



Enhancing long-term health and
well-being among people with HIV

HIVOutcomes
BEYOND VIRAL SUPPRESSION 

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Summary

With widespread availability of anti-retroviral therapy, life expectancy among people with HIV is approaching that of the general population. Yet this does not always mean years spent in good health.

Early diagnosis is key to ensuring that HIV is successfully treated.¹ Even then, health outcomes may be negatively affected by sub-optimal adherence and virologic failure, as well as co-infections (including hepatitis B and C and other sexually transmitted diseases).

People with HIV are at higher risk (than the general population) of developing a range of other physical and mental health conditions (comorbidities). These include cancers, cardiovascular disease, chronic kidney disease, diabetes, lower bone mineral density (and associated risk of bone fractures), frailty and other physical disabilities, as well as depression and anxiety.² The prevalence of poor health-related quality of life (HRQoL) is also higher among people with HIV than in the general population.³

To address these multi-faceted challenges, an integrated and person-centred approach is required. Integrated, person-centred care entails responsiveness and sensitivity to individual needs and preferences, including those associated with specific population groups. It requires a focus on what it means to grow older with HIV, as well as stigma and discrimination at all levels (including enacted, perceived, and internalised stigma).⁴

This HIV Outcomes policy paper, which was developed through collaboration between HIV Outcomes national country initiatives, Steering Group members, and General members from across the WHO European Region highlights 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 person-reported outcomes (PROs) and monitoring of HRQoL
- Combatting stigma and discrimination

In order to make progress in each of these areas, it is essential that national and regional health authorities ensure sufficient funding is allocated to HIV-related services, and that specific attention is paid to the needs of 'key populations' – which are vulnerable or most-at-risk groups for whom targeted policy responses are required. Stable funding should also be provided, both at EU and national level, for research focused on the themes and issues highlighted in this paper.

¹ M. May, 'Better to know: the importance of early HIV diagnosis', *The Lancet Public Health* 2, 1 (2017); Y-H. Chen *et al.*, 'Routine HIV Testing and Outcomes: A Population-Based Cohort Study in Taiwan', *American Journal of Preventative Medicine*, 62, 2 (2022)

² G. Guaraldi, *et al.* 'Premature Age-Related Comorbidities Among HIV-Infected Persons Compared with the General Population', *Clin Infect Dis.* (2011); R.A. Maciel, K.M. Klück, M. Durand & E. Sprinz, 'Comorbidity is more common and occurs earlier in persons living with HIV than in HIV-uninfected matched controls, aged 50 years and older: A cross-sectional study' *Int. J. Infect. Dis.* 70 (2018); M.A. Donaldson, *et al.* 'Comorbidity and polypharmacy among women living with HIV in British Columbia'. *AIDS* 33 (2019); M.J. Kruger and T.A. Nell, 'Bone mineral density in people living with HIV: a narrative review of the literature', *AIDS Research and Therapy* (2017); J. Falutz, 'Frailty in people living with HIV', *Current HIV/AIDS Reports* 17 (2020)

³ E.A.N. Engelhard *et al.* 'Health-related quality of life of people with HIV: An assessment of patient related factors and comparison with other chronic diseases' *AIDS* 32 (2018); N. Langebeek, *et al.* 'Impact of comorbidity and ageing on health-related quality of life in HIV-positive and HIV-negative individuals' *AIDS* 31 (2017); A. Miners *et al.* 'Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: A cross-sectional comparison with the general population', *Lancet HIV* 1 (2014)

⁴ World Health Organization, 'Framework on Integrated, People-Centred Health Services: Report by the Secretariat' (2016), available at: https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf



PRIORITY RECOMMENDATIONS



1

Comorbidity prevention, treatment and management

HIV CLINICS / CARE PROVIDERS

- Implement routine screening for all relevant comorbidities based on individual characteristics and needs, in line with national and international guidelines, using short, easy to administer, validated screening instruments.
 - Capture individual data on comorbidities using electronic health records as a tool to support integrated, personalised care.
 - Involve peers or community members to support with prevention, screening, treatment and management of comorbidities.

NATIONAL & REGIONAL HEALTH AUTHORITIES

- Develop/update a monitoring and evaluation framework for HIV care, incorporating indicators on comorbidities, leading causes of mortality and hospitalisation, and PROs including HRQoL.
 - Integrate the framework into the national HIV strategy and ensure funding for its implementation.

EUROPEAN UNION

- Expand the mandate of the Steering Group on Health Promotion, Disease Prevention, and Non-Communicable Diseases(NCDs) management to initiate work programmes on communicable diseases, such as HIV, including prevention, diagnosis and coordinated management of comorbidities.



2

Ageing with HIV

HIV CLINICS / CARE PROVIDERS

- Provide specialised, integrated healthcare services focused on the needs of older adults with HIV, including frailty and other geriatric syndromes, disability, age-related comorbidities, and mental health (e.g. depression).

NATIONAL & REGIONAL HEALTH AUTHORITIES

- Develop and implement training programmes for carers, in particular those working in retirement homes, focused on the specific health and well-being needs of older people with HIV– including mental health.

EUROPEAN UNION

- Provide funding for pilot studies on models of HIV care that employ or develop frameworks for healthy aging, frailty, functional ability, and other dimensions of health that are relevant to people with HIV, using HRQoL as a key outcome measure. People with HIV should be meaningfully involved in these efforts.



3

Measurement of PROs and monitoring of HRQoL

HIV CLINICS / CARE PROVIDERS

- Integrate person-reported outcomes measurement (PROMs) into clinical practice, which can then be used for shared decision-making with those living with HIV, to tailor interventions to individual needs and preferences, and for monitoring of health outcomes.

NATIONAL & REGIONAL HEALTH AUTHORITIES

- Establish annual surveys of people with HIV to collect and document data on HRQoL and on experiences of stigma and discrimination in healthcare settings.

EUROPEAN UNION

- Allocate funding for the inclusion of HIV within the OECD Paris Initiative to provide standardised, comparable data on PROs and experiences across countries.



4

Combatting stigma and discrimination

HIV CLINICS / CARE PROVIDERS

- Offer peer-to-peer and community-based interventions to address stigma and discrimination experienced by people with HIV, including a focus on the fact that an undetectable viral load means untransmissible virus.

NATIONAL & REGIONAL HEALTH AUTHORITIES

- Design and implement interventions that can strengthen empathy towards people with HIV among healthcare staff and decrease stigma and discrimination in healthcare settings. Monitor and regularly review the effectiveness of these interventions.

EUROPEAN UNION

- Given the negative impact of stigma and discrimination on mental health, ensure that any future EU mental health strategy includes a focus on reducing stigma and discrimination among groups at risk, including people with HIV.





Introduction

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 recognized that living long-term with HIV presents numerous other challenges to health and well-being, which health systems must address.

In November 2017, HIV Outcomes launched recommendations on long-term health, well-being and chronic care at the European Parliament.⁵ The five recommendations were to:

1. Adopt integrated, outcomes-focused and person-centred approaches to long-term HIV care
2. Expand national monitoring of long-term HIV care and outcomes
3. Fund cohort studies to provide information on the long-term health of people with HIV
4. Combat stigma and discrimination within health systems
5. Upscale the involvement of the HIV community in priority setting at country level

Country-level HIV Outcomes initiatives were subsequently established in Germany, Italy, Sweden, and Romania and, most recently, a multi-disciplinary expert panel developed and published a consensus statement on 'the role of health systems in advancing the long-term well-being of people with HIV'⁶.

Five years on from the launch of the HIV Outcomes recommendations, this policy paper focuses on continuing challenges and gaps in care for people with HIV and identifies areas for action by HIV clinics / care providers, national and sub-national health authorities, and the European Union.

The document has been developed through collaboration between HIV Outcomes members (in-country initiatives, General, Steering Group and Observer members) across the WHO European region, thereby ensuring multi-disciplinary expertise and balanced participation including organisations representing people with HIV, clinicians, academics, public health professionals, and industry.

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.

⁵ HIV Outcomes Recommendations, available at: <https://hivoutcomes.eu/annual-report-2020/recommendations/>

⁶ J.V. Lazarus *et al.*, 'Consensus statement on the role of health systems in advancing the long-term health and well-being of people living with HIV', *Nature Communications* 12 (2021), available at: <https://www.nature.com/articles/s41467-021-24673-w>



KEY AREA 1

Comorbidity Prevention, Treatment and Management

With widespread availability of anti-retroviral therapy, life expectancy among people with HIV who start treatment promptly can be the same as that of the general population. Yet this does not always mean years spent in good health.

Even with viral suppression, people 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.⁷ A higher number of comorbidities is correlated with worse health outcomes and increased costs for health systems.⁸

In 2016, the World Health Organization's Global Health Sector Strategy on HIV included 'chronic care' as a further stage in the care continuum ('beyond viral suppression') – highlighting the need to address 'broader health needs', including NCDs, mental health, and substance use disorders.⁹

UNAIDS' global strategy for 2021-26 includes a general health target for people with HIV – specifically that 90% of people with HIV should "have access to integrated or linked services for HIV treatment and cardiovascular diseases, cervical cancer, mental health, diabetes diagnosis and treatment, education on healthy lifestyles, counselling, smoking cessation advice and physical exercise."¹⁰

The 2017, HIV Outcomes recommendations called for the adoption of integrated, people-centred care for people with HIV and identified key 'elements' within an integrated, person-centred approach: i. comorbidity prevention, treatment and management; ii. coordinated care through a personalised care plan; iii. integration of services for mental health and neurocognitive impairment; iv. the need for an ongoing focus on sexual and reproductive health; and v. increasing systematic participation of people with HIV in decisions about their care.

Two of these themes are picked up in further detail below: mental health and sexual and reproductive health.¹¹

⁷ C.A Sabin & P. Reiss, 'Epidemiology of ageing with HIV: What can we learn from cohorts?' *AIDS* 31 (2017); D. Costagliola, 'Demographics of HIV and aging', *Curr. Opin. HIV AIDS* 9 (2014).

⁸ M.B. Millar, T.J. Starks, S. Gurung & J.T. Parsons, 'The Impact of Comorbidities, Depression, and Substance Use Problems on Quality of Life Among Older Adults Living With HIV' *AIDS Behav.* 21, (2017); A.T. Rodriguez-Penney et al. 'Co-morbidities in persons infected with HIV: Increased burden with older age and negative effects on health-related quality of life', *AIDS Patient Care STDS* 27 (2013); L. Emuren et al. 'Health-related quality of life among military HIV patients on antiretroviral therapy', *PLoS One* 12 (2017); C. Liu et al. 'Predictors for lower quality of life in the HAART era among HIV-infected men' *Acquir. Immune Defic. Syndr.* 42 (2006).

⁹ WHO, *Global Health Sector Strategy on HIV, 2016-2021: Towards Ending AIDS* (2016), available at: https://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026_en.pdf

¹⁰ UNAIDS. *End Inequalities. End AIDS. Global AIDS Strategy 2021–2026* (2021), available at: <http://www.infocop.es/pdf/global-AIDS.pdf>

¹¹ See HIV Outcomes Recommendations: <https://hivoutcomes.eu/annual-report-2020/recommendations/>

Mental health

Mental health remains a very significant challenge for people with HIV, in part due to the effects of stigma and discrimination, which can further discourage mental health seeking behaviours. Common mental health conditions among people with HIV include depression, anxiety, and cognitive disorders.¹² A study by Public Health England ('Positive Voices') found that people with HIV are twice as likely to experience feelings of depression or anxiety than the general population.¹³

Poor mental health, especially when determined by the experience of stigma and discrimination, can have repercussions across the HIV care continuum – including delayed diagnosis, delayed linkage to care, and challenges with adherence and retention in care (with the result that it becomes more difficult to maintain an undetectable viral load).¹⁴

Access to specialist HIV mental health services should be central to an integrated, person-centred approach to HIV care. In particular:

- An HIV specialist mental health professional should ideally be included within a multi-disciplinary care team. Where this does not happen or is not possible, clear and effective referral pathways to mental health services should be implemented.
- HIV clinicians should be provided with the knowledge and tools to be able to screen for mental health problems, make referrals to mental health specialists, and support prevention and/or non-progression of mental health conditions.
- HIV-specific training should be provided to mental health professionals with a view to ensuring greater knowledge, understanding and awareness of the linkages between HIV and mental health – in particular the impact of stigma and discrimination.
- Improved funding for general mental health services is essential to ensure that people with HIV have access to appropriate treatment and care.

Sexual and reproductive health (SRH)

People with HIV should have access to regular sexual health assessments, counselling and support services, and accurate information and advice on HIV transmission, other sexually transmitted infections and methods of contraception, as well as on conception, childbirth and parenting options. SRH services should be sensitive to the specific needs of individuals across different population groups.

For women with HIV, access to services for family planning and the management of menopause are especially important. HIV is associated with low bone mineral density and is of particular concern in relation to post-menopausal women.¹⁵ Screening and preventative interventions are therefore needed, including guidance on self-management, weight-bearing exercise and a calcium rich diet.

¹² See European AIDS Treatment Group, *HIV and Mental Health* (2021), available at: <https://www.eatg.org/publications/briefing-paper-mental-health-of-people-living-with-hiv/>

¹³ Public Health England, 'Positive Voices: The National Survey of People Living with HIV', 2017 survey (2020), available at: <https://www.gov.uk/government/publications/hiv-positive-voices-survey>

¹⁴ UNAIDS, 'Integration of mental health and HIV interventions: Key considerations' (2022) available at: https://www.unaids.org/sites/default/files/media_asset/integration-mental-health-hiv-interventions_en.pdf; R. Reimen, 'The impact of mental health across the HIV care continuum', *Psychology and AIDS Exchange Newsletter* (2018)

¹⁵ M.J. Kruger and T.A. Nell, 'Bone mineral density in people living with HIV: a narrative review of the literature', *AIDS Research and Therapy* (2017); F. Finnerty *et al.*, 'Osteoporosis in postmenopausal women living with HIV', *Maturitas* 95 (2017)

Recommendations

HIV CLINICS / CARE PROVIDERS

- Implement routine screening for all relevant comorbidities based on individual characteristics and needs, in line with national and international guidelines, using short, easy to administer, validated screening instruments.
 - Capture individual data on comorbidities using electronic health records as a tool to support integrated, personalised care.
 - Involve peers or community members to support with prevention, screening, treatment and management of comorbidities.
- Ensure care managers are trained to evaluate results of mental health screenings and establish pathways for referrals in case specialist care is required. Consider including a specialist HIV mental health professional as part of a multi-disciplinary HIV care team.
- Promote healthy living (exercise, nutrition, etc) and offer materials to enhance health literacy among people with HIV.
- Create and implement health services as part of routine care for women with HIV, encompassing family planning (with free of charge access to personalised contraceptive measures); sexual and reproductive health services; post-reproductive sexual health, including menopause.
- While fully protecting privacy, adopt digital tools (such as apps and electronic devices) that can support the collection and management of individual data, including PRO data, and improve the experience of people with HIV when accessing healthcare services (e.g. the Happi App in the Netherlands).
 - Monitor and evaluate the use of digital tools in clinical care to ensure that they provide the intended benefits and to identify (and if necessary respond to) any unforeseen consequences.
 - To avoid digital exclusion, use of such tools should take account of differing levels of health literacy and the fact that such tools may not be appropriate for all people/populations. Particular attention is needed to avoid the digital exclusion of vulnerable groups.

NATIONAL AND REGIONAL HEALTH AUTHORITIES

- Promote systematic data collection on comorbidities among people with HIV using a validated instrument.
- Develop/update a monitoring and evaluation framework for HIV care, incorporating indicators on comorbidities, leading causes of mortality and hospitalisation, and PROs including HRQoL.
- Integrate the framework into the national HIV strategy and ensure funding for its implementation.
- Ensure that all mental health professionals receive training on the specific mental health challenges faced by people with HIV, including stigma and discrimination, cognitive disorders, and challenges to mental health and well-being affecting key populations.
- Adopt and expand integrated HIV and primary care outreach services to locations, times and conditions that reduce access barriers for marginalized and vulnerable groups. Pilot integrated models of care for these

groups that link them with the formal health system, including community-based health and psychosocial services and peer support programs.

- While taking into account country-specific capacities as regards the digitalisation of health systems, promote and support the implementation of digital/telemedicine services that can enhance integrated and multi-disciplinary care, improve access to health services (particularly for people living in remote areas), and strengthen care retention.
- Privacy-protective exchange of health data, between medical specialists, should be enabled. The benefits of such services should also be carefully monitored and evaluated in comparison with more traditional (i.e. in-person) services to ensure they do not create new health inequities.

THE EUROPEAN UNION

- Expand the mandate of the Steering Group on Health Promotion, Disease Prevention, and NCDs management to initiate work programmes on communicable diseases such as HIV, including prevention, diagnosis and coordinated management of comorbidities.
- Ensure sustainable funding for cohort studies to provide information on the long-term health of people with HIV, including comorbidities and HRQoL.



KEY AREA 2

Ageing with HIV

As people age, they are at increased risk of frailty and other geriatric syndromes (such as functional limitation, depression and cognitive impairment) as well as polypharmacy.¹⁶ HIV further increases the complexity associated with care provision as people grow older, which national and regional health authorities must respond to with tailored health services.

That includes ensuring that long-term care providers, and carers, are appropriately trained and equipped to address the needs of older adults with HIV, and that specialist health care services are both available and accessible – for example through the creation of ‘Ageing Clinics’ for people with HIV.

Action to address the needs of older people with HIV should be informed by the WHO *World Report on Ageing and Health* (2015), which emphasises that the maintenance of ‘functional ability’ requires an ongoing focus on both physical and mental health, as well as the environments in which people with HIV live and work.¹⁷ In the case of HIV, this should include a strong focus on prevention and screening for comorbidities, frailty and other geriatric

¹⁶ On geriatric syndromes, see S.K. Inouye, ‘Geriatric Syndromes: Clinical, Research and Policy Implications of a Core Geriatric Concept’, *J Am Geriatr Soc.* 55, 5 (2007)

¹⁷ WHO, *World Report on Ageing and Health* (2015), available at: <https://apps.who.int/iris/handle/10665/186463>

syndromes. The UN Decade of Healthy Ageing also provides an important forum for consideration of challenges related to ageing with HIV, and for the exchange of best practices.

It is vital that consideration also be given to ways of addressing the 'digital divide', so that older people with HIV are not excluded from digitally-enabled health (and other) services.

Recommendations

HIV CLINICS / CARE PROVIDERS

- Provide specialised, integrated healthcare services focused on the needs of older adults with HIV, including frailty and other geriatric syndromes, disability, age-related comorbidities, and mental health (e.g. depression)

NATIONAL AND REGIONAL HEALTH AUTHORITIES

- Develop and implement training programmes for carers, in particular those working in retirement homes, focused on the specific health and well-being needs of older people with HIV – including mental health.

THE EUROPEAN UNION

- Provide funding for pilot studies on models of HIV care that employ or develop frameworks for healthy aging, frailty, functional ability, and other dimensions of health that are relevant to people with HIV, using HRQoL as a key outcome measure. People with HIV should be meaningfully involved in these efforts.



KEY AREA 3

Measurement of PROs and Monitoring of Health-Related Quality of Life

PROMs are questionnaires used to ascertain an individual's perspective on their health and health-related quality of life.¹⁸ This includes physical, mental and social dimensions – such as energy and fatigue, mental and cognitive health, sleep and rest, pain and discomfort, sexual and reproductive health and social isolation.¹⁹

At the individual level, PROMs can be used to monitor health outcomes over time, to enhance communication between people and their doctors, as well as to support decision-making and monitor – thereby strengthening person-centred care. Aggregated PRO data can also be used for quality improvement initiatives at the clinic level.²⁰

However, the experience of HIV Outcomes members suggests that very limited progress has yet been made in the integration of PROMs into routine HIV care provision. The reasons for this include: pressures on time and resource; a

¹⁸ K. Churruca *et al.*, 'Patient-reported outcome measures (PROMs): A review of generic and condition-specific measures and a discussion of trends and issues', *Health expectations* 24, 4 (2021)

¹⁹ K. Bristowe *et al.*, 'The development and cognitive testing of the positive outcomes HIV PROM: a brief novel patient-reported outcome measure for adults living with HIV', *Health and Quality of Life Outcomes* 18 (2020)

²⁰ Churruca *et al.* (2021)

lack of familiarity with relevant measurement tools (as well as how to interpret/analyse the responses); and broader cultural factors – such as PROMs not being commonly used within the wider health system.

Funding should also be dedicated to studies that can support the interpretation and actionability of PROs for people with HIV, and enhance the impact of PROM integration on quality of care – for example, due to improved communication between people with HIV and their doctor, satisfaction with care, and even health outcomes.

In addition, annual surveys of people accessing healthcare services, including questions on HRQoL, can also be used at an aggregate level (e.g. within a region or country) to better understand the challenges experienced by people with HIV, and so inform policies designed to improve HIV care and health outcomes.

Such surveys have been used in some countries (for example in England and Sweden) to enhance regional and national monitoring of HIV care quality, and to identify areas for improvement.²¹ However, these examples appear to be the exception. In 2018 only five of 48 countries in Europe who responded to the monitoring of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia reported that they included HRQoL in their HIV monitoring.²²

The development of national HIV registries could contribute to improved monitoring of HRQoL and other aspects of HIV care ‘beyond viral suppression’. Efforts should also be made to standardise data collection across countries as a basis for cross-country analyses and shared learning. The European Health Data Space holds particular potential in this context.

Recommendations

HIV CLINICS / CARE PROVIDERS

- Identify where, when and how in the pathway of care, PROM measurement is to take place, including which PRO questionnaire(s) are to be used, and how data collection will be organised.
- Integrate PRO measurement into clinical practice, which can then be used for shared decision-making with those living with HIV, to tailor interventions to individual needs and preferences, and for monitoring of health outcomes.

NATIONAL AND REGIONAL HEALTH AUTHORITIES

- Establish annual surveys of people with HIV to collect and document data on HRQoL and on experiences of stigma and discrimination in healthcare settings.
- In line with the GIPA principle to ‘support a greater involvement of people living with HIV/AIDS at all levels’, fully involve the HIV community in defining a framework for the monitoring and assessment of HRQoL among, which can provide the basis for annual surveys.
- Incorporate goals and targets on HRQoL into the national HIV strategy and ensure funding for its implementation.

²¹ Public Health England, ‘Positive Voices: The National Survey of People Living with HIV’, 2017 survey (2020), available at: <https://www.gov.uk/government/publications/hiv-positive-voices-survey>; HIV Outcomes case study, ‘Sweden – InfCare’, available at: https://hivoutcomes.eu/case_study/sweden-infcarehiv/

²² K. Safreed-Harmon *et al.*, ‘Ability to Monitor National Responses to the HIV Epidemic “Beyond Viral Suppression”’: Findings from Six European Countries’. *Front. Public Heal.* 8, 36 (2020).

- Provide financial (and, where applicable, administrative/technical) support for the creation of HIV registries. These can in turn support data collection, research and monitoring on the long-term care and HRQoL of people with HIV. Cross-country standardisation would strengthen international monitoring and comparison.

THE EUROPEAN UNION

- Allocate funding for the inclusion of HIV within the OECD Paris Initiative to provide standardised, comparable data on PROs and experiences across countries.



KEY AREA 4

Combatting Stigma and Discrimination

HIV-related stigma is ‘negative beliefs, feelings and attitudes towards people with HIV, groups associated with them (e.g. their families) and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people’.²³

Stigma may be enacted/experienced, perceived, and internalised. Internalised stigma is where an individual ‘become[s] aware of the public stigma, agree[s] with it and appl[ies] the discriminated attitudes to themselves’²⁴ HIV-related stigma may lead to the under-utilisation of health and social services, as well as poorer health outcomes, including mental health.²⁵

HIV-related discrimination is ‘the unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status’.²⁶ HIV-related discrimination is a behavioural consequence of stigma because it expresses or enacts stigma in social settings. In Eastern Europe and Central Asia, in particular, it is essential that legal and policy barriers - which restrict access to health services among key populations – are removed.²⁷

Addressing societal stigma and discrimination requires an inter-sectoral approach – including education and employment, for example – with tailored interventions required in each sector/policy area. The focus in this paper is on stigma and discrimination within health systems and the actions that are needed in that context.

There is ample evidence that HIV-related stigma and discrimination remains an issue in European health systems. In a survey of 1000 people with HIV in Germany, for example, 56% of respondents reported at least one negative

²³ UNAIDS, ‘Guidance note: reduction of HIV-related stigma and discrimination’ (2014)

²⁴ Lau, Y. W. et al. ‘Stigma resistance and its association with internalised stigma and psychosocial outcomes among psychiatric outpatients’ *Psychiatry Res.* 257 (2017); M. Pantelic, L. Sprague, A Stangl, ‘It’s not “all in your head”: critical knowledge gaps on internalized HIV stigma and a call for integrating social and structural conceptualizations’ 19 (2019)

²⁵ S. Rueda, S. Mitra, and S. Chen *et al.* ‘Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses’, *BMJ Open* 6, 7 (2016)

²⁶ UNAIDS, ‘Guidance note: reduction of HIV-related stigma and discrimination’ (2014)

²⁷ Avert, ‘HIV and AIDS in Eastern Europe and Central Asia Overview’, available at: <http://www.sidaventure.org/hiv-and-aids-eastern-europe-central-asia-overview.html>

experience (related to their HIV status) in the preceding 12 months. The most commonly reported experience was having a medical record marked due to HIV status.²⁸ In addition:

- 21% reported being given a special appointment time (e.g. at the end of the day)
- 17% said they were asked an inappropriate question about their HIV infection (e.g. route of transmission)
- 10% reported being refused a healthcare benefit because of their HIV status
- 9% said their HIV status was disclosed against their will.

In Spain, a recent survey of 500 people with HIV found that 24% of respondents had experienced rejection, 27% perceived that they had been treated differently from other people; while 23% people had avoided visiting a physician.²⁹

Actions are being implemented within countries, or foreseen as part of HIV national strategies, to combat stigma and discrimination. These focus, in particular, on education and training of healthcare professionals, improving awareness of HIV transmission routes and U=U (undetectable = untransmissible)³⁰. Relevant healthcare professionals should be trained to identify potential instances of discrimination – for example by asking people with HIV questions about their work, health and other forms of insurance, and legal status within the country.

The involvement of patient experts – who are associated with relevant organisations focused on people with HIV and trained to detect and advise on all aspects of stigma and discrimination, and who communicate ways that may seem more relatable/empathetic to other people with HIV – would provide additional tools and resources for combatting stigma and discrimination both within and outside the health system.

In France, there have been actions by community-based organisations to reduce self-stigma, empower people with HIV and enable them to limit the impact of stigma and discrimination on their lives.

Governments should provide resources and administrative capacity to improve data collection and reporting on stigma and discrimination – within the health system as well as within society more broadly (for example, in relation to employment) – in line with UNAIDS monitoring. Strategies should be developed to address stigma and discrimination in these different contexts.

²⁸ Deutsche Aidshilfe, 'Positive stimmen 2.0: Living with HIV, breaking down discrimination' (2021), available at: https://hiv-diskriminierung.de/sites/default/files/documents/broschuere_englisch_final.pdf

²⁹ Fuster-Ruiz de Apodaca et al., 'Percepción de las personas con VIH sobre la calidad de la atención médica y su impacto en la calidad de vida relacionada con la salud', Congreso GESIDA. Málaga 2021

³⁰ Consensus Statement following a conference in Italy in November 2019: 'Italian Consensus Conference on U=U (U=U)', available at: <https://www.salute.gov.it/portale/hiv/dettaglioPubblicazioniHIV.jsp?lingua=italiano&id=2903>

Recommendations

HIV CLINICS / CARE PROVIDERS

- Offer peer-to-peer and community-based interventions to address stigma and discrimination experienced by people with HIV, including a focus on the fact that an undetectable viral load means untransmissible virus.
 - Peer-to-peer services focused on key populations – including trans people, sex workers, people who inject drugs and people in closed settings – are also needed to more effectively address and respond to the stigma and discrimination experienced by those populations.

NATIONAL AND REGIONAL HEALTH AUTHORITIES

- Design and implement interventions that can strengthen empathy towards people with HIV among healthcare staff and decrease stigma and discrimination in healthcare settings. Monitor and regularly review the effectiveness of these interventions.
- Provide training that enables healthcare professionals to detect/identify potential instances of discrimination in the lives of people with HIV.
- Provide support and funding for interventions involving peers and community members.
- Strengthen data collection and reporting on stigma and discrimination in line with UNAIDS monitoring.

THE EUROPEAN UNION

- Given the negative impact of stigma and discrimination on mental health, ensure that any future EU mental health strategy includes a focus on reducing stigma and discrimination among groups at risk, including people with HIV.
 - This strategy should adopt a societal approach to combatting stigma and discrimination, in particular among vulnerable groups, and within health systems.
 - The EU should provide guidance to Member States on actions to combat stigma and discrimination, drawing on best practices from across the EU.

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