

B DAH Advisory Service

Website serving as a contact point for people living with HIV who have experienced discrimination as a patient in a healthcare setting, as a customer, as an employee, or in their private life. The website has educational resources, allows people to anonymously report discrimination, and encourages people to stand up against discrimination.

C Netzwerk Plus

Online courses to educate doctors on HIV-specific knowledge and prevent stigma and discrimination in healthcare settings. The network has compiled a list of trained doctors that have extensive knowledge of dealing with the needs of people with HIV.

D Buddy Project Springboard

People who have recently tested positive for HIV can request a HIV-positive 'buddy' as a companion during the initial steps after diagnosis. Buddies do not provide any professional advice but offer personal support, a sense of community and help to fight self-isolation.

E Positive Voices 2.0

Participatory research project to analyse HIV-specific stigma and discriminatory practices. It concluded that 57% of people with HIV had encountered discrimination in healthcare settings and identified lack of social awareness as a key issue. Data collection is important to understanding the many settings where discrimination happens.

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Portugal

A Stigma Index 2.0: measuring discrimination against people living with HIV

Applied in Portugal in 2021/2022 to measure the stigma and discrimination experienced by people living with HIV. A report on the initiative touches upon disclosure of HIV status, internal stigma, testing and treatment, discrimination in healthcare settings, sexual and reproductive health and rights violations.



Romania

A Stigma in healthcare services: The Baylor Foundation Model

Introducing a 'medical navigator' to assist, refer and protect people with HIV from the moment of diagnosis and beyond. The Baylor Foundation model has proven useful for people with HIV and viral hepatitis (confirmation of cases, maintenance, quick access to treatment) and has been applied to people with other chronic diseases.

B The impact of stigma and discrimination on mental health: evaluation and budgeting

Periodic evaluation of stigma and discrimination reported by people with HIV in the care system, collection of examples and development of action priorities. The use of longitudinal questionnaires/ tools allow authorities to track long-term changes.

C UNOPA psychological support and legal counselling services

The national Romanian patient association (UNOPA) offers psychological support and legal counselling services for victims of HIV-related stigma and discrimination. They are legally supported to document the situation and to report it to institutions. UNOPA calls on employers/institutions to prevent similar cases and to sanction employees who stigmatise or discriminate.



Spain

A Monitoring HIV-related Institutional and structural discrimination

This initiative will gather evidence on institutional and structural discrimination in Spain following the global monitoring indicators proposed by UNAIDS. Methodological experts will contribute to propose a structural discrimination index for Spain

B Monitoring regional healthcare systems

Project to evaluate whether regional healthcare systems monitor the quality of life of people with HIV, including co-morbidities, such as mental health problems. National epidemiological institutions will be included, and the data obtained will contribute towards structured recommendations.



The Netherlands

A Happi App – Value Based HIV Care

Implementation of Value Based HIV Care through the development of an HIV app: 'Happi App'. The app includes questionnaires related to quality of life of people living with HIV and translates the user's answers into health goals. The app covers various quality of life domains such as anxiety/ depression, stigma, social support, sexuality, self-esteem and sleeping difficulties.

INITIATIVE PARTNERS





United Kingdom

A Greater Manchester: A Fast Track City

A peer-led campaign 'HIV: let's sort this together' to address HIV stigma, prevention and management. Among other activities, an e-learning module was co-produced to provide mandatory training in HIV-related stigma for patient-facing staff at Manchester Foundation Trust, featuring real-life experiences of people living with HIV. This training complements the Trust's HIV Awareness module, with the goal of improving knowledge and addressing stigma in healthcare.

C HIV and Mental Health Report

The National AIDS Trust studied the impact of living with HIV on mental health, which for more than half of the participants was impacted by stigma and discrimination.

E BHIVA: New person-centred standards of care for people living with HIV

The BHIVA Standards of Care focus on achieving person-centered care by addressing stigma and discrimination, promoting self-management and peer support, involving people living with HIV in their care, and promoting their well-being. By doing so, care becomes more equitable and non-discriminatory for people living with HIV.

B Improving Care for People Ageing with HIV in Greater Manchester and Newcastle

The report shows shortcomings in care of people ageing with HIV and provides recommendations on better and coordinated care, information sharing, access to key services (including mental health services). It highlights the importance of relationships between HIV clinics and mental health services and the need for an integrated approach that addresses the physical, social, and mental health needs.

D HIV Awareness Training for health and social care staff in Belfast

A mandatory HIV Awareness Training for health and social care professionals developed and led by the Belfast Health & Social Care Trust. The programme aims to raise awareness of the impact of prejudice and stigma on people living with or affected by HIV.

F Anti-Stigma HIV Charter

Development of a charter to tackle HIV stigma. An accreditation mark will be given to organisations that demonstrate a commitment to reducing HIV stigma and discrimination in their workplace. The goal is to raise awareness of ongoing stigma, its impact and encourage more organisations to address it. The charter will also provide a framework for organisations to improve their policies and practices.

Other

A UNAIDS: Protecting Personal Health Information for PLHIV and Key Populations

UNAIDS and PEPFAR (President's Emergency Plan for AIDS relief) developed guidelines for countries to safeguard the confidentiality and security of the personal health information of people living with HIV. The guidelines, published in 2016, include tools for assessing confidentiality and security at clinics, data repositories, and national levels.

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