

Ending the HIV epidemic in Europe: Moving toward the 2030 sustainable development goals

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Glossary

Antiretroviral therapy (ART)

Antiretroviral therapy (ART) is designed to maximally suppress the replication of HIV in the infected patient and to decrease and/or prevent systemic acute and chronic inflammation associated with the virus.

Comorbidity

The presence of two or more diseases or medical conditions at the same time.

Epidemic

A large number of cases of a particular disease or medical condition happening at the same time in a particular community.

Morbidity

The fact of having a particular disease.

PLHIV

People Living with HIV.

Mortality

The number of deaths in a particular situation or period of time.

Pre-exposure prophylaxis (PrEP)

Pre-exposure prophylaxis (or PrEP) is medicine taken to prevent getting HIV.

Undetectable=Untransmittable (U=U)

U=U means that people with HIV who achieve and maintain an undetectable viral load—the amount of HIV in the blood—by taking antiretroviral therapy (ART) daily as prescribed cannot sexually transmit the virus to others.

Executive summary

Despite significant progress, the human immunodeficiency virus (HIV) epidemic continues to pose a public health threat in Europe. The COVID-19 pandemic has exacerbated challenges by disrupting healthcare services and diverting attention and resources away from HIV prevention and treatment. Stigma and discrimination against those affected by HIV persist and are additional obstacles, slowing down progress to end the HIV epidemic.

To meet the United Nations Sustainable Development Goals (SDG) target of ending the HIV/AIDS epidemic by 2030, Europe must prioritise ending the transmission of HIV while also ensuring quality care for the people living with HIV. The European Union's global health strategy, launched in 2022, aims to regain ground lost during the COVID-19 pandemic and achieve universal health-related goals. The EU can also play a significant role in advancing UNAIDS goals and ending the epidemic within its borders.

This Discussion Paper explores the current HIV prevalence in Europe, identifies barriers and challenges, and offers policy recommendations to overcome these obstacles and meet the SDG targets in Europe. It emphasises the need for renewed political commitment and cooperation among the EU and its member states to prioritise HIV, as well as strong partnership and collaboration between authorities and stakeholders concerned, ultimately striving for success in ending the epidemic.

Introduction

HIV remains a pressing and complex global public health issue. Progress in relation to HIV is slowing down in various regions, including Europe. While the prevalence of HIV is generally lower in Europe compared to other regions, such as sub-Saharan Africa, it continues to be a significant health concern. Access to HIV testing and diagnosis in Europe has encouraged proactive detection, facilitating the timely commencement of treatment and care. Despite a noteworthy decline in HIV in Europe over the last three decades, ending the epidemic remains a challenge that must be addressed at the highest political level.

The ongoing permacrisis¹ has had consequences for individuals living with or at risk of contracting HIV. The COVID-19 pandemic disrupted healthcare services, testing, diagnosis, treatment, and prevention programmes. Unequal levels of commitment and reduced investments in HIV prevention and care harm outcomes both for individuals living with the virus and for the overall fight to end the epidemic in Europe. Moreover, those affected by HIV frequently face the additional burden of stigma and discrimination associated with the infection.

The EU's global health strategy, launched in November 2022, seeks to regain the ground lost due to the COVID-19 pandemic to reach the universal health-related targets in the 2030 Sustainable Development Goals. The EU's global efforts also include initiatives such as the European Developing Countries Clinical Trials Partnership (EDCTP) Joint Undertaking. However, the EU can and must

also play a part in advancing the Joint United Nations Programme on HIV/AIDS UNAIDS goals and ending the transmission of HIV within its borders. This is a critical time for the EU to renew its commitment to global goals and inspire its member states to potentially make Europe the first region to end the HIV epidemic.

This is particularly true in the context of the 2024 European Parliament elections and the new mandate of the European Commission. The next legislative term will run until 2029 and thus will be of significant importance when it comes to achieving the targets of the SDGs by 2030, including those related to HIV. Upcoming Presidencies of the Council of the EU will be of utmost importance given the commitment of member states needed at a national level. The Spanish Presidency has recognised HIV and its link with the stigma and discrimination as a priority, bringing it to the fore of their health agenda. Thus, with this recognition and an anticipated high-level political declaration, ending the HIV epidemic should be a priority for the EU and all Member States. In particular, the upcoming Presidencies, notably starting with Belgium, could play a key role in continuing the political momentum and setting the tone for a clear and ambitious roadmap to achieve this goal in Europe.

This Discussion Paper explores the current prevalence of HIV in Europe before examining the barriers and challenges to eliminating the virus and setting out policy recommendations to overcome those challenges to achieve the targets of the SDGs.

Assessing the situation: HIV in Europe

Despite considerable progress in recent decades, HIV is still a prevalent communicable disease associated with consistently high treatment and care costs, a notable mortality rate, and a reduction in life expectancy.² In the European Union/European Economic Area alone, current estimates indicate that there are approximately 780,000 individuals living with HIV. In 2021, a total of 16,624 new cases of HIV were documented across 29 countries in the EU/EEA region. When considering the reporting delay, the adjusted rate stood at 4.3 per 100,000 individuals.³

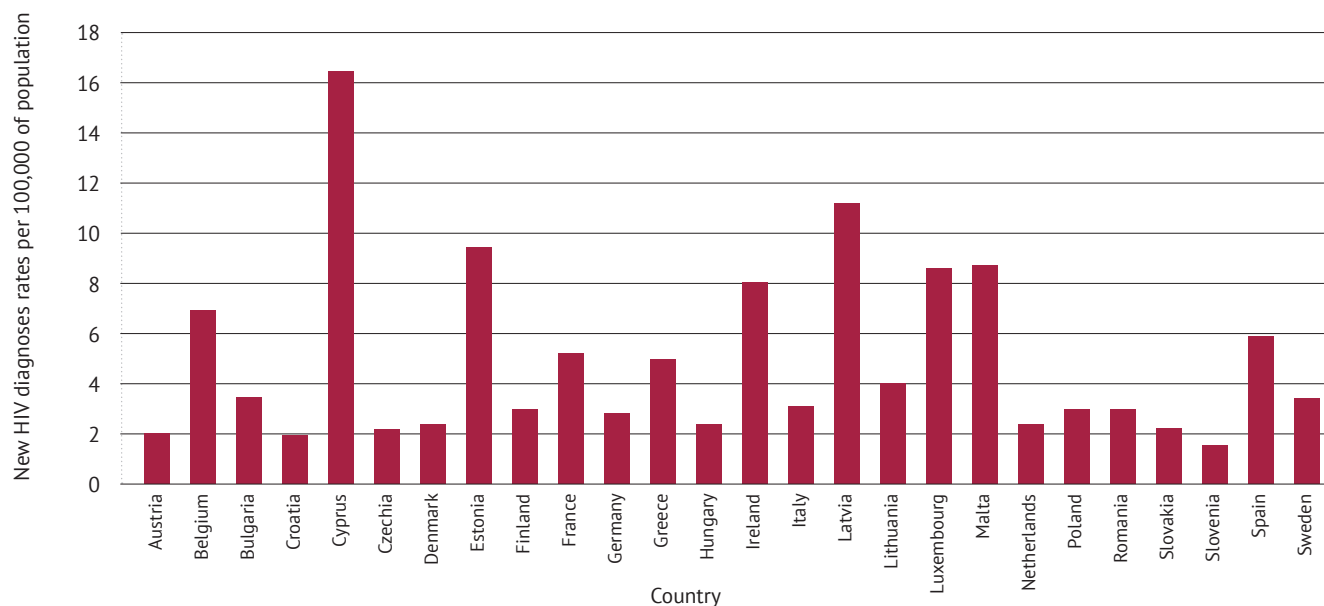
However, the rate of HIV diagnosis varies among different member states of the European Union. For example, Cyprus has reported a new HIV diagnosis rate of 16 per 100,000, while Slovenia has a rate of 1.5 per 100,000. Additional examples include France with a rate of 5.2, Italy with 3, and Germany with 2.7. HIV diagnoses are more common among the male population in Europe, with an overall male-to-female ratio of

3.6: 1. Data shows that the rate of a new diagnosis in men in EU/EEA countries was 5.8 per 100,000 population in 2021. This is compared to 1.6 per 100,000 for women.⁴ Additionally, The European Centre for Disease Prevention and Control (ECDC) World Health Organization (WHO) report states that 149 individuals with unknown or other gender were diagnosed with HIV in 2021.

HIV is deemed a concentrated epidemic for most of Europe, disproportionately impacting specific populations.⁵ This includes individuals and their sexual partners who use intravenous drugs, men who have sex with men, transgender people, sex workers, prisoners, and migrants.⁶ Evidence also shows that people who belong to the above-mentioned population groups face heightened vulnerability to HIV infection. Moreover, they may encounter significant challenges when trying to access services for HIV prevention, testing, diagnosis and ultimately, treatment and care.⁷

Fig. 1

NEW HIV DIAGNOSES AND RATES PER 100 000 POPULATION 2021⁸



Source: World Health Organization.

Sex between men is the most common transmission mode of HIV in the EU/EEA, with 40% of all new diagnoses of HIV contracted as a result of sex between men. It accounted for more than 60% of new HIV diagnoses in 11 countries, including Austria, Croatia, Czechia, Germany, Hungary, Ireland, Malta, Netherlands, Poland, Slovakia, and Spain.⁹ Sex between men and women accounted for 29% of all HIV diagnoses in EU/EEA, making it the second most reported mode of transmission. Injecting drug use is also used to explain cases of HIV in Europe; however, this occurs in much lower proportions, with only 3.5% of all new diagnoses in EU/EEA attributed to injecting drug use.

In 2021, 42% of the individuals diagnosed in the EU/EEA were categorised as migrants, denoting that they originated from a different country than the one where they were diagnosed. Among this migrant population, 14% were from countries in sub-Saharan Africa, 10% from Latin America and the Caribbean, 8% from other countries in Central and Eastern Europe, and 3% from other countries in Western Europe.¹⁰

ACCESS AND AVAILABILITY OF TREATMENT

Despite a decade-long drop in new HIV cases in the EU/EEA, an estimated 780,000 people are living with HIV in the EU/EEA, of whom 692,000 (88%) are diagnosed.¹¹ However, the success of antiretroviral therapy (ART) has drastically reduced HIV-related morbidity and mortality while also improving the life quality and expectancy of people living with HIV (PLHIV). The development of ART has also allowed for research to conclude that HIV Undetectable=Untransmittable (U=U). Individuals who

achieve and maintain an undetectable viral load by taking antiretroviral therapy as prescribed cannot transmit the virus to others. Thus, treatment is also an important preventative tool.

This highlights the importance of access and availability to HIV treatment and prevention options in the pursuit of ending the epidemic. Access to prevention and treatment options have greatly improved globally in the last two decades, especially when compared to the early 2000s and the controversy of the WTO Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) waiver and its negative impact in relation to access, leading to the signing of the Doha declaration.¹² This eventually allowed for greater access, especially in low and middle-income countries. However, access varies across the region, with antiretroviral therapy coverage is lower in central Europe.

With adequate access to prevention, treatment and care, HIV is no longer a life-limiting condition with better outcomes for those living with the disease.¹³ This efficacy has resulted in an older population living with HIV, which can be explained by the fact that young people with HIV are surviving and ageing combined with increasing rates of HIV diagnosis in older people.

Although treatment has greatly improved the outcomes for PLHIV, challenges remain. Such challenges include the development of chronic complications and comorbidities, including noncommunicable diseases and negative implications on mental health. Studies have shown that among these comorbidities, cardiovascular diseases, chronic kidney disease, and osteoporosis are more prevalent in PLHIV compared to non-HIV populations in high-income countries.¹⁴

Additionally, PLHIV frequently encounters stigma and discrimination, which profoundly impacts the health, well-being, and lives of individuals living with or at risk of HIV, particularly among key populations. HIV-related stigma encompasses various stigmatising encounters such as avoidance, gossip, verbal abuse, and social rejection. At the same time, discrimination can involve these behaviours when they impede employment rights,

instances of physical abuse, denial of health or social services, loss of employment or education opportunities, and even arrests. Moreover, it may be institutionalised through criminal laws, travel restrictions, mandatory testing, and employment limitations. Individuals may also face intersectional discrimination or stigma based on multiple factors, such as race, disability, and socioeconomic status.¹⁵

Towards ending the HIV epidemic: Progress to date

Since 2012, there has been a downward trend in the number of reported HIV diagnoses in EU/EEA countries that consistently provide data. In 2012, the rate was six per 100,000 population, but by 2019, it had decreased to 5.5 per 100,000. In 2020, the rate further declined to 4.0 per 100,000 but saw a slight increase in 2021, reaching 4.3 per 100,000.¹⁶ The decline observed in 2020 is likely due to reduced case detection due to less testing during the height of the COVID-19 pandemic. The rise in reported HIV diagnoses from 2020 to 2021, on the other hand, could be explained by a return to HIV testing levels similar to those seen before the pandemic.

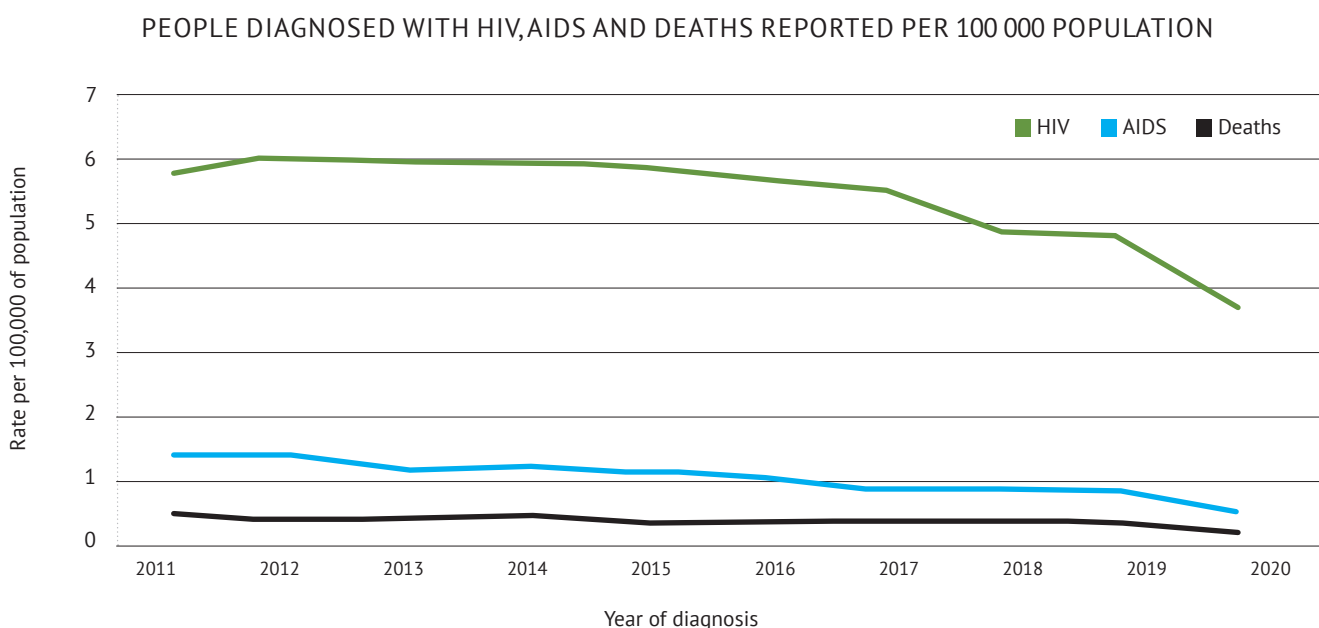
Although overall, there has been a decrease in the number of reported cases per 100,000 population, there are stark differences across member states, with some experiencing an increase in the rate of diagnosis. Data reflected in the joint ECDC WHO report “HIV/AIDS surveillance in Europe 2022” shows a decline in HIV diagnosis in approximately two-thirds of EU/EEA countries. However, it also depicts that in Cyprus and Slovakia, diagnosis rates have more than doubled, while in Bulgaria, they have increased by

more than 50%. Therefore, while progress has been made concerning eliminating the transmission of the virus, the extent of this progress varies across the EU, with some countries reporting increases.

ACHIEVING THE SDGS

This signals a need for increased momentum to ensure that Europe meets the sustainable development goals by 2030. To meet these goals, the Joint United Nations Programme on HIV/AIDS (UNAIDS) established targets, which sought to ensure that by 2020, 90% of all people living with HIV would be diagnosed, 90% of those diagnosed would be receiving treatment, and 90% of those receiving treatment would have achieved viral suppression. This implies aiming for a 73% viral suppression rate among all individuals living with HIV (PLHIV). It is frequently referred to as the 90-90-90 target. Modelling conducted by UNAIDS estimated that by reaching these targets, the SDG of eliminating the AIDS epidemic by 2030 would be achievable.¹⁷

Fig. 2

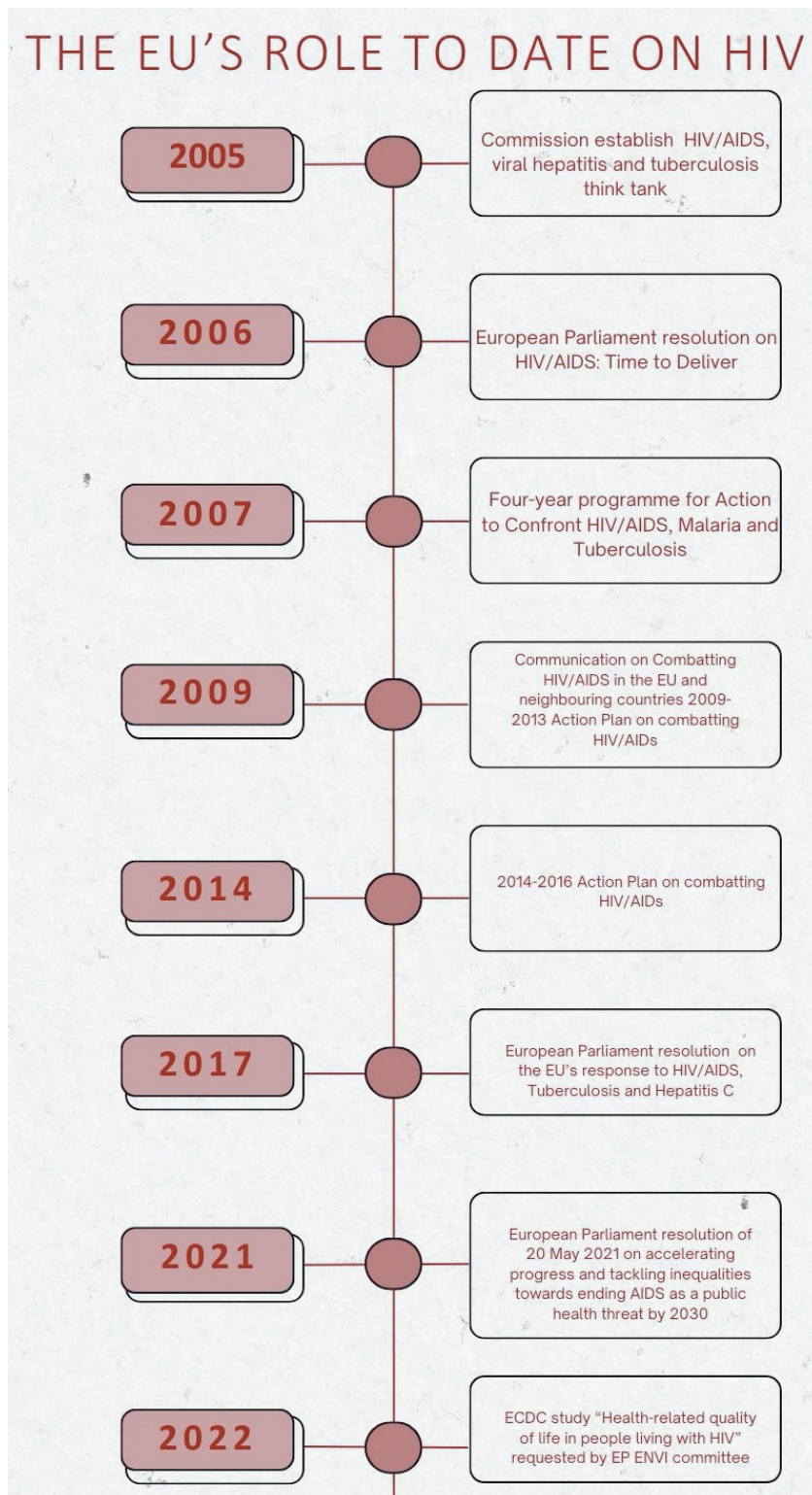


Source: European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2021 – 2020 data.

Overall, the EU/EEA had, by 2020, reached two of the three 90-90-90 targets whereby 88% of people living with HIV were diagnosed, 93% diagnosed started treatment, and 91% of those on treatment were virally suppressed. However, not all EU countries met the target, with only Belgium, Czechia, Denmark, Finland, France, Germany, Ireland, Italy, the Netherlands, Portugal, Slovenia, Spain and Sweden achieving 73% viral suppression among all people estimated to be living with HIV.¹⁸

This infers that further action is needed to meet the targets in the remaining 14 member states. In December 2020, UNAIDS released a new set of ambitious targets, 95-95-95, calling for 95% of all people living with HIV to know their HIV status, 95% of all people with diagnosed HIV infection to receive sustained antiretroviral therapy, and 95% of all people receiving antiretroviral therapy to have viral suppression by 2025.

Fig. 3



Focusing on the 20 countries in the EU/EEA that reported data in 2022 for all four stages, it was estimated that 671,091 individuals were living with HIV in the EU/EEA. Of those, 89% had received a diagnosis. Among the diagnosed individuals, 95% received treatment, and of those on treatment, 93% (526,412) had achieved viral suppression. Across the EU/EEA, 78% of people living with HIV had attained viral suppression.¹⁹

EU'S ROLE TO DATE ON HIV

Europe has made substantial progress when it comes to reducing both the rate of HIV diagnosis and the impact of the virus on those diagnosed. Developments regarding testing, prevention and treatment options have greatly aided this progress. This has been complimented by interventions and policies aimed at declining the spread and impact of the virus. On the global scale, initiatives such as the United Nations Joint Program on HIV/AIDS (UNAIDS)²⁰ have played a significant role since its launch in 1994, as well as the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia²¹ which was adopted in 2004.

In 2007, the European Commission launched a four-year programme for Action to Confront HIV/AIDS, Malaria and Tuberculosis, asserting itself as a leader in HIV response, committing to a right-based approach.²² In 2009, the Commission published a Communication on Combating HIV/AIDS in the EU and neighbouring countries.²³ This was accompanied by two successive action plans: Action Plan 2009-2013 and Action Plan 2014-2016. From 2005 to 2019, the Commission established the HIV/AIDS, viral hepatitis, and tuberculosis think tank to assist with policy implementation and strengthen cooperation and information sharing between countries. However, this approach has changed since this period, with no follow-up to the last Action Plan in 2016 or a specific formal

forum for discussion on HIV. Instead, the Commission has pursued a non-disease-specific approach (beyond cancer and COVID-19), moving away from the more targeted approach to eliminating the transmission of HIV. EU efforts on HIV are concentrated on the global scale with a particular focus on sub-Saharan Africa. While this is undoubtedly important, the EU should also continue to prioritise efforts to end HIV transmission within its borders.

However, the EU continues through its various programmes and funding mechanisms to support projects which address HIV. Under the Horizon 2020 programme, the EU has funded the European AIDS Vaccine Initiative 2020, which provides a platform for the discovery and selection of several new vaccine candidates for HIV/AIDS that can prevent HIV infection and establish long-term remission of those infected. Additionally, the European HIV Vaccine Alliance (EHVA) has been established under Horizon 2020 to promote a comprehensive approach to develop an effective and multidisciplinary HIV vaccine platform. The EU4Health programme also funds activities related to HIV including, EU4Health action grants to support the implementation of best practices in community-based services for HIV, AIDS, tuberculosis, viral hepatitis and STIs; INTEGRATE Joint Action which seeks to improve awareness, prevention, early diagnosis and linkage to care of HIV, viral hepatitis, tuberculosis and sexually transmitted infections (STIs) in Europe and E-Detect a research consortium dedicated to the elimination of tuberculosis (TB) in the EU by utilising evidence-based interventions.

The European Parliament has also continued to advocate for action to meet the SGDs. Most recently the Parliament adopted a resolution focused on accelerating progress and tackling inequalities towards ending AIDS as a public health threat by 2030, while the ENVI committee requested an ECDC study on health-related quality of life in people living with HIV.

Barriers to ending the HIV epidemic in Europe

Progress has been made in relation to HIV in Europe. However, this has been insufficient in so far as ending the epidemic. With 2030 and thus the deadline for sustainable development goals fast approaching, efforts must be made to end the transmission of HIV. However, there exists a number of challenges that must be addressed to achieve this objective:

ADDRESSING THE IMPACT OF THE PERMACRISIS

The current era of permacrisis presents a challenge to combating HIV in Europe. Evidence shows that the COVID-19 pandemic had an adverse effect on critical aspects of public health, including HIV prevention, testing and healthcare service delivery. The strict

lockdown measures introduced to curb the spread of the virus resulted in disruption to HIV prevention services. Research indicates a decrease in the rate of diagnosis during the height of the pandemic, which is likely attributable to a drop in HIV testing rates. Data from ten EU member states (Belgium, Bulgaria, Czech Republic, Estonia, France, Latvia, Poland, Portugal, Romania, and Slovenia) estimates that 100,000 HIV tests were not performed in 2020. This represents an 18% decrease in HIV tests.²⁴ It is difficult to assess the implications of the decrease in testing during this period. However, it will likely mean an increase in under- or late diagnosis.

The strain on healthcare systems due to the COVID-19 pandemic resulted in reduced capacities for non-emergency healthcare services, including those related to HIV. For example, routine check-ups, HIV testing, and

counselling services experienced limitations or delays, which could have implications for early diagnosis and timely treatment initiation. In the WHO Europe region, 4% of PLHIV reported an interruption of ART due to lockdowns, and 6% (around 120,000) were unable to collect ART due to mobility restrictions. Additionally, some EU member states, namely Romania, Italy, Portugal and Ireland encountered shortages of HIV medicines and the discontinuation of PrEP programmes. The war in Ukraine also has implications with regard to HIV. Since the onset of the war, more than 13.5 million people have been internally displaced or forced to seek refuge in neighbouring countries, including PLHIV (estimated between 10,000 to 30,000).²⁵ Ukraine has the second-largest AIDS epidemic in Eastern Europe and Central Asia, with a rising number of new HIV diagnoses in recent years. Before the Russian invasion, the country was making significant progress in its AIDS response, with free HIV care and treatment available at governmental clinics and a large percentage of people living with HIV on antiretroviral treatment (ART). However, the war threatens this progress with difficulties in accessing HIV testing, treatment and care services. Ukrainian PLHIV who have been forced to flee their country require support from EU members to which they have fled to ensure continuity of care as well as provisions for testing, prevention and treatment.

NEED FOR STRONG POLITICAL COMMITMENT

Unwavering political commitment is essential to meet the SDGs and end HIV in Europe. Evidence from a recent study shows that strong political leadership is essential for HIV responses to achieve success.²⁶ The progress made to date in relation to HIV was supported by political will at national, European and global levels. However, with a decrease in rates of HIV diagnosis in Europe came to a stagnation in its political commitment to ending the epidemic. The fight against HIV/AIDS requires continuous political will, innovative strategies and preventive and care options, and increased resources to meet the 2030 target of ending the epidemic. HIV has fallen off the top of the political agenda, especially at the EU level, where action is important and can help set the agenda and garner commitments from member states to meet the HIV targets.

While remaining a feature of global efforts, attention should also be given to eliminating the virus within Europe, considering the ambitions of the EU Global Health Strategy. While the EU must also support ending the transmission of HIV in other regions, in particular in sub-Saharan Africa, it should also lead by example by ensuring that the SDGs targets are met in Europe. This must be complemented by continued political buy-in at the member state level. Without such buy-in, reaching the SDGs becomes unattainable, which given the progress to date, would be a missed opportunity.

OBSTACLES TO HIV TESTING

HIV testing is essential to address the HIV epidemic. Current and country-specific national HIV testing strategies play a vital role in enhancing the effectiveness of HIV testing services. To ensure increased access to testing across the EU, the obstacles often impeding testing must be addressed using an intersectional approach. For example, research has shown that late diagnosis in women is common and even more so for migrant women. Barriers to testing for migrant women include a perceived low risk of HIV and a knowledge gap in HIV symptoms and services. This is further compounded by sociocultural barriers, including language and communication challenges, as well as stigma.²⁷ Addressing challenges specific to particular groups in society will be important to increase testing to end the HIV epidemic.

Additional barriers to testing include issues such as written consent for HIV testing. Guidance issued by the ECDC and WHO advocate for the elimination of legal and health policy mandates regarding written consent for HIV testing, with verbal consent viewed as an adequate and appropriate form of consent. However, despite this, some EU countries still require written consent for testing, which has been proven to act as a barrier.

HETEROGENEITY WITH REGARD TO PREVENTION

The variation in prevention measures between member states is also a barrier to eliminating the spread of the virus, particularly regarding the availability and use of pre-exposure prophylaxis (or PrEP). PrEP reduces the risk of HIV transmission and has played a significant role in reducing the rates of HIV infection in Europe. In fact, PrEP reduces the risk of getting HIV from sex by about 99%, and the risk of transmission from injection drug use by at least 74%.²⁸ However, in the EU, 500,000 gay, bisexual, and other men who have sex with men (MSM) who would like to take PrEP don't have access to it.²⁹

The availability of PrEP varies across member states with five EU countries failing to formally implement PrEP in their healthcare systems, namely Greece, Cyprus, Bulgaria, Romania and Latvia. Interestingly, Cyprus and Latvia have two of the highest rates of HIV diagnosis in the EU. Although the implementation of PrEP disparities remain in terms of its availability and accessibility. According to data presented by the ECDC, PrEP was nationally available and reimbursed in Belgium, Croatia, Denmark, France, Germany, Netherlands, Ireland, Luxembourg, Portugal, Slovenia, Spain and Sweden. Studies also show that PrEP is most commonly available in medicalised settings such as infectious disease clinics, and most countries' health systems and policies allow only doctors to prescribe PrEP. This is viewed as a barrier to access, especially

for target groups. The ECDC recommends that to address this barrier, governments should look beyond typical medical settings and explore how PrEP could be provided through community-based organisations.

The development and implementation of PrEP guidelines have been reported by several EU member states, including Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Ireland, Italy, Netherlands, Poland, Portugal, Spain and Sweden. Where implementation is not in place, a range of issues are cited as impeding implementation. This includes concerns related to the reduced use of condoms leading to increased transmission of other STI's along with limited technical capacity and costs. These barriers must be addressed to ensure access and availability of PrEP across all EU member states. Failure to do so will only increase health inequalities between member states with regard to HIV and threaten overall efforts to end HIV in Europe.

STIGMA AND DISCRIMINATION:

Stigma and discrimination also act as a barrier to ending the transmission of HIV as they affect various aspects of HIV prevention, testing, treatment, and overall well-being. Fear of judgement and discrimination combined with the stigma associated with HIV can result in late diagnosis and missed opportunities for early intervention and treatment. Additionally, stigma and discrimination can prevent PLHIV from seeking medical care, which can have negative health implications with early diagnosis and treatment are essential to managing the virus and prevent progression to AIDS. Research shows that PLHIV who perceive high levels of HIV stigma are 2.4 times more likely to delay enrolment in care until they are very ill.³⁰

Reluctance to seek care can also be explained by stigmatising attitudes from healthcare providers. Such attitudes can lead to poor adherence to antiretroviral therapy and treatment programmes, which are hazardous to health and HIV prevention. Furthermore, stigma and discrimination can lead to poor mental health amongst PLHIV. The stigmatisation linked to HIV can result in mental health problems such as psychological distress, anxiety, depression, and feelings of inadequacy among PLHIV. This emotional burden can compound health problems and diminish the overall quality of life and health-related quality of life of PLHIV. Additionally, stigma and discrimination can impede PLHIV to access education, employment and justice. A study conducted by the European HIV Legal Forum found that despite scientific progress in comprehending the risk of HIV transmission, there is a gap between the scientific knowledge and the comprehension held by judges, prosecutors, and law enforcement officials. This discrepancy is primarily attributed to the absence of proper training and national guidelines which can result in stigma and discrimination against PLHIV.

DATA GAPS

Data collection and monitoring are essential in the quest to end the epidemic. However, several data gaps hinder a comprehensive understanding of the well-being of those affected by HIV in the EU. Many countries lack sufficient data to monitor progress towards the 95-95-95 targets, particularly for key populations. Enhancing efforts to fill these data gaps is crucial to ensuring effective tracking of progress toward achieving these vital targets and implementing tailored interventions for key populations. Additionally, there is an absence of data on HIV transmission routes in many member states. A significant proportion of reported cases in 2020 lacked information on the mode of HIV transmission (27%). Further data collection is required to analyse the health-related quality of life of PLHIV in the majority of EU member states.

The recent European Commission proposal for a European Health Data Space (EHDS) offers potential for the collection and sharing of health data, including that of PLHIV. The proposal, which needs agreement by the European Parliament and Council aims to improve the accessibility and exchange of health data across EU member states. It seeks to facilitate the secure and interoperable sharing of health-related data, to support healthcare innovation, research, and policymaking by promoting the use of health data, while ensuring privacy, data protection, and security. Such data collection must also be accompanied by efforts to increase reporting on stigma and discrimination.

HIV-related stigma continues to be a significant barrier to HIV prevention, testing, treatment, and care. To truly mitigate the impacts of stigma and discrimination, more data is required. Only a few countries in Europe currently report stigma data to global and regional monitoring systems due to the lack of standardised indicators and resources for data collection at the national level. Addressing the data gaps in understanding the quality of life among people living with HIV in the EU/EEA is crucial for developing evidence-based interventions and strategies. Improving data completeness, harmonising monitoring efforts, and enhancing collaboration with key stakeholders, can ensure better tracking of progress, design targeted interventions, and ultimately enhance the well-being of those affected by HIV in the region.

Recommendations

OVERCOMING THE OBSTACLES: ENDING THE HIV EPIDEMIC IN EUROPE

In order to overcome the obstacles and meet the SDGs, actions are required at EU and member state level:

At the EU level:

Renew political buy-in and commitment

Reaching the SDGs and reducing the HIV epidemic in Europe cannot be achieved without political commitment. Thus, the high-level political pronouncement planned under the Spanish Presidency in the second half of 2023 is welcome and vital to refocus attention on HIV. However, for this political declaration to have a meaningful impact endorsement from EU institutions and all member states is required. Without political buy-in from the EU27 the declaration will not have influence. The Spanish Presidency should cooperate with other member states to ensure their commitment to the declaration and boost political momentum to end the epidemic and meet the SDGs in Europe.

The inclusion of HIV in the priorities of the Spanish Presidency is a step in the right direction. However, these efforts cannot cease once the Spanish Presidency ends but should also be a priority for the Belgian Presidency, by supporting and facilitating a multi-stakeholders dialogue and setting a formal EU roadmap towards 2030 with guidance on actions needed to end the HIV epidemic in Europe during their semester. For HIV to get renewed political support, incoming presidencies should endorse council conclusions that support SDG momentum and incorporate measures like the EU roadmap towards 2030.

The next mandate of the European Parliament and Commission will play a central role in ensuring the targets of the SDGs are met. Thus, HIV must be on the Commission's 2024-2029 agenda. Research by UNAIDS⁵¹ indicates that if the correct measures are implemented, the epidemic can be ended by 2030. While political will at the EU and member state level is undoubtedly required, without support and collaboration between all levels of governance and relevant stakeholders, its potential will not be realised. Given the importance of local and regional government in HIV testing, prevention and treatment, the high-level declaration must be accompanied by a multi-level governance approach to ending the transmission of the virus.

Establish an EU-wide awareness campaign

The European Commission should allocate budget and promote EU-level communication to raise awareness about HIV. Such a communication campaign should focus on U=U (Undetectable=Untransmittable) to increase awareness, knowledge, and understanding of HIV, and

the importance of testing, prevention and treatment. A communication campaign rolled out across all member states should aim to encourage regular testing, preventative measures and early treatment, as well as prevention options. Such a campaign would encourage testing and prevention, highlighting how individuals can access PrEP. This should help to reduce transmission, which should result in lower rates of new diagnoses across Europe, contributing to overall efforts to end the HIV epidemic.

Furthermore, increasing knowledge and understanding would have positive ramifications for stigma and discrimination. Involving PLHIV and civil society in the design and implementation of the campaign would be most beneficial to identify the key areas where stigma and discrimination are most palpable and to ensure accurate messaging to rebuff misconceptions.

Create a dedicated HIV best practice platform and EU guideline document.

The European Commission should also establish a dedicated online platform for member states to exchange information on their HIV prevention, treatment, and support initiatives.

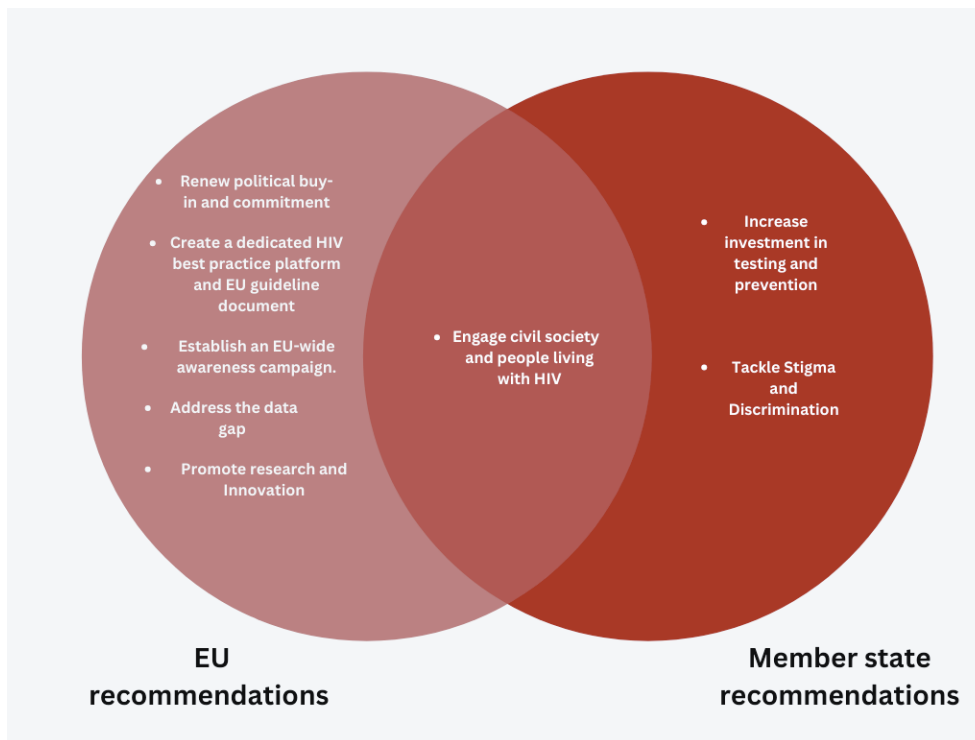
This platform should include comprehensive information on evidence-based practices, innovative approaches, and successful treatments. The sharing of best practices would improve dialogue among member states to share lessons learned and customise successful practices to adapt effective practises to their circumstances. This approach promotes resource efficiency and effectiveness by preventing redundant efforts and encouraging the adoption of evidence-based approaches.

Member states best practices should also be used to formulate an EU guidance document providing guidelines to member states on how to eradicate HIV in their country and the EU. Such guidelines should focus on how member states can ensure access and availability to testing models, especially for vulnerable populations. Furthermore, the publication should provide guidance on removing barriers to PrEP and encourage greater access to drugs and progress in implementing preventive options to reach wider populations. Such guidance should include not only measures to end HIV transmission, for example, through treatment and prevention but should also include best practices to support those living with HIV from a broader perspective on access to better integrated healthcare services.

Address the data gap

Effective planning, implementation, and monitoring of HIV prevention, treatment, and support programmes to end the virus requires accurate and current HIV data.

OVERCOMING THE OBSTACLES: ENDING THE HIV EPIDEMIC IN EUROPE



Efforts must be made to address data gaps in relation to the 95-95-95 targets. Standardised data collection and reporting across EU member states would allow for consistency and comparability of data. As it currently stands several European countries lack sufficient data to monitor one or multiple stages of the 95-95-95 targets. Monitoring and collection of data should also be encouraged in EU neighbourhood countries.

By leveraging health data, the EHDS can enhance surveillance and research, contributing to more effective prevention and care for PLHIV. Increased sharing of cross-border data should result in a more comprehensive overview of the HIV epidemic in Europe, allowing for targeted interventions. The EHDS could also help collect individual health data to enable PLHIV treatment programmes that account for comorbidities and enhance health outcomes. The Commission's EHDS proposal must be prioritised during the current legislative term to secure its adoption by the end of the mandate in 2024 for EU27 implementation.

Promote research and Innovation

Greater emphasis must be placed on HIV research and innovation. Sufficient and sustained funding to support HIV research and innovation initiatives should be provided at the EU level. Adequate funding is essential to foster innovation, encourage cross-disciplinary collaborations, and accelerate progress toward finding new prevention methods, treatments, and a cure for HIV.

With the possibility of innovations for treatment and prevention will come the need to ensure access and affordability for people living with HIV and the broader population. Thus, any advancements in treatment and prevention must be accompanied by policies to promote access and affordability across Europe.

Research and innovation efforts and funding should reflect the EU efforts on the global scale which focus on a range of issues including novel preventive and therapeutic technologies such as antiretroviral-based interventions and HIV vaccines and cures. Increased funding mechanisms should focus on implementation research on the uptake of HIV treatment and tests, building on efforts to shift towards community-based approaches to facilitate timely testing and diagnosis to ensure long-term retention in care and achieving effective integration with other services.

At the member state level:

Increase investment in testing and prevention

Member states to guarantee access and availability to HIV testing for their populations, with a particular emphasis on high-risk populations. They must also erode barriers to testing using an intersectional approach to ensure testing is available and accessible for all groups in society. Expanding the availability of a variety of HIV testing methods, particularly those conducted in non-traditional settings is essential to enhance accessibility

for key populations with a higher risk of HIV transmission. This expansion should be accompanied by initiatives to strengthen the link between care and treatment. To further improve accessibility, HIV testing services should be made available in diverse settings and include community-based testing, home testing, self-testing, lay provider testing, routine testing during pregnancy, routine testing in sexual health clinics, emergency departments, provider-initiated testing in primary and secondary care, and testing in other health settings. Offering multiple testing options will foster an environment where individuals from high-risk populations feel at ease and free from stigma. Focus must be given to high-risk populations such as sex workers, migrants, and transgender individuals. Provision must also be made to ensure the availability and access to testing and treatment for those fleeing the war in Ukraine.

Member states must also facilitate access to innovative combination prevention tools that promote a combination of biomedical, behavioural, and structural interventions. Ensuring access to PrEP must also be prioritised, particularly in those member states that have failed to implement PrEP into their health systems. Prevention is an effective method of reducing HIV diagnosis, and as such, will be paramount in reducing and ending the transmission of the virus in Europe.

Tackle Stigma and Discrimination

To eliminate the transmission of the virus, action must also be taken to address stigma and discrimination. Tackling HIV stigma and prejudice requires a multifaceted approach that includes improved data collection, education and knowledge upgrading, and meaningful participation of PLHIV. Accurate and reliable data on the prevalence and impact of stigma and discrimination are crucial for understanding the extent of the problem and designing effective interventions. Member states should prioritise the collection and reporting of data on stigma experiences faced by PLHIV in healthcare settings, communities, workplaces, and other domains. This data can help identify trends, vulnerable populations, and indicate where targeted efforts are needed the most.

Education and training programs targeting healthcare professionals are essential to promote a better understanding of HIV and reduce stigma in healthcare settings. To dispel HIV myths, healthcare providers must be current on transmission, treatment, and prevention. Thus, member states must be encouraged to incorporate HIV awareness training in education programmes for those working across the health ecosystem. Training should also focus on fostering empathy and compassion, encouraging healthcare workers to provide non-discriminatory care that respects the dignity and rights of PLHIV.

Dispelling the stigma associated with PLHIV goes beyond the healthcare sector. Schools can also play a crucial role in promoting HIV awareness by incorporating accurate information about HIV into the curriculum and promoting open discussions, it can help reduce fear and stigma and create a supportive environment for PLHIV. Thus, at the national, regional and local level, health and social ministries must collaborate with ministries of education to adopt programmes aimed at dispelling stigma and discrimination.

Engage civil society and people living with HIV

Civil society actors and organisations representing PLHIV are essential stakeholders in the fight against HIV/AIDS. Platforms such as the Civil Society Forum should, therefore, be utilised. Their involvement is crucial in raising awareness, providing services, advocating for policy changes, and promoting community engagement. Working with PLHIV is paramount in the design and implementation of initiatives that resonate with communities to drive this sustainable change.

- ¹ Zuleeg, Fabian; Janis A. Emmanouilidis and Ricardo Borges de Castro (2021), "[Europe in the age of permacrisis](#)", Brussels: European Policy Centre.
- ² World Health Organization. Regional Office for Europe & European Centre for Disease Prevention and Control (2022) "[HIV/AIDS surveillance in Europe: 2022 – 2021 data](#)" Copenhagen: WHO Regional Office for Europe; 2022.
- ³ *Ibid.*
- ⁴ World Health Organization. Regional Office for Europe & European Centre for Disease Prevention and Control (2022) "[HIV/AIDS surveillance in Europe: 2022 – 2021 data](#)" Copenhagen: WHO Regional Office for Europe; 2022.
- ⁵ European Centre for Disease Prevention and Control (2022) "[Continuum of HIV care. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2021 progress report](#)". Stockholm: ECDC.
- ⁶ Barbieri Pietro Vittorio, Merlo Nicoletta (2023) "[Measures to fight stigma against HIV](#)". Brussels: European Economic and Social Committee.
- ⁷ Stengaard Annemarie Rinder, Combs Lauren, Supervie Virginie, Croxford Sara, Desai Sarika, Sullivan Ann K, Jakobsen Stine Finne, Santos Quenia, Simões Daniel, Casabona Jordi, Lazarus Jeffrey V, de Wit John B F, Amort Frank M, Pharris Anastasia, Nerlander Lina, Raben Dorthe (2021) "[HIV seroprevalence in five key populations in Europe: a systematic literature review, 2009 to 2019](#)". Euro Surveillance.
- ⁸ Portugal is not included due to a lack data from 2021.
- ⁹ World Health Organization. Regional Office for Europe & European Centre for Disease Prevention and Control (2022), *op.cit.*
- ¹⁰ World Health Organization. Regional Office for Europe & European Centre for Disease Prevention and Control (2022), *op.cit.*
- ¹¹ World Health Organization. Regional Office for Europe & European Centre for Disease Prevention and Control (2022), *op.cit.*
- ¹² The Declaration on the TRIPS Agreement and Public Health (Doha Declaration) provides responses to some specific concerns concerning the implementation of intellectual property rights in the field of health.
- ¹³ The Lancet Healthy Longevity Home Editorial (2023) "[Ageing with HIV](#)" (accessed 2 August 2023).
- ¹⁴ Daniel R. Morales Moreno-Martos David, Matin Na shaba, Patricia McGettigan (2022) "[Health conditions in adults with HIV compared with the general population: A population-based cross-sectional analysis – eClinicalMedicine](#)" The Lancet VOLUME 47, 101392.
- ¹⁵ UNAIDS (2021) "[HIV and stigma and discrimination – Human rights fact sheet series 2021](#)" (accessed 6 August 2023).
- ¹⁶ World Health Organization. Regional Office for Europe & European Centre for Disease Prevention and Control (2022), *op.cit.*
- ¹⁷ UNAIDS "[90-90-90: AN AMBITIOUS TREATMENT TARGET TO HELP END THE AIDS EPIDEMIC](#)" (accessed 3 August 2023)
- ¹⁸ European Centre for Disease Prevention and Control (2022)
- ¹⁹ https://urlisolation.com/browser?clickId=7D6BF893-AFDA-48B5-9B0D-DFC4BA376373&frameUrl=%2Fpage%3Furl%3Dhttps%253A%252F%252Fwww.ecdc.europa.eu%252Fen%252Fpublications-data%252Fhiv-testing-europe-and-central-asia%26token%3Dlnlvo245-gmoix82ysz&traceToken=1697032305%3Bgilead_hosted%3Bhttps%3A%2Flinklock.titanhq.com%2Fanal&url=https%3A%2F%2Fwww.ecdc.europa.eu%2Fen%2Fpublications-data%2Fhiv-testing-europe-and-central-asia.
- ²⁰ The United Nations Joint Programme on HIV/AIDS (UNAIDS) is an international initiative aimed at coordinating and accelerating global efforts to prevent new HIV infections, provide care and support to those living with HIV, and reduce the impact of the HIV/AIDS epidemic. UNAIDS brings together various UN agencies, governments, civil society organizations, and other partners to collaborate on strategies, policies, and programs to achieve these goals and work towards ending the AIDS epidemic by 2030.
- ²¹ The Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia is a commitment made by European and Central Asian countries to enhance collaboration and action against the HIV/AIDS epidemic in the region. The declaration outlines strategies for preventing the spread of HIV, improving access to treatment and care, and reducing the stigma and discrimination associated with the disease.
- ²² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5395003/>.
- ²³ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52009DC0569>.
- ²⁴ HIV Outcomes "[The impact of Covid-19 on HIV in Europe](#)" (accessed 28 July 2023).
- ²⁵ Barbieri Pietro Vittorio, Merlo Nicoletta (2023), *op.cit.*
- ²⁶ UNAIDS (2023), *op.cit.*
- ²⁷ Woode Owusu Melvina, Dagny Clea Krankowska Dagny, Lourida, Panagiota Lourida, Weis Nina, (2023) "[Late HIV diagnosis among migrant women living in Europe – a systematic review of barriers to HIV testing](#)" IIID Regions, Volume 7.
- ²⁸ Centres for Disease Control and Prevention "[Pre-Exposure Prophylaxis \(PrEP\)](#)" (accessed "9 July 2023).
- ²⁹ ECDC (2019) "[Around half a million men who have sex with men in the EU need PrEP but cannot access it](#)" (accessed 2 August 2023).
- ³⁰ UNAIDS (2021), *op.cit.*
- ³¹ UNAIDS "[90-90-90: AN AMBITIOUS TREATMENT TARGET TO HELP END THE AIDS EPIDEMIC](#)" (accessed 3 August 2023).

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The **Social Europe and Well-being** (SEWB) programme is structured around the following priorities:

- (1) strengthening the social dimension of EU policies and governance for upward social convergence;
- (2) moving towards a modern and inclusive labour market;
- (3) making European welfare states and social protection systems 'future-fit' in the light of ongoing labour market transformation; and
- (4) investing in human capital for greater well-being and less inequality, with a particular focus on health.

The activities under this programme are closely integrated with other EPC focus areas, especially those related to migration and the economy, with a view to providing more 'joined-up' policy solutions.