

Health-related quality of life in people living with HIV



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Abstract

The evolution of HIV from a fatal to a long-term condition poses challenges for people living with HIV and for health and social care systems across the EU. This paper aims to help Members of the European Parliament and other interested stakeholders to obtain a better picture of the current situation in relation to HIV among people living with HIV in the EU, HIV-related stigma and issues which impact on health-related quality of life for people living with HIV.

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LIST OF ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral treatment
ECDC	European Centre for Disease Prevention and Control
HIV	Human immunodeficiency virus
HRQOL	Health-Related Quality of Life
MSM	Men who have sex with men
PLHIV	People living with HIV
PREP	Pre-exposure prophylaxis
PROMS	Patient-related outcomes measures
PWID	People who inject drugs
QOL	Quality of life
SDG	Sustainable Development Goal
SMR	Standardised mortality ratio
SOP	Standard operating procedure
STI	Sexually transmitted infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

EXECUTIVE SUMMARY

HIV infection continues to affect the health and well-being of millions of people in the European Region. Although new HIV infections appear to be declining overall, nearly 15,000 people in the EU/EEA and more than 100,000 people in the broader WHO European Region are diagnosed with HIV annually. About half of new HIV diagnoses occur at a late stage and are associated with higher HIV-morbidity and mortality. Overall, only 8% of countries in the WHO European Region (53% of all EU/EEA countries) have met or exceeded the UNAIDS Fast Track targets of 90% diagnosed, 90% on antiretroviral treatment (ART), 90% virally suppressed and 73% of all people living with HIV (PLHIV) virally suppressed. The EU/EEA as a whole achieved two of the three 90-90-90 targets by 2020 (88% of people living with HIV were diagnosed, 93% diagnosed started treatment and 91% of those on treatment were virally suppressed).

HIV remains a concentrated epidemic in the European region, meaning people belonging to key populations, including men who have sex with men, people who inject drugs, migrants, sex workers and prisoners, constitute most of those affected by HIV in many countries. For all of these key populations, it is important that accessibility along the entire HIV continuum of care is supported by implementing patient-centred services in a non-stigmatising and inclusive environment, preferably with the involvement of civil society.

With expanded access to effective treatment, HIV infection has increasingly become a chronic disease, and PLHIV are now surviving, ageing, and requiring lifelong care and treatment. Adequate understanding of what it means to be healthy as a PLHIV on treatment today requires a more holistic approach to the measurement of health. Health-related quality of life (HRQoL) describes all aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment across physical, mental and social domains of health. Measures of HRQoL could provide a more comprehensive picture of how infection and treatment affect an individual's life when used alongside clinical and biological markers in evaluations of HIV interventions and can be used to re-direct or refine services to maximise HRQoL. However, only a minority of countries in the European Region report routinely collecting such measures for PLHIV.

A key factor underpinning quality of life for many individuals in Europe is the degree to which living with HIV is impacted by HIV-related stigma. Historically few countries in the WHO European region have been able to report stigma data to global or regional monitoring systems. Still, there is evidence that HIV-related stigma is prevalent, impacting self-esteem and quality of life for many PLHIV in the European Region.

Strides made to reduce HIV incidence and to support PLHIV in the European Region to achieve long and healthy lives have been impacted by the COVID-19 pandemic including prevention, testing, health care service delivery, surveillance and monitoring systems. The extent to which these services will rebound to pre-pandemic levels will greatly affect European countries' ability to achieve the targets set forth in the 2030 Sustainable Development Goal 3.3 on health.

Accelerated action in the following areas is suggested in order to reduce HIV incidence and to improve HRQoL for PLHIV in the European Region:

- A combination approach to HIV prevention (including includes access to condoms, pre-exposure prophylaxis, and harm reduction services such as needle exchange and drug treatment);
- Expanded accessibility to HIV testing and, for those found positive, rapid linkage to care, treatment and adherence support;

- Development of integrated, patient-centred, patient-involved services and approaches;
- Improved measurement and expand monitoring of HRQoL, including patient-reported outcomes;
- Monitoring and addressing HIV-related stigma, particularly in health care systems; and
- Assessing the impact of COVID-19 pandemic on PLHIV and on HIV services.

BACKGROUND

The European Parliament's (EP) Committee on the Environment, Public Health and Food Safety (ENVI), as the lead committee at the EP on health matters, requested a compilation of evidence on factors affecting health-related quality of life of people living with HIV in the EU/EEA from the European Centre for Disease Prevention and Control (ECDC).

For the purposes of this paper, Health-Related Quality of Life (HRQoL) is defined as the health, social and psychological aspects of well-being and functioning which most impact on people living with HIV. The concept of HRQoL is based on the WHO's 1948 definition of health as "the state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1948).

The evolution of HIV from a fatal to a long-term condition poses challenges for people living with HIV and for health and social care systems across the EU. Health systems increasingly need to manage the complex care needs of a growing number of people living with HIV, notably reduced quality of life (and as a sub-set of this, HRQoL), a higher proportion of comorbidities (diseases that are often a consequence of the HIV infection and its associated risk factors) as well as stigma and discrimination. This situation has possibly been further exacerbated by the COVID-19 pandemic.

The present paper aims to help Members of the European Parliament and other interested stakeholders to obtain a better picture of the current situation in relation to HIV among people living with HIV in the EU, HIV-related stigma and issues which impact on HRQoL. The background paper aims to support discussion and to inform EU and national policy options to improve the HRQoL of people living with HIV.

Scope

This background paper covers:

- an overview of the situation of HIV in the EU/EEA and, for some measures, in the wider European Region;
- an assessment of Quality of life (QoL) and HRQoL measures for people living with HIV;
- an assessment of the impact of COVID-19 on health services for people living with HIV in the EU/EEA and in the wider European Region; and
- data gaps and conclusions on strengthening HRQoL for PLHIV in EU and national policies;

The background paper primarily focuses on those people who have been diagnosed with and are receiving treatment for HIV, but also reflects issues impacting those who are at-risk for HIV, who are undiagnosed or who are diagnosed but not on treatment for HIV.; and

The background paper is based on information available to ECDC as of 4 October 2022 and includes published well as unpublished, preliminary data.

1. BASELINE ASSESSMENT: THE SITUATION FOR PEOPLE LIVING WITH HIV IN THE EU/EEA

1.1. HIV in the EU/EEA

HIV infection continues to affect the health and well-being of millions of people in the WHO European Region (the 53 countries of Europe and Central Asia, including the countries of the EU/EEA). Over the course of the last three decades, over 2.3 million people have been diagnosed with HIV in the WHO European Region, including over 560,000 people in the EU/EEA¹. In 2021, nearly 107,000 people were newly diagnosed with HIV. The vast majority of people newly diagnosed (78%) were diagnosed in the East, 16% were diagnosed in the West, and 6% in the Centre (see Table 1 for countries included in West, Centre and East). Newly diagnosed infections in the Russian Federation contributed 55% of all cases in the WHO European Region. The share of the cases reported from Ukraine was 14% in the Region.

In the EU/EEA, slightly more than half (55%) of new HIV diagnoses where there is information on the route of transmission are in men who have sex with men (MSM), about 40% of new diagnoses are attributed to heterosexual transmission, and about 5% to injecting drug use. In 2021, 42% of those diagnosed with HIV in the EU/EEA were born outside of the country in which they were diagnosed, indicating that migrants are disproportionately represented among those diagnosed with HIV. HIV prevalence is highly diverse across population groups and countries in the EU/EEA, however, where data exists, prevalence is higher among MSM, migrants, people who inject drugs, sex workers, transgender individuals and people in prison than in the general population. It is also well-documented in and beyond Europe that people belonging to multiple key population groups are particularly vulnerable to HIV infection and may experience greater difficulties accessing services for HIV diagnosis and care².

In the EU/EEA, HIV surveillance data show a continuing decline in the number and rate of new HIV cases diagnosed in the EU/EEA during the last decade¹. However, reduced testing and extra demands due to the COVID-19 pandemic on clinical sectors and public health institutes responsible for reporting and surveillance have likely impacted case detection for 2020 and 2021. Despite evidence of some progress in reducing the number of new HIV diagnoses in the EU/EEA overall, in 2021 about half of EU/EEA countries reported the same or increasing numbers of new diagnoses as compared to 2020. Still, many (about 56%) of HIV diagnoses are made late, at an advanced stage of illness, leading to increased HIV-related morbidity and AIDS-related mortality. Rates of AIDS and AIDS-related deaths in the EU/EEA as a whole have decreased substantially during the past decade. Although AIDS and AIDS-deaths for 2021 have also probably been affected by reporting issues due to the COVID-19 pandemic, the reduced trends prior to 2020 likely reflect greater access to treatment and better case management, indicating continued progress towards the Sustainable Development Goal of ending the AIDS epidemic as a public health threat and decreasing AIDS-related deaths.

¹ European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2022 – 2021 data. Stockholm: ECDC; 2022 Forthcoming on 30 November at www.ecdc.europa.eu.

² Stengaard et al. HIV seroprevalence in five key populations in Europe: a systematic literature review, 2009 to 2019. *Euro Surveill.* 2021;26(47):pii=2100044. <https://doi.org/10.2807/1560-7917.ES.2021.26.47.2100044>.

1.2. Continuum of HIV care for people living with HIV in the WHO European Region

The data on the continuum of HIV care will be published by ECDC on 28 November 2022.³ This section discusses each stage of the continuum of HIV care in more detail. Annex 1 provides a full overview of what data were provided by which countries at each stage, and their performance against the global 90-90-90 targets.

1.2.1. Stage 1: Estimated number of people living with HIV

Based on reported data from 47 of 53 WHO European Region countries plus, an estimated 2,343,885 people are living with HIV (Table 1). Of the eight countries that did not provide estimates on the number of PLHIV, two countries⁴ lacked empirical estimates and six countries⁵ did not participate in Dublin Declaration/GAM reporting in 2021.

Table 1: Estimated number of people living with HIV: countries in the West, Centre and East sub-regions, reported by 2021

West WHO sub-region		Centre WHO sub-region		East WHO sub-region	
Countries	PLHIV	Countries	PLHIV	Countries	PLHIV
Austria	7,655	Albania	3306	Armenia	4,771
Belgium	19,090	Bulgaria	3,690	Azerbaijan	9,937
Denmark	6,700	Croatia	1,700	Belarus	28,315
Finland	3,265	Cyprus	1,293	Estonia	6,855
France	178,700	Czechia	3,503	Georgia	8,358
Germany	90,700	Hungary	7205	Kazakhstan	35,201
Greece	16,743	Montenegro	392	Kyrgyzstan	9,222
Iceland	296	North Macedonia	404	Lithuania	3,558
Ireland	7,200	Poland	18,923	Moldova	14,474
Israel	8,039	Romania	18,000	Russia	1,000,000
Italy	137,000	Serbia	3,341	Tajikistan	14,246
Luxembourg	1,315	Slovakia	1 041	Ukraine	257,548
Malta	740	Slovenia	806	Uzbekistan	57,555
Monaco	48				
Netherlands	23,700				
Norway	4,455				
Portugal	41,889				

³ European Centre for Disease Prevention and Control. 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; 2022; (unpublished).

⁴ Bosnia and Latvia

⁵ Andorra, Kosovo*, Liechtenstein, San Marino, Turkey and Turkmenistan.

* This designation is without prejudice to positions on status, and is in line with UNSC 1244 and the ICJ Opinion on the Kosovo Declaration of Independence.

West WHO sub-region		Centre WHO sub-region		East WHO sub-region	
Countries	PLHIV	Countries	PLHIV	Countries	PLHIV
Spain	151,387				
Sweden	8,971				
Switzerland	17,100				
United Kingdom	105,248				

Source: Author's own elaboration

1.2.2. Stage 2. Number of people living with diagnosed HIV

In the 47 countries reporting data within Europe and Central Asia for both stage 1 and stage 2, an estimated 2 343 427 people are living with HIV, 1 911 489 of whom (82%; range 50–100%) have been diagnosed (Table 2). This is equivalent to approximately one in five (18%; range 0–50%) people living with HIV in Europe and Central Asia being unaware of their HIV status. Overall, the proportion of undiagnosed people living with HIV is highest in the countries of the East sub-region and lowest in those of the West sub-region. These data differ to the overall results presented in the '2021 at a glance' table since the results in the table only include data where all four stages are reported.

In the 21 West sub-region countries with data for both stages, an estimated 830 241 people are living with HIV, 743 836 whom have been diagnosed (89%; range 75–100%). This means that one in ten PLHIV (11%; range 0–25%) in these countries have an undiagnosed HIV infection.

In the 13 Centre sub-region countries with data for both stages, an estimated 63 146 people are living with HIV, 50 726 of whom have been diagnosed (80%; range 50–91%). This means approximately one in six people living with HIV (20%; 9–50%) in these countries have an undiagnosed HIV infection.

In the 13 East sub-region countries with data for both stages, an estimated 1 450 040 people are living with HIV, 1 116 927 of whom have been diagnosed (77%; range 66–87%). This means that approximately one in five PLHIV (23%; range 13–34%) in these countries have undiagnosed HIV infection.

Table 2: Number and percentage of people living with HIV with diagnosed and undiagnosed HIV infection in 47 countries in Europe and Central Asia, reported in 2021

Countries	Estimated number of PLHIV	Number of PLHIV diagnosed	% of PLHIV diagnosed	% of PLHIV undiagnosed
West (n=21)	830 241	743 836	89%	11%
Centre (n=13)	63 146	50 726	80%	20%
East (n=13)	1 450 040	1 116 927	77%	23%
All countries (n=47)	2 343 427	1 911 489	82%	18%
EU/EEA (n=28)	766 380	676 675	88%	12%

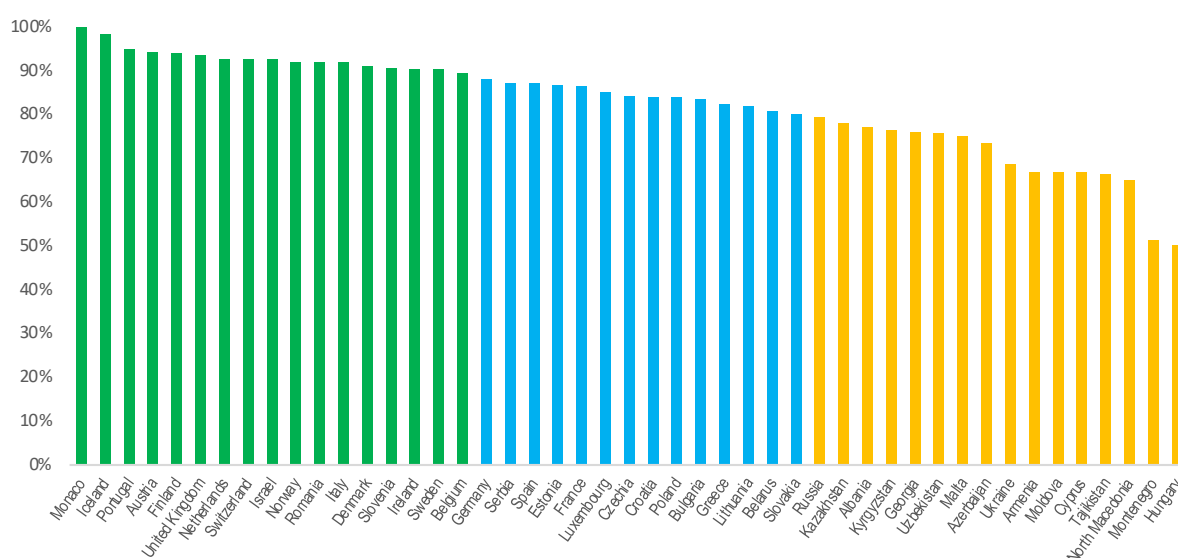
Source: Author's own elaboration

A total of 16 of the 47 countries (Austria, Belgium, Denmark, Finland, Iceland, Ireland, Israel, Italy, Monaco, Norway, the Netherlands, Portugal, Slovenia, Sweden, Switzerland, and the United Kingdom)

have achieved the first of the UNAIDS targets, with 90% or more of all PLHIV knowing their status (Figure 1).

Of the other 31 countries, 15 are within 10% of meeting the target, reporting that 80% or more (range 81–89%) of PLHIV know their status (five West; seven Centre; three East), and 16 countries are more than 10% away from reaching the target, reporting that fewer than 80% (range 50–79%) of PLHIV know their status (one West; five Centre; ten East).

Figure 1: Percentage of all people living with HIV who know their status in 47 countries of Europe and Central Asia, reported in 2021⁶



Source: Author's own elaboration

1.2.3. Stage 3. Number of people diagnosed who are on treatment

In the 46 countries that reported data for both stage 2 and stage 3 within Europe and Central Asia, an estimated 1 911 489 PLHIV have been diagnosed, 1 616 099 (85%; range 43–100%) of whom were reported to be on treatment (Table 3). Based on available data, around one in four people (15%; range 0–57%) with diagnosed HIV infection in Europe and Central Asia are therefore currently not receiving antiretroviral therapy (ART). These data differ to the overall results presented in the '2021 at a glance' table since the results in the table only include data where all four stages are reported.

In the 21 West sub-region countries that reported data for both stage 2 and stage 3, an estimated 743 836 PLHIV have been diagnosed, 704 387 (95%; range 57–100%) of whom were reported to be on treatment. This means that around one in 20 PLHIV diagnosed in these countries are not benefitting from HIV treatment.

In the 12 Centre sub-region countries that reported data for both stages (Hungary was excluded due to inconsistent information), an estimated 50 726 people living with HIV have been diagnosed, 42 463 (84%; range 57–98%) of whom were reported to be on treatment. This means that one in five people living with HIV (22%; range 2–43%) who have been diagnosed in these countries are not benefitting from HIV treatment.

⁶ Latest available data reported by countries in 2020. See Annex 2 for information on which year reported data relate to.

In the 13 East sub-region countries that reported data for both stages, an estimated 1 116 927 people living with HIV have been diagnosed, 869 856 (78%; range 43–83%) of whom were reported to be on treatment. This means that one in five PLHIV (22%; range 7–57%) diagnosed in these countries are not benefitting from HIV treatment.

Table 3: Number and percentage of people living with diagnosed HIV who are on treatment in 46 countries in Europe and Central Asia, reported in 2021

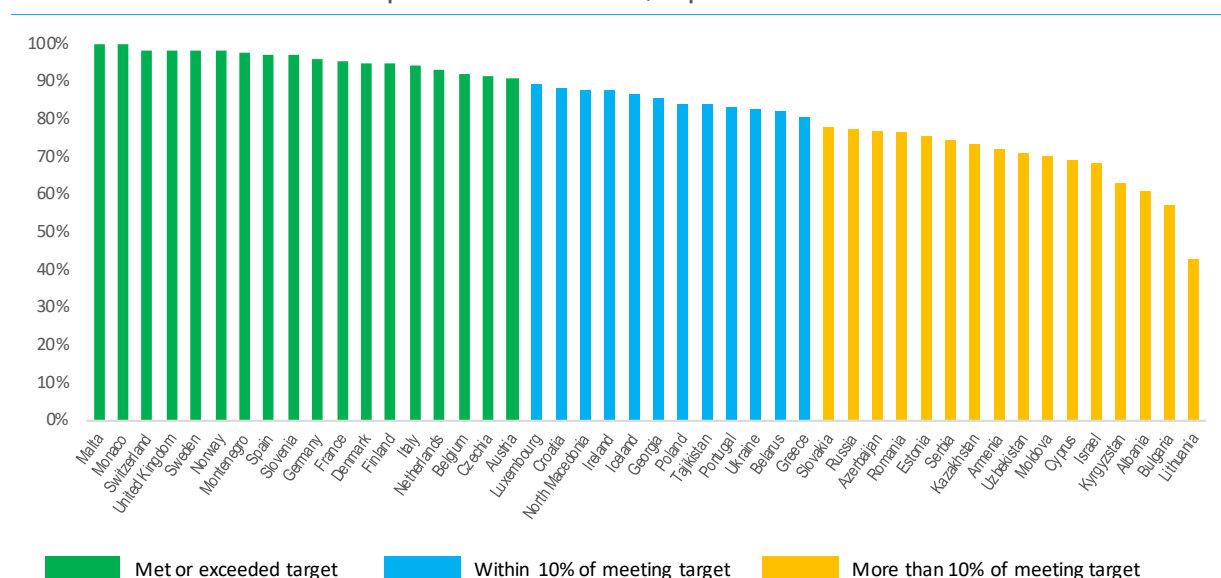
Countries	Number of PLHIV diagnosed	Number of PLHIV diagnosed on ART	% of PLHIV diagnosed on ART	% of PLHIV diagnosed currently not on ART
West (n=21)	743 836	704 387	95%	5%
Centre (n=12)	50 726	42 463	84%	16%
East (n=13)	1 116 927	869 856	78%	22%
All countries (n=46)	1 911 489	1 1 616 099	85%	15%
EU/EEA (n=27)	673 060	626 215	93%	7%

Source: Author's own elaboration

In total, 18 of the 46 countries (Austria, Belgium, Czechia, Denmark, Finland, France, Germany, Italy, Malta, Monaco, Montenegro, the Netherlands, Norway, Spain, Slovenia, Sweden, Switzerland, the United Kingdom) have achieved the second of the UNAIDS targets: 90% of PLHIV know their status and are on treatment (Figure 2). Hungary was excluded for inconsistent information.

Overall, 12 countries are within 10% of meeting the target, reporting that 80% or more (range 80–89%) of PLHIV who know their status are on treatment with the remaining 16 more than 10% away from the target.

Figure 1: Percentage of all people living with diagnosed HIV who are on treatment in 46 countries of Europe and Central Asia, reported in 2021



Source: Author's own elaboration

1.2.4. Stage 4. Viral suppression among people living with HIV on treatment

In the 39 countries across Europe and Central Asia that reported data for both stage 3 and stage 4, an estimated 1 574 630 PLHIV were on treatment, 1 459 959 of whom (93%; range 57–100%) were virally suppressed (Table 4. Seven per cent (range 0–51%) currently on ART in Europe and Central Asia have therefore not achieved viral suppression. These data differ to the overall results presented in the ‘2021 at a glance’ table since the results in the table only include data where all four stages are reported.

In the 18 West sub-region countries with data for both stages, an estimated 688 171 PLHIV were on treatment, 640 297 (93%; range 54–100%) of whom were virally suppressed.

In the nine Centre sub-region countries with data for both stages, an estimated 21 085 PLHIV were on treatment, 13 464 (64%; range 49–98%) of whom were virally suppressed.

In the 12 East sub-region countries with data for both stages, an estimated 865 374 PLHIV were on treatment, 806 198 of whom (93%; range 57–100%) were virally suppressed.

Table 4: Number and percentage of people in treatment who are virally suppressed in 40 countries across Europe and Central Asia, reported in 2021

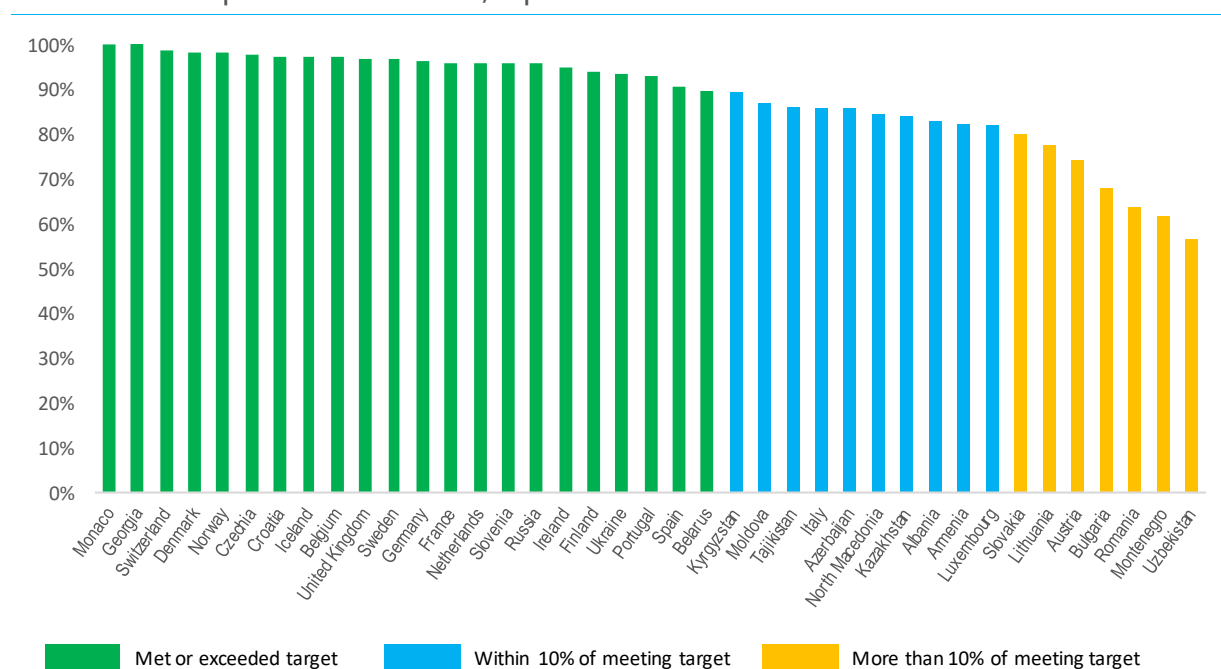
Countries	Number of PLHIV on ART	Number of PLHIV virally suppressed	% of PLHIV on ART who are virally suppressed	% of PLHIV diagnosed on ART who are not virally suppressed
West (n=18)	688 171	640 297	93%	7%
Centre (n=9)	21 085	13 464	64%	36%
East (n=12)	865 374	806 198	93%	7%
All countries (n=39)	1 574 630	1 459 959	93%	7%
EU/EEA (n=22)	596 070	545 882	92%	8%

Source: Author's own elaboration

In all, 22 of the 40 countries (Belarus, Belgium, Croatia, Czechia, Denmark, Finland, France, Germany, Georgia, Iceland, Ireland, Monaco, the Netherlands, Norway, Portugal, Russia, Slovenia, Spain, Sweden, Switzerland, Ukraine and the United Kingdom) have achieved the third of the UNAIDS targets: 90% of PLHIV who are on treatment are virally suppressed (Figure 3).

Of the other 18 countries, 11 are within 10% of meeting the target, reporting that 80% or more (range 80–89%) of PLHIV who are on treatment are virally suppressed, and seven are more than 10% away from reaching the target, reporting that fewer than 80% (range 53–79%) of PLHIV are virally suppressed.

Figure 2: Percentage of people on treatment achieving viral suppression in 39 countries of Europe and Central Asia, reported in 2021



Source: Author's own elaboration

1.2.5. Viral suppression among all people living with HIV

Overall, 39 countries (18 West; nine Centre; 12 East) reported data on all four stages of the continuum of HIV care, compared with 34 countries in 2018 (Table 5 and Figure 4). Based on data reported by these countries for stage 1 and 4, an estimated 2 281 028 people were living with HIV, 1 459 959 (64%; range 27–100%) of whom were virally suppressed (Table 9). This means that one third of PLHIV (36%; range 0–73%) in Europe and Central Asia have still not achieved viral suppression.

In the 18 West sub-region countries with data for all four stages, an estimated 805 459 people were living with HIV, 640 297 (79%; range 40–100%) of whom were virally suppressed. This means that around one in five (21%; range 0–21%) PLHIV in these countries are not virally suppressed.

In the nine Centre sub-region countries with data for all four stages, an estimated 32 384 people were living with HIV, 13 464 (42%; range 31–84%) of whom were virally suppressed. This means that over half (58%; range 16–69%) of PLHIV in these countries are not virally suppressed.

In the 12 East sub-region countries with data for all four stages, an estimated 1 443 185 people were living with HIV, 806 198 (56%; range 27–54%) of whom were virally suppressed. This means that almost half (44%; range 46–73%) of PLHIV in these countries are not virally suppressed.

Table 5: Number and percentage of people living with HIV who are virally suppressed in 39 countries of Europe and Central Asia, reported in 2021

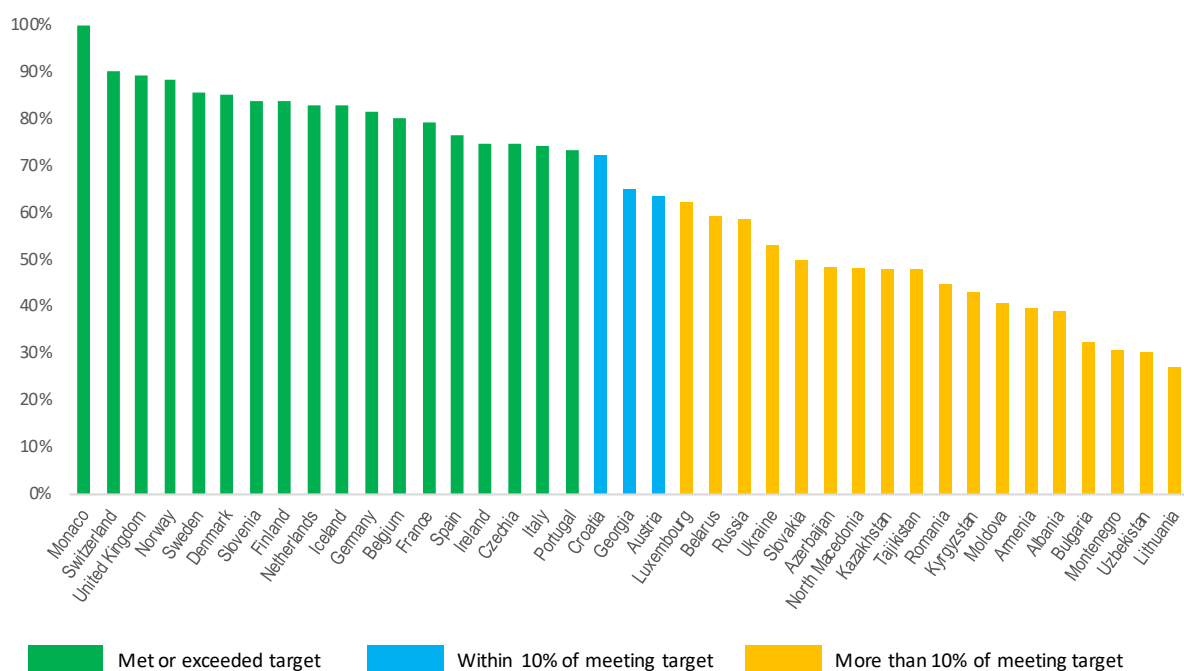
Countries	Estimated number of PLHIV	Estimated number of people virally suppressed	% of all PLHIV who are virally suppressed	% of all PLHIV who are not virally suppressed
West (n=18)	805 459	640 297	79%	21%
Centre (n=9)	32 384	13 464	42%	58%
East (n=12)	1 443 185	806 198	56%	44%
All countries (n=39)	2 281 028	1 459 959	64%	36%
EU/EEA (n=22)	714 621	545 882	76%	24%

Source: Author's own elaboration

Overall, 18 of the 40 countries (Belgium, Czechia, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Monaco, the Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, and the United Kingdom) have achieved the UNAIDS substantive target of 73% viral suppression among all people estimated to be living with HIV (Figure 4).

Among the remaining 22 countries, three were within 10% of meeting the target and 19 were more than 10% away, reporting that fewer than 63% (range 27–62%) of all estimated PLHIV being virally suppressed (two West, six Centre; 11 East).

Figure 3: Percentage of all people living with HIV who know their status, are on treatment and are virally suppressed in 39 countries across Europe and Central Asia, reported in 2021



Source: Author's own elaboration

1.2.6. Conclusion on the continuum of HIV care among all people living with HIV

Overall, few countries reached the fast-track 90-90-90 targets since they were first set in 2014. Only 8% of countries in the region (53% of all EU/EEA countries) have met or exceeded the targets of 90% diagnosed, 90% on ART, 90% virally suppressed and 73% of all PLHIV virally suppressed. However enormous progress has been made and it is a huge achievement for the majority of countries within the region to collect these data both nationally and for key populations; this information is critical in informing each country to consider how to maintain and increase rates of progress. Significant variation exists within sub-regions, which group countries with similar contexts and epidemics. The EU/EEA as a whole achieved two of the three 90-90-90 targets by 2020 (88% of people living with HIV were diagnosed, 93% diagnosed started treatment and 91% of those on treatment were virally suppressed. This shows that there are policy and implementation issues which need to be addressed. It is essential that a full combination prevention strategy incorporating improved implementation of multifaceted testing strategies, effective linkage into care, adherence and retention support, and a policy of treatment on diagnosis, all in the context of a human rights-based supportive environment for those affected by and living with HIV, is implemented in order to deliver improvements in performance across the continuum of care.

1.2.7. Conclusion on the continuum of HIV care key populations

HIV remains a concentrated epidemic for the majority of Europe and Central Asia, meaning people belonging to key populations, including men who have sex with men, people who inject drugs (PWID), migrants, sex workers and prisoners, constitute most of those affected by HIV in many countries. Although most countries in the wider WHO Region are able to report progress toward the 90-90-90 testing and treatment targets for the general population, countries are still facing challenges in disaggregating this data by key populations. It is important that for all these key populations, accessibility along the entire HIV continuum of care is prioritised by implementing patient-centred services in a non-stigmatising and inclusive environment, preferably with the involvement of civil society. Adoption of a combination prevention approach which includes access to condoms, PrEP, and frequent testing for those at high-risk, will be key to reducing the HIV infection rate. High coverage of harm reduction remains important for people who inject drugs, particularly in the East sub-region but also across the other sub-regions where localised HIV outbreaks continue to occur amongst people who inject drugs (PWID). Expanding accessibility of testing through different testing modes, such as lay-provider testing and self-testing, is particularly important in countries which have been previously identified as having a limited range of testing modes available. Prompt linkage to treatment, and support for adherence and retention in care, should be implemented to improve rates of viral suppression. Evidence-based national policies and strategies will be crucial to the successful implementation and scaling up of these approaches.

1.3. Access to pre-exposure prophylaxis for HIV (PrEP)

The data on pre-exposure prophylaxis (PrEP) is taken from the latest ECDC evidence brief on PrEP⁷.

Pre-exposure prophylaxis (PrEP) is very effective at preventing novel HIV infections when taken as prescribed. It is an essential element in the 'combination prevention' necessary to reach the United Nations (UN) Sustainable Development Goal of ending the AIDS epidemic by 2030. Figure 5 provides information on which countries have made PrEP available through their health system in 2022.

⁷ Pre-exposure prophylaxis for HIV prevention in Europe and Central Asia. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia – 2020/2021 progress report. Stockholm: ECDC; 2022. www.ecdc.europa.eu/en/publications-data/evidence-brief-pre-exposure-prophylaxis-hiv-prevention-europe-and-central-asia.

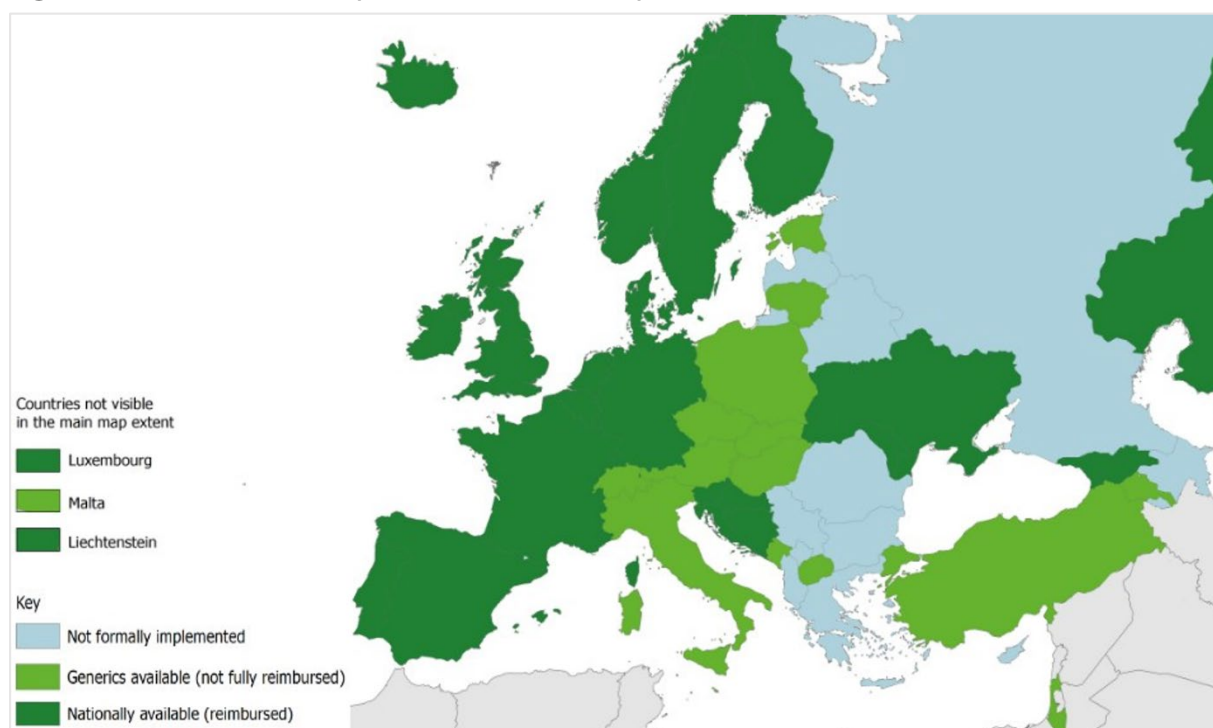
It does not account for online PrEP access, usually of generic PrEP sourced from abroad, or access via private healthcare where PrEP is usually available at relatively high patent prices. The two categories of availability are nationally available (reimbursed) and generics, available in healthcare settings but not reimbursed.

PrEP implementation in Europe and Central Asia has improved substantially since 2016, however, 17 of 55 countries still have not formally implemented PrEP through their healthcare systems. In 2022, 23 countries reported that PrEP was available and reimbursed through their healthcare system, either through insurance or paid by the public sector⁸. In addition, 15 countries reported that generic PrEP was available in healthcare settings, although it is not fully reimbursed.

1.3.1. Barriers to PrEP implementation

The fifteen countries which have not yet developed PrEP guidelines reported a number of barriers which are preventing or limiting PrEP implementation (Figure 6). Key concerns reported by the countries include concerns about increased transmission of other STI, concerns about lower condom use, concerns about drug costs and concerns about adherence. Seven countries reported 'other' concerns, which included legal barriers, impacts of the COVID-19 pandemic and government priorities as barriers to PrEP guideline development and implementation. With low rates of data on these barriers and substantial variation between countries, it is important not to overinterpret these responses.

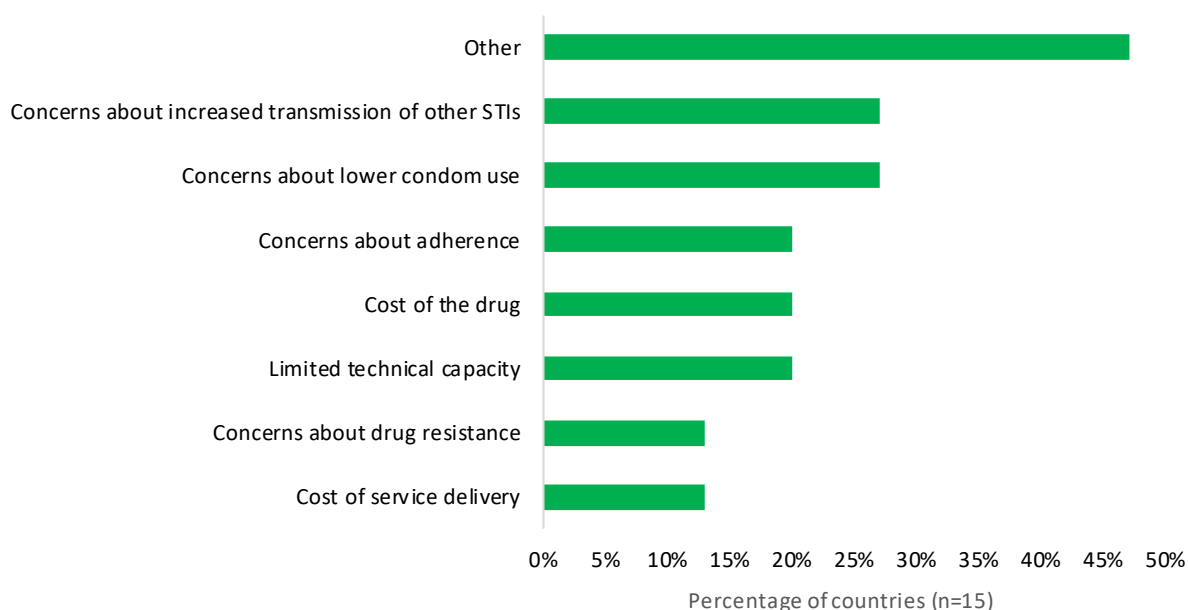
Figure 4: Status of PrEP implementation in Europe and Central Asia, 2021



Source: Author's own elaboration

⁸ Belgium, Bosnia & Herzegovina, Croatia, Denmark, Finland, France, Georgia, Germany, Iceland, Ireland, Kazakhstan, Kyrgyzstan, Liechtenstein, Luxembourg, Monaco, North Macedonia, Norway, Portugal, Slovenia, Spain, Sweden, Ukraine, United Kingdom.

Figure 5: Issues preventing or limiting PrEP implementation across Europe and Central Asia (n=15), 2021

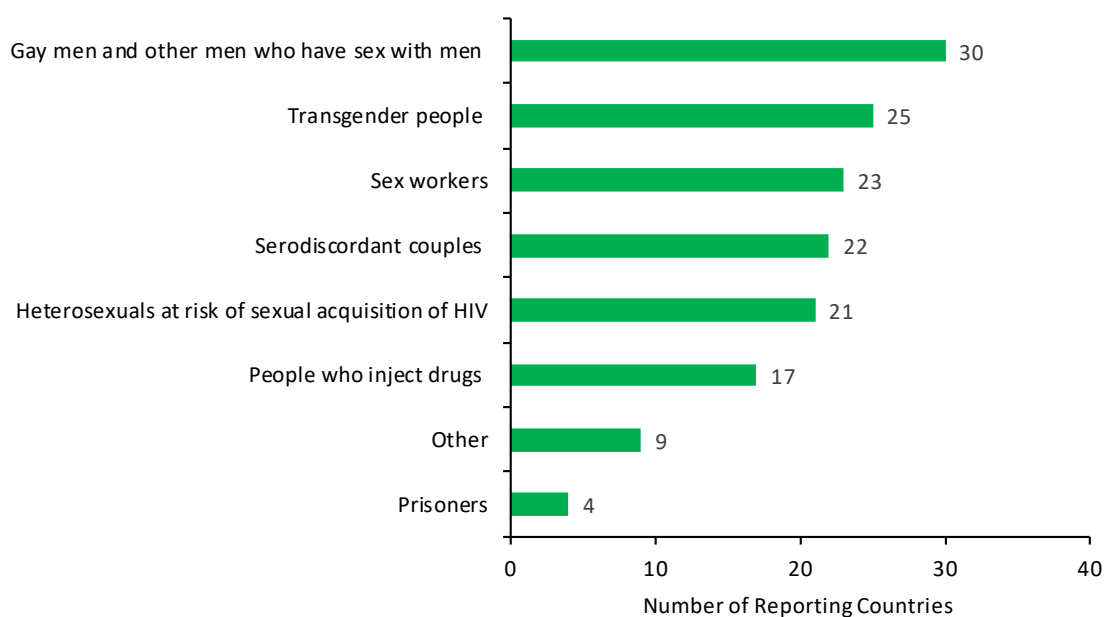


Source: Author's own elaboration

1.3.2. PrEP Eligibility for Key Populations

In 2022, 35 countries provided data on which key populations were eligible for PrEP (Figure 7). Gay men and other men who have sex with men were most frequently reported as eligible for PrEP: 30 of 35 countries reported that they are eligible for PrEP. Prisoners were least frequently reported as eligible for PrEP, with only 4 of 35 countries reporting them eligible.

Figure 6: Populations deemed eligible for PrEP across Europe and Central Asia (n=35), 2021

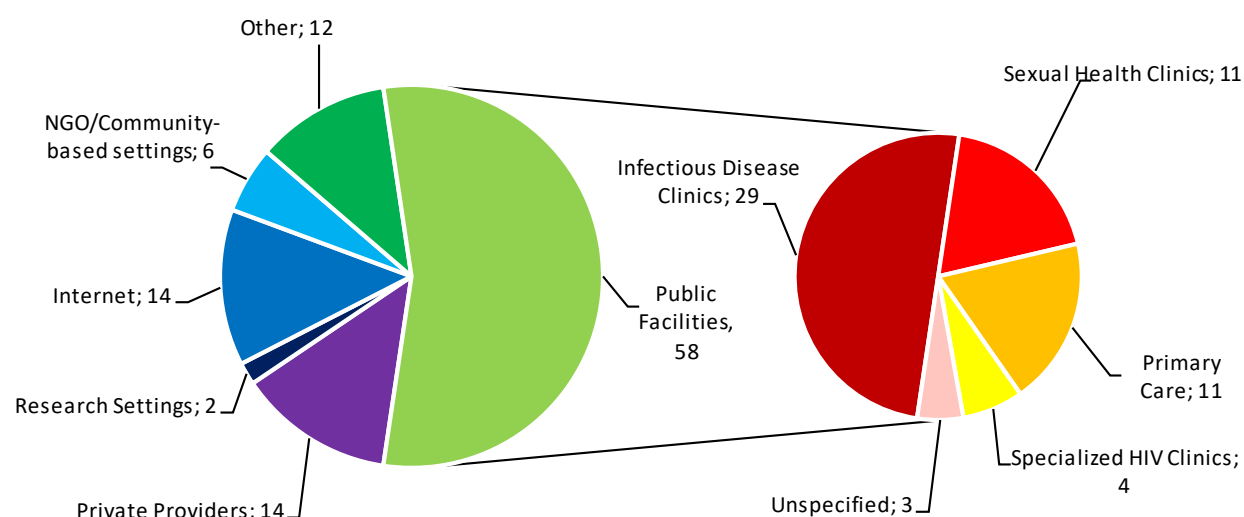


Source: Author's own elaboration

1.3.3. Settings for the provision of PrEP

Countries were asked about the settings in which PrEP is available (Figure 8). In 2022, countries most commonly reported that PrEP was available in public infectious diseases clinics, cited by 29 countries. Other commonly reported settings for PrEP provision included private providers (14), the internet (14), public sexual health clinics (11), and primary care (11).

Figure 7: Settings in which PrEP is available across Europe and Central Asia (n=49 countries, multiple sites per country), 2021

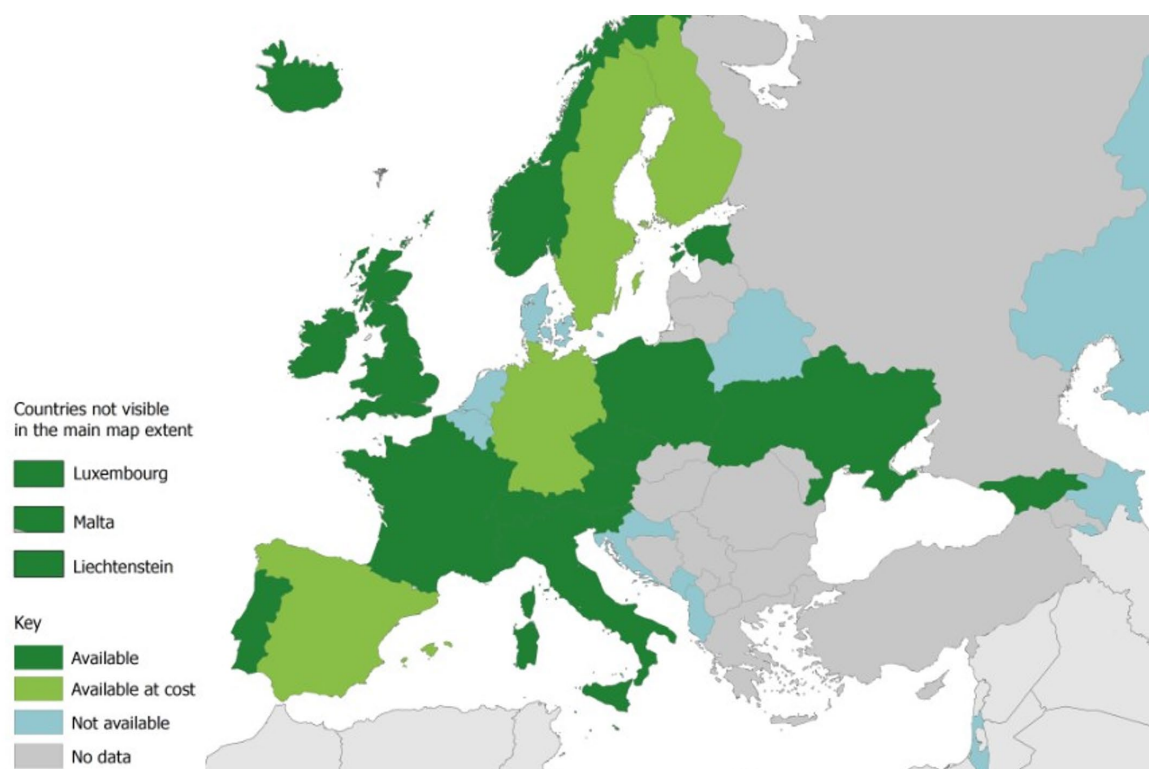


Source: Author's own elaboration

1.3.4. Availability of PrEP for undocumented migrants

In 2022, 19 countries reported that PrEP was available for undocumented migrants (Figure 9). An additional four countries reported that PrEP was only available for undocumented migrants through private practices or at cost, which may limit the number of undocumented migrants able to access PrEP in these countries. One country reported that PrEP may be available through NGOs, however, reported PrEP was not formally available for undocumented migrants through their healthcare system.

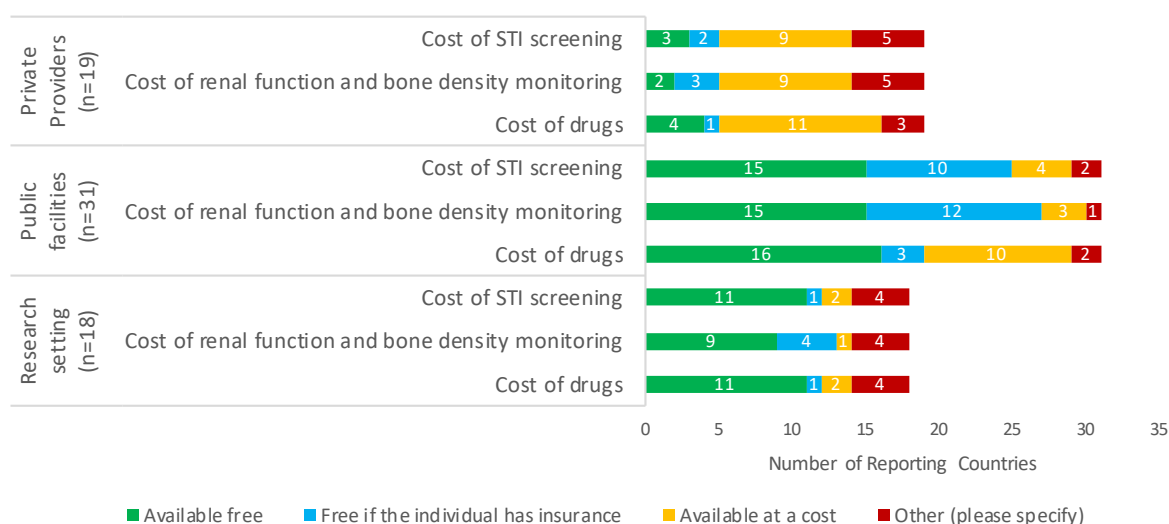
Figure 8: Availability of PrEP for undocumented migrants, 2021



1.3.5. The cost of accessing PrEP

Thirty-one countries provided data on the cost of accessing PrEP (Figure 10). Ten of them said that PrEP was not reimbursed at public facilities. Three countries stated that it was reimbursed through insurance (Croatia, Germany, Malta) and 14 said it was reimbursed through the public sector (Denmark, Finland, France, Georgia, Iceland, Ireland, Kazakhstan, Kyrgyzstan, Moldova, Netherlands, Norway, Slovenia, Spain, United Kingdom). Two countries reported 'Other', explaining that access to free PrEP is restricted to certain clinics (Ukraine) and that there is no official programme for reimbursing PrEP (Austria).

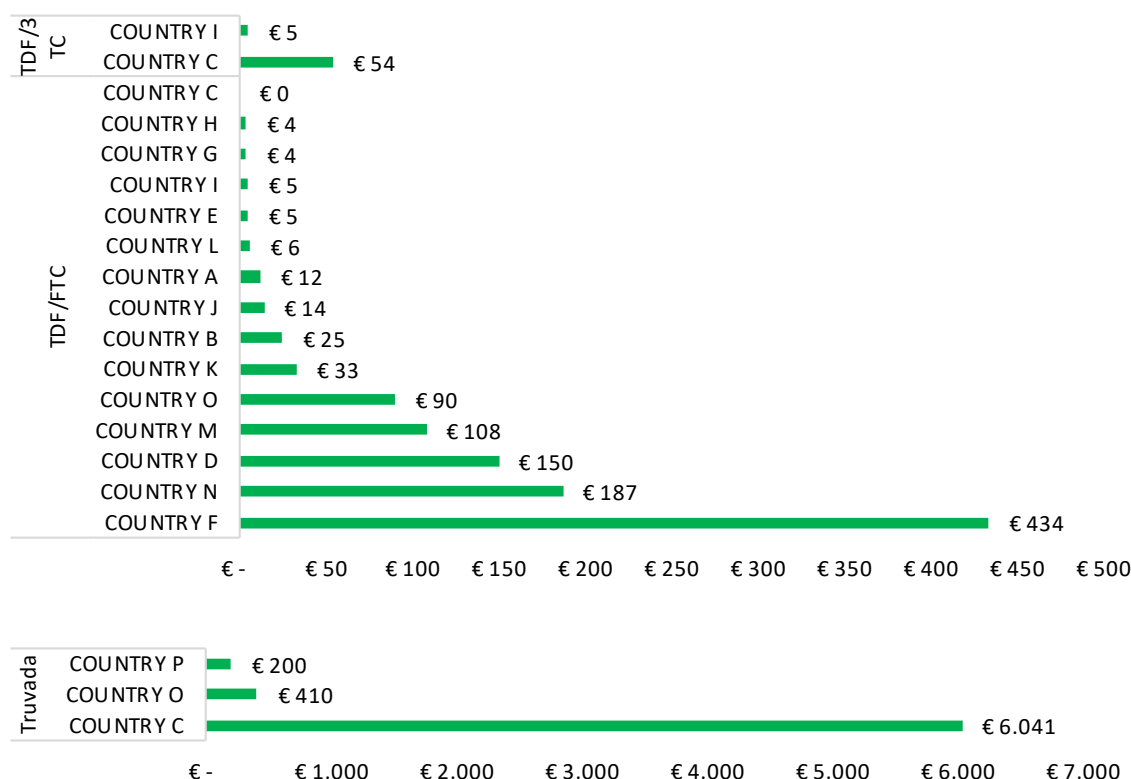
Figure 9: Cost to the individual when receiving PrEP in different settings across Europe and Central Asia



Source: Author's own elaboration

Countries in Europe and Central Asia were able to purchase PrEP at different prices (Figure 11). For example, for 28–30 tablets of generic PrEP (TDF/3TC and TDF/FTC), the lowest purchase price reported was EUR 0 (donation from the private sector) and the highest was EUR 434. Truvada was generally more expensive, with the highest purchase price being EUR 6 041 and the lowest EUR 200.

Figure 10: Cost of PrEP (28–30 tablets), as purchased by governments across Europe and Central Asia (n=16)⁹



Source: Author's own elaboration

1.3.6. Conclusions on PrEP availability

The provision of PrEP in Europe and Central Asia has significantly increased since 2016, however, there is still a great deal of variation among the countries. Data collected via Dublin Declaration monitoring on state provision of PrEP provides a snapshot of a rapidly changing situation. In 2022, 30 countries in the WHO European Region had developed and implemented national PrEP guidelines, and PrEP was available free through the healthcare system of 23 countries. However, even within the countries with developed and implemented PrEP guidelines, PrEP availability varies across regions and some countries have restrictions on who is eligible for PrEP. In particular, PrEP remains inaccessible for certain key populations (i.e. undocumented migrants). While progress has been made on increasing PrEP accessibility in Europe and Central Asia, wider scale implementation of PrEP is necessary to accelerate progress towards the UN Sustainable Development Goal 3.3: ending the AIDS epidemic by 2030.

In addition, while some countries have reported PrEP availability in NGO/community-based settings, PrEP is still mainly provided in medicalised settings, with infectious disease clinics being the most

⁹ This data has been anonymised due to its commercial sensitivity.

common setting and most countries allowing only doctors to prescribe PrEP. Research indicates that this may create barriers to access for target groups¹⁰.

In the 15 countries without national PrEP guidelines, various barriers to PrEP implementation have been identified, including concerns about increased transmission of other STI, concerns about lower condom use, concerns about drug costs and concerns about adherence.

However, there is substantial variation between countries. It is important to understand the specific barriers to preventing the implementation of PrEP programmes in individual countries to facilitate improvements in availability, and this should be a priority for these countries.

To facilitate PrEP implementation across Europe and Central Asia, ECDC has developed minimum standards on the principles of PrEP programming, monitoring and surveillance¹¹. Countries should consider these standards when developing and implementing national guidelines, and they are also encouraged to place a stronger focus on increasing PrEP accessibility for all key populations.

1.4. Co-morbidities impacting PLHIV in the EU/EEA

With expanded access to effective treatment, HIV infection has increasingly become a chronic disease, and PLHIV are now surviving, ageing, and requiring lifelong care and treatment. Co-infections are common among PLHIV, regardless of immune status. Some of those coinfections can be silent and do not cause significant impact on HIV disease nor are affected by it. In contrast, certain co-infections can affect the natural history of HIV infection and vice-versa with implications in diagnosis, susceptibility, clinical presentation, and care, including timing and choice of drug regimens for treatment and prevention.

Across all age groups, PLHIV are at risk of developing chronic complications and comorbidities, such as noncommunicable diseases (cancers, cardiovascular diseases, hypertension, chronic kidney diseases, diabetes and osteoporosis) and mental health disorders (alcohol and drug dependency, anxiety, depression, neurocognitive disorders, sleep disorders)^{12, 13}. These conditions may be pre-existing, HIV-associated, or due to ageing. Furthermore, some infectious co-morbidities are more common in PLHIV than persons not living with HIV, including tuberculosis, hepatitis B and hepatitis C. WHO has developed specific guidance to manage some of these co-infections, focusing on the screening, prophylaxis, treatment for these conditions¹⁴.

UNAIDS 2025 Targets call for 90% of people living with HIV and people at risk to be linked to people-centred and context-specific integrated services¹⁵. While important for all PLHIV, this is particularly key for population groups such as people who inject drugs who are more likely to suffer from multi-morbidities. The people-centred and integrated approach to care should include integrated testing for diseases associated with HIV (particularly hepatitis B and C and tuberculosis) and the monitoring of a patient's comorbidities.

¹⁰ Kornilova M, Roshchupkin G. Assessment of the Availability of PrEP, the Main Barriers to Implementing PrEP, and Scaling Up PrEP in the EECA Region. Tallinn: Eurasian Coalition on Male Health; 2019.

¹¹ European Centre for Disease Prevention and Control. HIV Pre-Exposure Prophylaxis in the EU/EEA and the UK: implementation, standards and monitoring. Operational guidance. Stockholm: ECDC; 2021. Available at: [www.ecdc.europa.eu/en/publications-data/HIV-PrEP-eueea-and-uk-implementation-standards-monitoring-guidance](https://ecdc.europa.eu/en/publications-data/HIV-PrEP-eueea-and-uk-implementation-standards-monitoring-guidance).

¹² Sabin, C. A. & Reiss, P. Epidemiology of ageing with HIV: What can we learn from cohorts? AIDS 31, S12..1–S128 (2017). <https://pubmed.ncbi.nlm.nih.gov/28471942/>.

¹³ HIV Outcomes. Co-morbidities. <https://hivoutcomes.eu/wp-content/uploads/2021/07/Factsheet-4-Comorbidities-2-1.pdf>

¹⁴ WORLD HEALTH ORGANIZATION. CHRONIC COMORBIDITIES & COINFECTIONS AMONG PLHIV. Available at: <https://www.who.int/teams/global-hiv-hepatitis-and-stis-programmes/hiv/treatment/chronic-comorbidities-and-coinfections>.

¹⁵ UNAIDS. 2025 AIDS Targets. <https://aidstargets2025.unaids.org/> (2020).

Information on co-morbidities should be regularly reviewed, as part of routine surveillance systems, or through special studies or period audits to help countries monitor and improve the health and HRQoL of PLHIV.

1.5. Mortality among PLHIV

Rates of AIDS and AIDS-related deaths in the EU/EEA have decreased substantially during the past decade, likely reflecting greater access to treatment and better case management, indicating continued progress towards the Sustainable Development Goal of ending the AIDS epidemic as a public health threat and decreasing AIDS-related deaths. Still, in 2020 EU/EEA countries reported more than 500 deaths due to AIDS-related illness¹⁶. Most AIDS-related deaths in Europe are associated with late diagnosis of HIV, when the individual is at an advanced stage of infection with a heavily compromised immune system.

In an in-depth review of causes of death among PLHIV in England and Wales diagnosed between 1997 and 2012, 58% of deaths were attributable to AIDS-defining illnesses¹⁷. Mortality among PLHIV was significantly higher than the general population for all causes particularly non-AIDS infections and liver disease. All-cause mortality was highest in the year after diagnosis.

Fewer AIDS-related deaths and an ageing cohort have resulted in an increase in the proportion of HIV patients dying from non-AIDS-related disorders. In a cohort study in Spain among PLHIV who died between 2009–2018 mortality was found to be more than 8.1 times higher among PLHIV than in the general population; even after excluding HIV-related deaths it was nearly 5 times higher¹⁸. Excess mortality was observed in non-AIDS cancers (standardised mortality ratio, SMR = 3.7), cardiovascular disease (SMR = 4.2), respiratory diseases (SMR = 7.9), liver diseases (SMR = 8.8), drug abuse (SMR = 47), and suicide (SMR = 5.3). HIV-related mortality was found to decline during the period, while non-HIV-related mortality remained stable.

A review of 16 studies reporting on outcomes of COVID-19 in people living with HIV did not link HIV infection with an increased risk of COVID-19 mortality, however higher COVID-19 related mortality did seem to be observed in PLHIV with CD4 count <200 cells/mm³¹⁹.

Overall, these findings highlight the importance of prompt diagnosis, care engagement, and optimum management of HIV care and comorbidities with a people-centred integrated approach in reducing mortality in people with HIV.

1.6. Freedom of movement and HIV status

HIV-related travel restrictions are defined as mandatory HIV testing for, and/or preventing people living with HIV from, legally entering, transiting through or studying, working or residing in a country solely based on their HIV status. In 2019, 48 countries, territories and areas globally impose some form of HIV-related restriction²⁰, of which four countries are in the Eastern part of the WHO European Region.

¹⁶ European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2021 – 2020 data. Stockholm: ECDC; 2021 Available at: <https://www.ecdc.europa.eu/en/publications-data/hiv-aids-surveillance-europe-2021-2020-data>.

¹⁷ Croxford et al (2016). Mortality and causes of death in people diagnosed with HIV in the era of highly active antiretroviral therapy compared with the general population: an analysis of a national observational cohort. The Lancet. Available at: [https://www.thelancet.com/article/S2468-2667\(16\)30020-2/fulltext](https://www.thelancet.com/article/S2468-2667(16)30020-2/fulltext).

¹⁸ Fontela et al (2020). Trends and causes of mortality in a population-based cohort of HIV-infected adults in Spain: comparison with the general population. Scientific Reports, 10 (8922), <https://www.nature.com/articles/s41598-020-65841-0>.

¹⁹ Dzinamarira et al (2022). Risk of mortality in HIV-infected COVID-19 patients: A systematic review and meta-analysis [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9110010/#:~:text=suggested%20that%20PLHIV%20had%20a,%E2%80%931.524\)%20%5B25%5D](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9110010/#:~:text=suggested%20that%20PLHIV%20had%20a,%E2%80%931.524)%20%5B25%5D).

²⁰ UNAIDS/UNDP (2019). Still not welcome: HIV-related travel restrictions. www.unaids.org/sites/default/files/media_asset/hiv-related-travel-restrictions-explainer_en.pdf.

HIV-related travel restrictions usually involve a mandatory declaration of HIV status and/or testing, which is often conducted without appropriate counselling, confidentiality or referral to HIV prevention, treatment, care or support services.

Out of the 48 countries and territories that maintain restrictions, 7 countries are in the WHO European Region, although none are in the EU/EEA. Azerbaijan and Kazakhstan are among countries, territories and areas that require HIV testing or disclosure for certain types of entry, study, work and/or residency permits. Bosnia and Herzegovina, Kyrgyzstan and Ukraine are among countries, territories and areas that prohibit short- and/or long-term stay based on HIV status. Russia and Turkmenistan are among countries that deport non-nationals based on HIV status.

2. ASSESSMENT OF QOL AND HRQOL FOR PLHIV

Shifts towards HIV as a chronic disease, raise questions about whether biomarkers such as CD4 count at diagnosis and viral suppression are adequate indicators to determine overall value in HIV treatment. Although excellent metrics of disease state, these indicators do not provide a broader view of health, as defined by WHO (i.e. “a state of complete physical, mental and social well-being, and not merely the absence of disease”). Adequate understanding of what it means to be healthy as a PLHIV on treatment today requires a more holistic approach to the measurement of health. Only through recognising and measuring the entire spectrum of associated health, mental and social outcomes related to HIV will the health status of PLHIV be fully understood.

HRQoL describes all “those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment,” across physical, mental, and social domains of health. Measures of HRQoL could provide a more comprehensive picture of how treatment affects an individual’s life when used alongside clinical and biological markers in evaluations of HIV interventions and can be used to re-direct or refine services to maximise HRQoL.

2.1. The use of QoL and HRQoL measures to assess the situation experienced by PLHIV in EU/EEA

The data on the HRQoL is collected through the ECDC Dublin Declaration monitoring system and is currently being analysed for formal publication. The data in this report should therefore be considered preliminary. In 2022, 10 countries (out of 55) reported including HRQoL assessments in national monitoring of people living with HIV (see Annex 2). Twenty-eight countries report that they do not have HRQoL monitoring, and 17 countries did not respond. This is an improvement on previous years, with seven countries reporting use of HRQoL assessments in 2020, and five countries reporting their use in 2018. Moreover, three countries that reported collecting HRQoL data in 2020 (Estonia, Iceland and Kazakhstan) were unable to report in 2022, indicating that the actual number of countries collecting HRQoL data may be as high as 13. Data from these three countries have been added to the 2022 data for analysis.

However, of the 13 countries reporting inclusion of HRQoL measurement in national monitoring, five (Austria, Iceland, Kazakhstan, Liechtenstein, and Romania) described cohort studies or similar with insufficient evidence that HRQoL questions are asked and did not provide information on what HRQoL measurements are monitored. The data below describe the HRQoL monitoring in the remaining nine countries: Estonia, Germany, Italy, Kazakhstan, Serbia, Spain, Sweden, Ukraine and United Kingdom.

A range of instruments were used to collect HRQoL data: WHOQOL/HIV-Brief (two countries), EQ-5D (two countries), WHODAS2.0, MOS-HIV, Treatment Satisfaction Questionnaire for Medication (TSQM), patient surveys (four countries). Some countries report using multiple tools and in Italy, different instruments are used in different hospitals, with guidelines suggesting using one of the standardised tools listed above.

There is considerable variation between the eight countries in the recency of data collection. Data reported by Estonia and Serbia are from 2013 and by the UK from 2017. Data reported by the five remaining countries are from 2019 or more recent. Frequency of data collection is not formalised with most countries reporting ‘planned’ rather than actual frequency.

Four countries (Germany, Italy, Sweden and Ukraine) report using patient-related outcomes measures (PROMs). In Ukraine, PROMs are generic but in the other three countries both generic and HIV specific

PROMs are used. In Sweden, PROMs are collected annually, but in the other three countries data collection via PROMs is ad hoc.

Six countries are able to report disaggregated data, but there is considerable variation in the categories used for disaggregation. For example, Sweden reports disaggregation by gender, key populations (MSM, migrants, trans people, PWID, and race/ethnicity), and by region and city, whereas data from Ukraine is disaggregated by gender and region only. The remaining countries disaggregate data by gender and by key populations, but each has data available for different key populations.

Three countries (Spain, Ukraine and the United Kingdom) compare QoL of people living with HIV with those who are HIV negative in their monitoring.

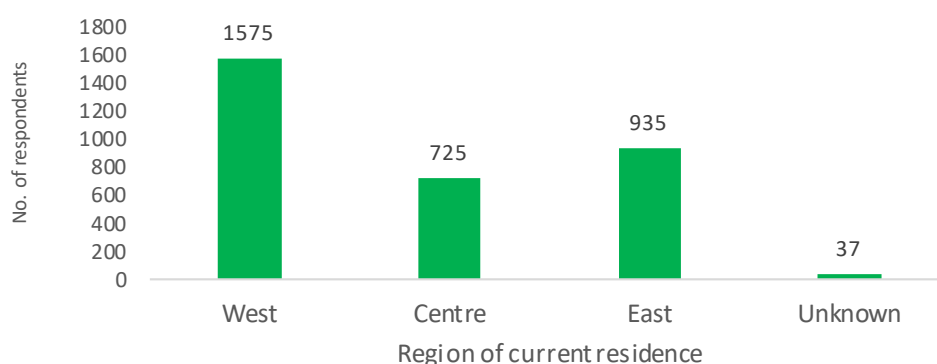
2.2. Impact on stigma and discrimination experienced by PLHIV

The data on stigma and discrimination is currently being analysed for formal publication. The data in this report should therefore be considered preliminary. Historically few countries in the European Region have been able to report stigma data to global (UNAIDS) or regional (ECDC) monitoring systems. The main reason for this is the lack of standardised indicators and resources to collect these data at national level. Consequently, ECDC in partnership with the European AIDS Treatment Group (EATG) and AIDS Action Europe (AAE) developed a stigma survey that was rolled out in 2022. The objective of this survey was to collect data on the experiences of HIV-related stigma among people living with HIV in the WHO European Region. In total, we received 3,272 responses from across the European Region (Figure 12). Almost one-half of respondents currently live in the West sub-region, and approximately one-quarter live in each of the Centre and East sub-regions.

The data collected are currently being analysed and a report will be published towards the end of 2022. Below are some preliminary results that have yet to be published.

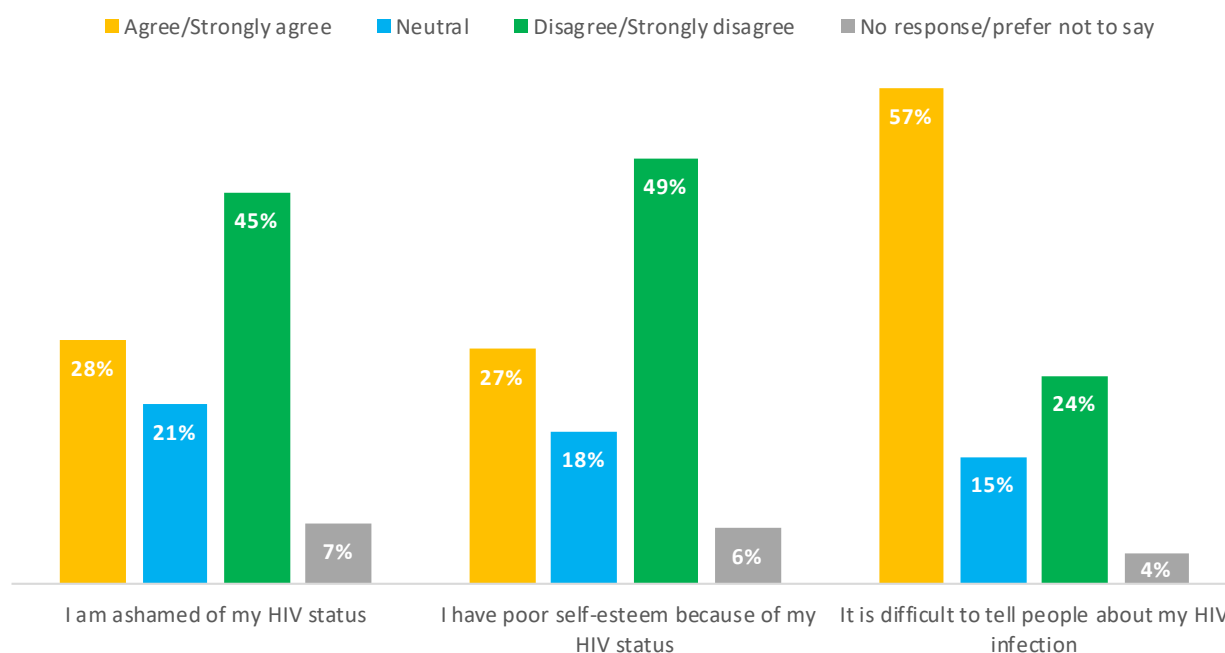
As a measure of self-stigma, respondents were asked how having HIV makes them feel (Figure 13). One in four respondents agreed or strongly agreed with the statement that they felt ashamed of their HIV status and had poor self-esteem because of their HIV status. Almost three of five respondents agreed or strongly agreed that it is difficult to tell others about living with HIV.

Figure 12: Sample size for the stigma survey among PLHIV in Europe and Central Asia, by sub-region, 2021



Source: Author's own elaboration

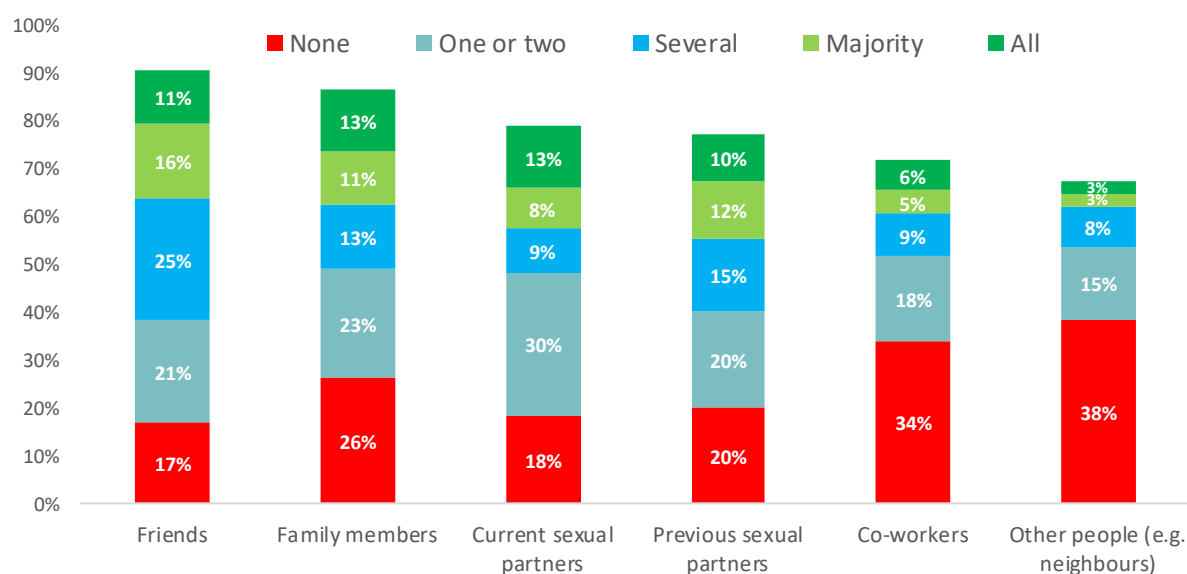
Figure 13: Responses from people living with HIV to the question “How does HIV make you feel?”, 2021



Source: Author's own elaboration

As a marker of self-stigma, respondents were asked how many people they had told they have HIV, apart from healthcare workers (Figure 14). One in seven (14%) respondents said that they had told no one that they were living with HIV. Respondents were most likely to have told friends (52% had told at least several friends), and least likely to have told co-workers and neighbours (34% and 38% respectively had not told anyone in these circles).

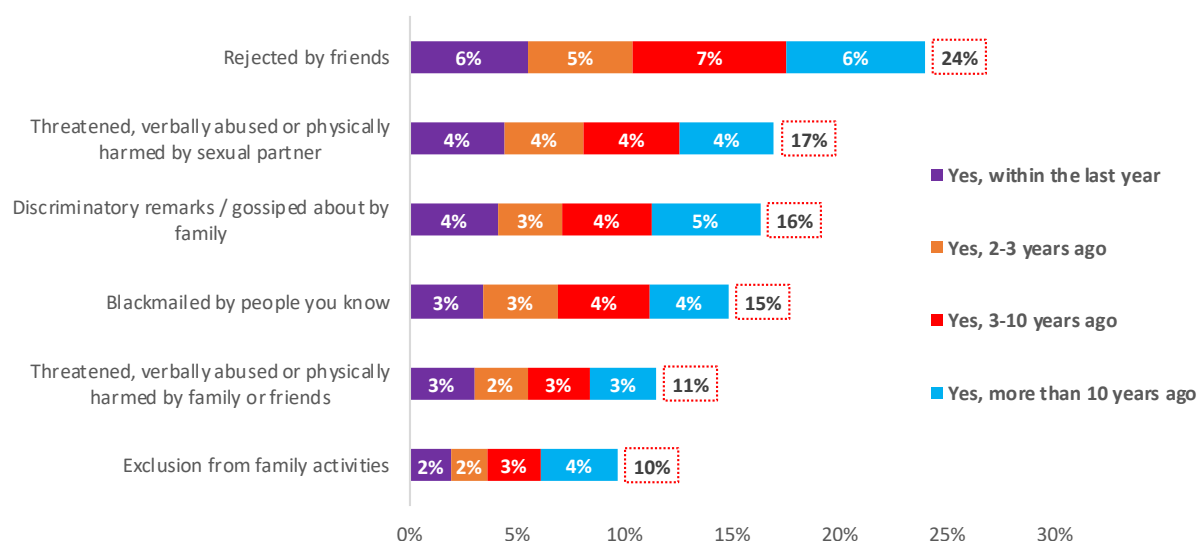
Figure 14: Responses from people living with HIV to the question “Who have you told that you have HIV?”, 2021



Source: Author's own elaboration

Respondents were asked if they had experienced stigma from family and friends, and the recency of experienced stigma (Figure 15). Rejection by friends is the most common stigmatising practice experienced, by 24% of respondents. Stigma from family is least evident, with 10% ever having been excluded from family activities.

Figure 15: Experience of stigma by people living with HIV from family and friends, 2021



Source: Author's own elaboration

3. ASSESSMENT OF HEALTH SERVICES: THE IMPACT OF COVID-19

The data in this section is collected through the ECDC Dublin Declaration monitoring system and is currently being analysed for formal publication. The data should therefore be considered as preliminary.

3.1. Impact of COVID-19 on HIV services and prevention

The COVID-19 pandemic has created unprecedented challenges for healthcare and public health systems worldwide. As of 3rd October 2022, the WHO (World Health Organization) European Region had counted over 254 million confirmed cases and almost 2.1 million deaths due to COVID-19²¹. While healthcare system capacity has been strained in a wide range of ways, it is crucial to assess the impact of the COVID-19 pandemic on access to HIV services and monitoring capacity, and thus on the HIV pandemic and progress towards ending HIV transmission by 2030.

ECDC and the WHO Regional Office for Europe conducted a survey of countries in the region in 2021 to understand the impact of COVID-19 on testing and detection of HIV cases²². Overall, 12 of the 21 respondents, including eight of 15 respondents from the EU/EEA and four of six non-EU/EEA countries, reported reduced testing and detection of HIV cases which had affected their national HIV surveillance data. Countries that reported reduction in case detection were additionally asked to provide estimates of the magnitude of the reduction in HIV testing. On average, they indicated a 20% reduction in case detection in 2020 compared to the earlier years. One-third of countries responding (seven of 21) indicated that limited surveillance capacity had led to reduced reporting of HIV cases in 2020. This was less the case for the EU/EEA countries (4/15) than for the non-EU countries (3/6). Countries that reported limited surveillance capacity affecting HIV surveillance capacity estimated on average a 30% reduction in reporting of HIV cases compared to previous years.

An ECDC survey was developed to assess the impact of COVID-19 on HIV service delivery and monitoring capacity. While, undoubtedly, there will have been an impact on diagnoses and incidence, due to impact on testing services and reporting delay at various levels of health care, the full extent of these will be difficult to fully assess for two years or more. Under these conditions, it was decided that largely qualitative indicators should be used as proxies, drawing on assessments from key personnel in country rather than hard surveillance data.

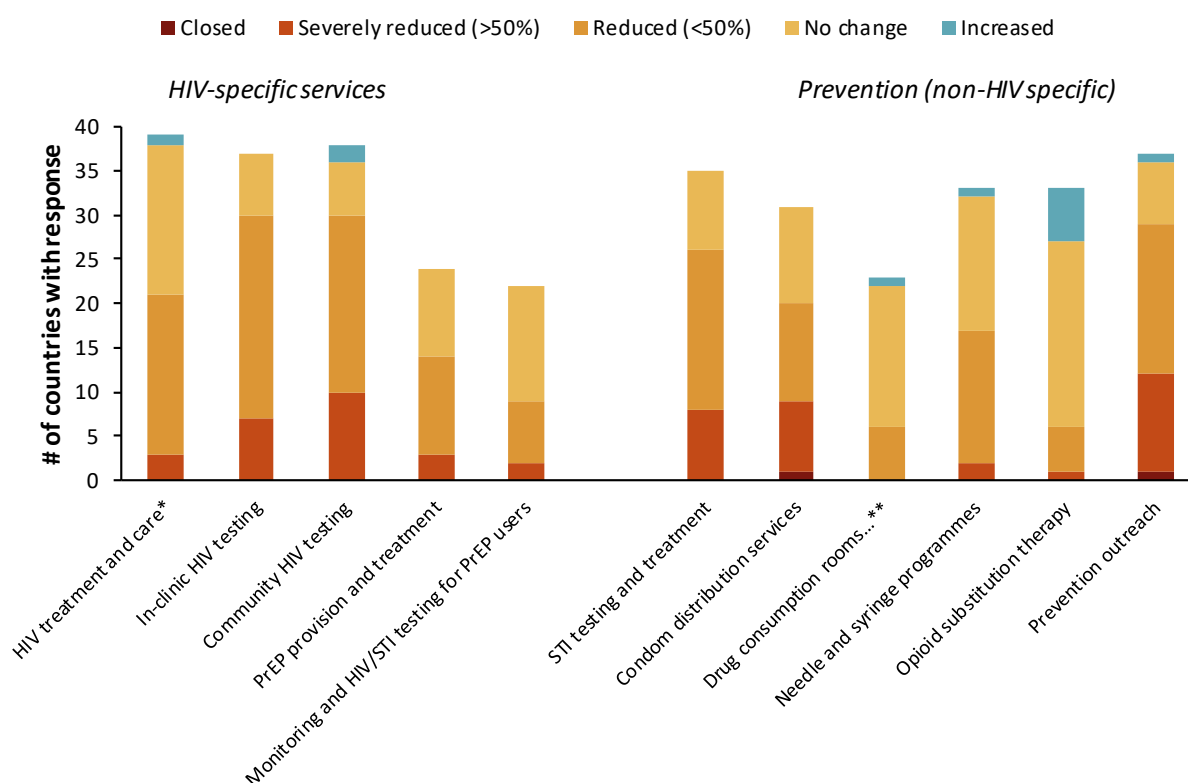
Forty countries reported on whether COVID-19 had an impact on a number of HIV-specific and non-HIV specific services (Figure 16). Overall, some degree of reduction was reported in HIV treatment and care services by 21 countries, in in-clinic testing by 30 countries, in community HIV testing by 30 countries, in PrEP provision and treatment by 14 countries and in monitoring and HIV/STI testing for PrEP users by 9 countries. However, many countries that were able to report on the impact of COVID-19 on services generally, did not know the impact on PrEP treatment (16/40) and PrEP monitoring services (18/40). Countries mainly reported that HIV-specific services were 'reduced' (<50% reduction in services). Where countries reported 'severe reduction' (>50% reduction in services), it was most commonly reported in community-based HIV testing, with ten countries reporting this level of disruption. No HIV-specific services were reported to have been fully closed, and increased service provision was reported in HIV treatment and care by one country, and in community HIV testing by two countries.

²¹ WHO Coronavirus (COVID-19) Dashboard at <https://covid19.who.int>.

²² European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2021 – 2020 data. Stockholm: ECDC; 2021 Available at: <https://www.ecdc.europa.eu/en/publications-data/hiv-aids-surveillance-europe-2021-2020-data>.

For non-HIV specific prevention services, some level of reduction (severe reduction, reduction or closure) was reported in STI testing and treatment services by 26 countries, in condom distribution services by 20 countries, in drug consumption rooms and supervised injecting facilities by six countries, in needle and syringe programmes by 17 countries, in opioid substitution therapy (OST) by 6 countries and in prevention outreach by 29 countries. Of these, closure of condom distribution and prevention outreach were both reported as having closed by one country. An increase in the provision of OST was reported in six countries, and drug consumption rooms, needle and syringe programmes and prevention outreach were each reported by one country to have increased. Several countries were unable to report on the level of disruption to non-HIV specific services, with this being especially pronounced for drug consumption rooms where 17/40 countries were unable to report the impact of COVID-19 on service levels.

Figure 16: The impact of the COVID-19 pandemic on HIV service provision in Europe and Central Asia from March 2020, reported in 2021



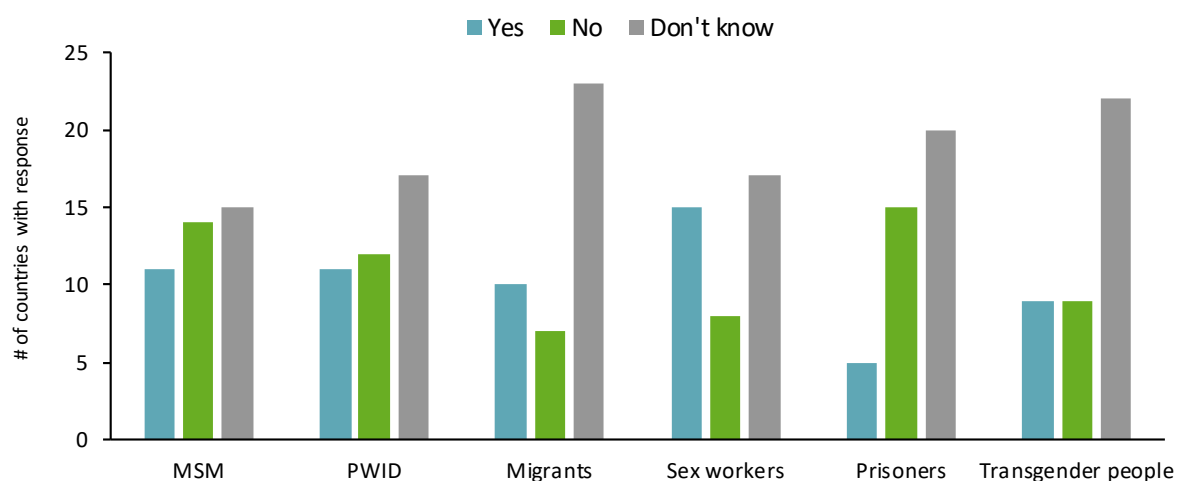
Source: Author's own elaboration

Notes: *Includes HIV care initiation, monitoring, and treatment
 **...and supervised injecting facilities

3.2. Impact of COVID-19 on HIV services to key populations

Countries were asked to report whether the pandemic had a disproportionate impact on six key populations living with or at risk of HIV (Figure 17). In the entire region, sex workers were most frequently reported as having experienced a disproportionate impact, while people in prisons were least frequently identified having been disproportionately impacted by the pandemic. Across all key populations, the most frequent response from countries was that they did not know the impact of COVID-19 on population-specific service provision, although this was most pronounced for migrants and transgender people.

Figure 17: Countries reporting a disproportionate impact of COVID-19 on six key populations, in Europe and Central Asia, 2021

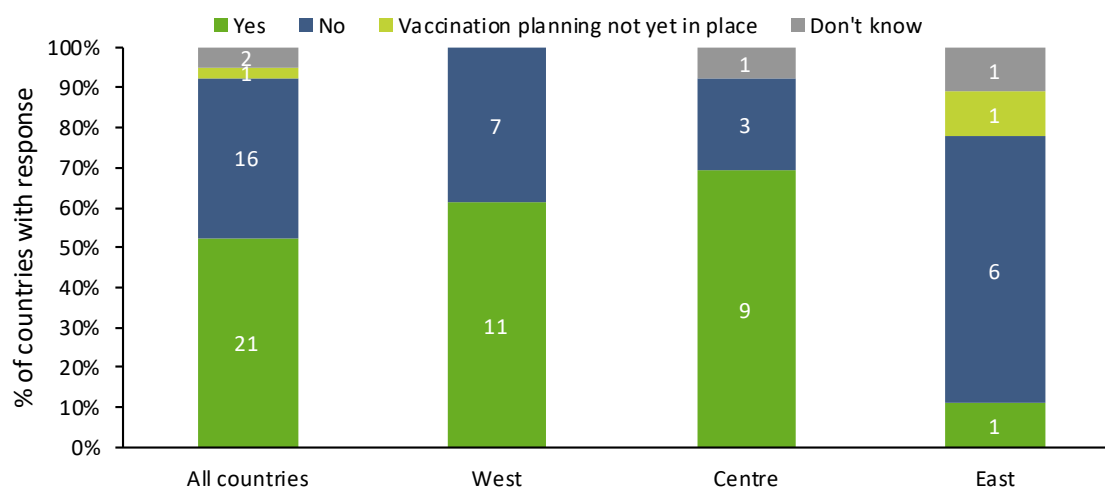


Source: Author's own elaboration

3.3. Impact of COVID-19 on policies on the HIV response

The survey included questions on vaccination plans for people living with HIV and the diversion of resources, including funds, staff, and facility, from the HIV response to the COVID-19 response. Most countries in the West (11/18) and Centre (9/13) sub-regions reported that people living with HIV were a priority group for COVID-19 vaccinations (Figure 18), although three countries specified that vaccine eligibility was dependent on having a CD4 count below a specific threshold. Conversely, in the East sub-region only one country reported that people living with HIV were a priority group for vaccination.

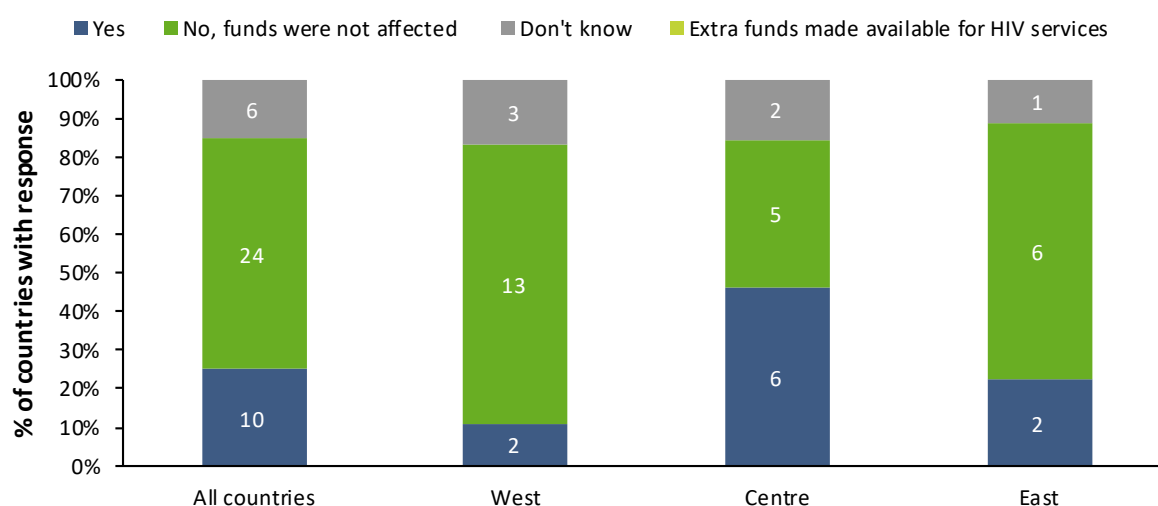
Figure 3-1: Countries offering people living with HIV priority access to COVID-19 vaccination, in Europe and Central Asia (total and by sub-region), 2021



Source: Author's own elaboration

Twenty-four out of 40 countries reported that funds for the HIV response were not diverted to the COVID-19 response during the pandemic, while ten countries reported that funds were diverted (Figure 19). No country identified that extra funds had been made available for HIV services during the COVID-19 pandemic. The Centre sub-region had the largest proportion of countries (6/13) reporting that funds had been diverted.

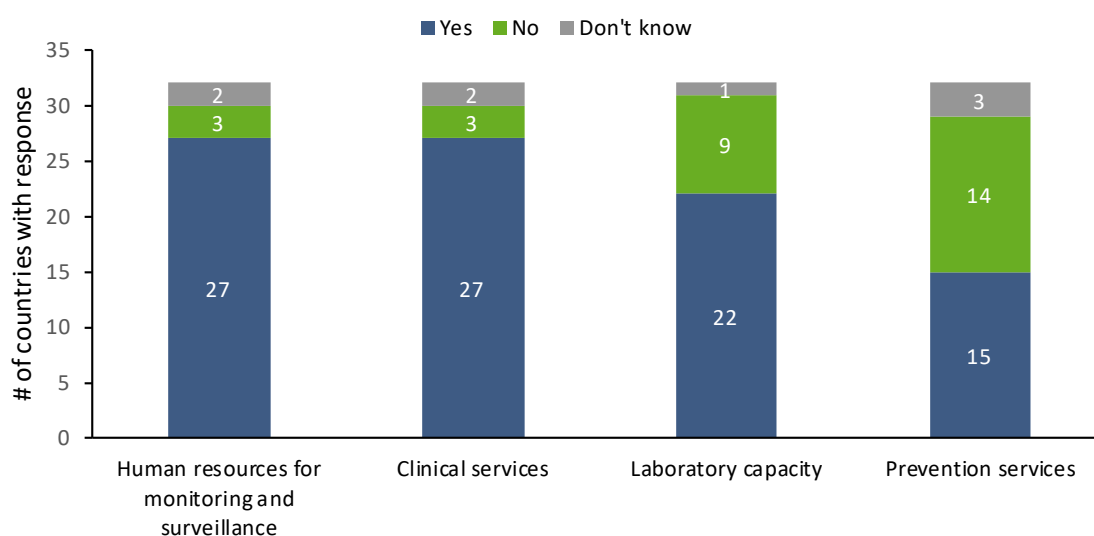
Figure 18: The impact of COVID-19 on HIV response funds in Europe and Central Asia, 2021



Source: Author's own elaboration

Thirty-two countries reported that staff and facility resources were diverted from the HIV response to the COVID-19 response, five countries reported that this was not the case, and three countries did not know. The diversion of staff and facility resources away from the HIV response to COVID-19 was reported much more frequently than the diversion of funds. The largest impacts on resources were reported in clinical services for people living with HIV and human resources for HIV monitoring and surveillance (Figure 20). This was reflected in expert focal point text responses, which highlighted that doctors, nurses, and other human resources were often transferred between departments to urgently address COVID-19 clinical needs. Laboratory capacity was reported to have been diverted in 22 countries. Prevention services were least frequently reported to have been impacted by diversion of resources.

Figure 19: Diversion of staff and facility resources due to the COVID-19 pandemic in Europe and Central Asia, 2021

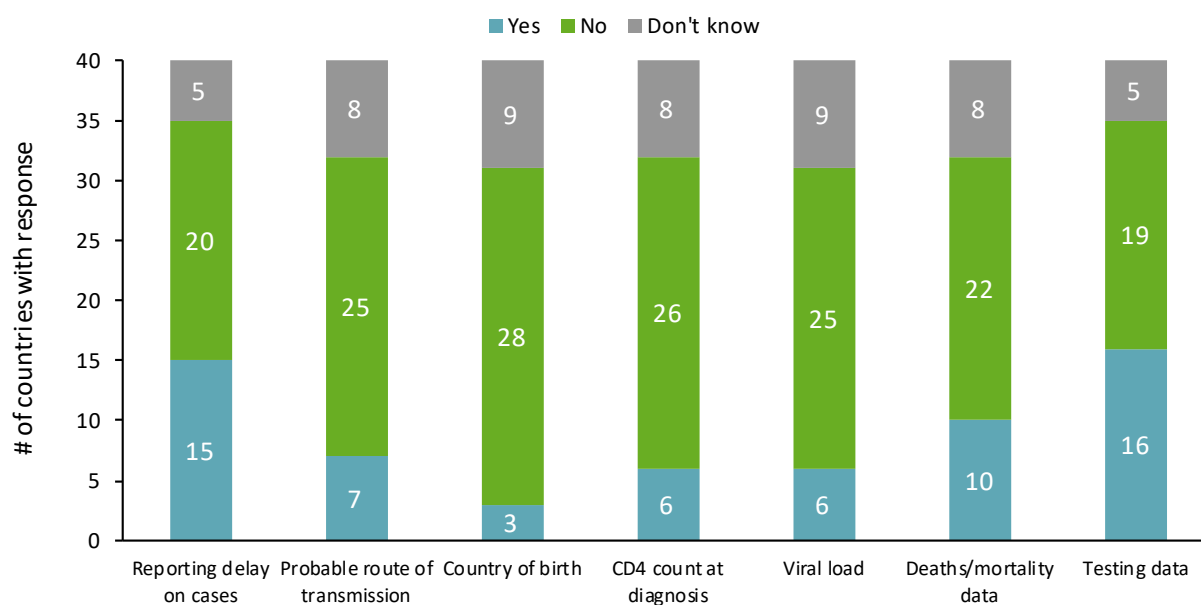


Source: Author's own elaboration

3.4. Impact of COVID-19 on HIV monitoring

The survey also posed questions relating to country-level HIV surveillance and monitoring in public health institutions. Most countries responded that the COVID-19 pandemic had not impacted their ability to collect HIV surveillance data (Figure 21). The impacts most frequently reported by countries were reporting delays on cases (15 countries) and inability to collect testing data (16 countries).

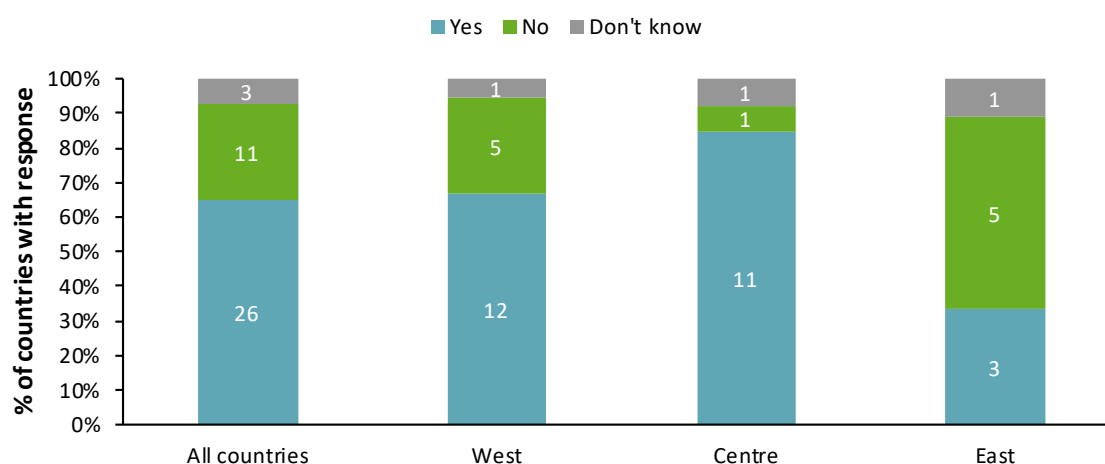
Figure 20: The impact of COVID-19 on the ability to collect HIV surveillance data in Europe and Central Asia, 2021



Source: Author's own elaboration

However, when asked whether COVID-19 affected capacity for HIV surveillance and/or response monitoring in public health institutions, most countries (including a strong majority in the Western and Centre sub-regions) reported that COVID-19 had affected capacity (Figure 22).

Figure 21: The impact of COVID-19 on HIV surveillance capacity and response monitoring in public health institutions in Europe and Central Asia, 2021



Source: Author's own elaboration

4. DATA GAPS

The following data gaps inhibit a comprehensive understanding of quality of life among people living with HIV in the EU/EEA and represent areas for improved data quality and availability.

Dublin Declaration monitoring: Many countries in the European region lack data to monitor one or several steps of the 90-90-90 targets, in particular for key populations. Additional efforts should be placed on filling those gaps to adequately monitor progress towards these essential targets.

HIV surveillance: Recent years have seen a worrying trend in reduced data completeness in HIV surveillance, particularly data on HIV transmission route, with more than one-quarter (27%) of cases reported in 2020 lacking this important information and CD4 count at diagnosis, where 36% did not report this information. Information on probable route of transmission is crucial to better inform HIV-prevention interventions and programme-planning while CD4 count at diagnosis provides understanding of how timely the HIV diagnosis was made. Greater efforts to improve collaboration with clinicians and follow-up with other data providers may improve the HIV transmission route and CD4 data.

Health-related quality of life: Only a minority of countries (13 in the wider European region) reported collecting any data on HRQoL. A variety of instruments were used, at times within the same country and many countries were unable to disaggregate data collected on HRQoL by key population. Few countries used patient-reported outcomes. At present, due to gaps in data availability and harmonised monitoring, it is not possible to obtain a comprehensive overview of the situation of HRQoL in the EU/EEA or the wider European region.

Stigma: Historically few countries in the European region have been able to report stigma data to global (UNAIDS) or regional (ECDC) monitoring systems. The main reason for this is the lack of standardised indicators and resources to collect this data at national level. For this reason, at present it is not possible to obtain a comprehensive overview of the situation of HIV-related stigma in the EU/EEA or the wider European region.

5. CONCLUSIONS

Accelerated action in the following areas is suggested to continue to reduce HIV incidence in the EU/EEA and the wider European region and to improve HRQoL for PLHIV:

HIV prevention: A combination prevention approach which includes access to condoms, PrEP, and frequent testing for those at high-risk, will be key to reducing the HIV infection rate. High coverage of harm reduction remains important for people who inject drugs, particularly in the East sub-region but also across the other sub-regions where localised HIV outbreaks continue to occur amongst PWID.

HIV testing and linkage to care: Expanding accessibility of testing through different testing modes, such as lay-provider testing and self-testing, is particularly important in countries which have been previously identified as having a limited range of testing modes available.

Linkage to treatment and adherence support: Prompt linkage to treatment, and support for adherence and retention in care, should be implemented to improve rates of viral suppression.

Integrated, patient-centred, patient-involved services and approaches: It is important, particularly for key populations, that accessibility along the entire HIV continuum of care is prioritised by implementing patient-centred services in a non-stigmatising and inclusive environment, preferably with the involvement of civil society. Integrated, outcomes-focused and patient-centred approaches to long-term HIV care, including health in the broad sense as defined by WHO, will improve HRQoL measures among PLHIV. Such approaches will support the cohort of aging Europeans living with HIV, particularly those with co-morbidities.

Improved measurement of HRQoL: Develop more holistic approaches to the measurement of health. Only through recognising and measuring the entire spectrum of associated health, mental and social outcomes related to HIV will the health status of PLHIV be fully understood. This will include expanded monitoring of long-term HIV care and outcomes, through the use of patient-reported outcomes. Europe's HIV cohorts could be harnessed to accelerate and expand long-term monitoring of HRQoL measures across the region.

Expanded monitoring of HRQoL: Currently, only a minority of countries in the European region report routinely collecting HRQoL measures for PLHIV. Expanded monitoring could provide a more comprehensive picture of how treatment affects an individual's life when used alongside clinical and biological markers in evaluations of HIV interventions and can be used to re-direct or refine services to maximise HRQoL.

Expanded monitoring of HIV-related stigma: There is evidence that HIV-related stigma is prevalent, impacting self-esteem and quality of life for PLHIV in Europe, still, few countries in the WHO European region have been able to report stigma data to global (UNAIDS) or regional (ECDC) monitoring systems. Efforts to develop and use standardised indicators and resources to collect this data at national level and to, in turn, report these the global and regional monitoring systems will help direct interventions to impact on this critical issue.

Address HIV-related stigma, particularly in health care systems: There is evidence that PLHIV experience stigma related to their HIV status within the health care system. Training and education of healthcare staff should be a priority, both in order to raise awareness of stigma and discrimination within healthcare settings, and to help combat the underlying attitudes that give rise to it.

Assess the impact of COVID-19 pandemic on PLHIV and on HIV services: There is evidence from across Europe that prevention services, testing health care service delivery and surveillance and monitoring systems have been adversely impacted by the COVID-19 pandemic. The extent to which

these services will re-bound to pre-pandemic levels will greatly impact European countries' ability to achieve the targets set forth in the 2030 Sustainable Development Goal 3.3 on health. Continued attention to monitoring the impact of the pandemic on PLHIV and HIV services, including monitoring and surveillance, is crucial.

REFERENCES

- Croxford et al., 2016, *Mortality and causes of death in people diagnosed with HIV in the era of highly active antiretroviral therapy compared with the general population: an analysis of a national observational cohort*. The Lancet - Public Health, Volume 2, Issue 1, Pages e35–e46. Available at: [https://www.thelancet.com/article/S2468-2667\(16\)30020-2/fulltext](https://www.thelancet.com/article/S2468-2667(16)30020-2/fulltext)
- Dzinamarira et al., 2022, *Risk of mortality in HIV-infected COVID-19 patients: A systematic review and meta-analysis*. J Infect Public Health; 15(6): 654–661. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9110010/>
- European Centre for Disease Prevention and Control, 2021, *HIV Pre-Exposure Prophylaxis in the EU/EEA and the UK: implementation, standards and monitoring. Operational guidance*. Available at: www.ecdc.europa.eu/en/publications-data/HIV-PrEP-eueea-and-uk-implementation-standards-monitoring-guidance
- European Centre for Disease Prevention and Control, 2022, *Pre-exposure prophylaxis for HIV prevention in Europe and Central Asia. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia – 2020/2021 progress report*. Available at: www.ecdc.europa.eu/en/publications-data/evidence-brief-pre-exposure-prophylaxis-hiv-prevention-europe-and-central-asia
- 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*. (unpublished).
- European Centre for Disease Prevention and Control/WHO Regional Office for Europe, 2021, *HIV/AIDS surveillance in Europe 2021 – 2020 data*. Available at: <https://www.ecdc.europa.eu/en/publications-data/hiv-aids-surveillance-europe-2021-2020-data>
- European Centre for Disease Prevention and Control/WHO Regional Office for Europe, 2022, *HIV/AIDS surveillance in Europe 2022 – 2021 data*. Forthcoming on 30 November 2022 at www.ecdc.europa.eu
- Fontela et al., 2020, *Trends and causes of mortality in a population-based cohort of HIV-infected adults in Spain: comparison with the general population*. Scientific Reports, 10 (8922). Available at: <https://www.nature.com/articles/s41598-020-65841-0>
- HIV Outcomes, 2021, *Co-morbidities*. Available at: <https://hivoutcomes.eu/wp-content/uploads/2021/07/Factsheet-4-Comorbidities-2-1.pdf>
- Kornilova M, Roshchupkin G., 2019, *Assessment of the Availability of PrEP, the Main Barriers to Implementing PrEP, and Scaling Up PrEP in the EECA Region*. Tallinn: Eurasian Coalition on Male Health.
- Sabin, C. A. & Reiss, P., 2017, *Epidemiology of ageing with HIV: What can we learn from cohorts?* AIDS 31, S121–S128. Available at: <https://pubmed.ncbi.nlm.nih.gov/28471942/>
- Stengaard et al., 2021, *HIV seroprevalence in five key populations in Europe: a systematic literature review, 2009 to 2019*. Euro Surveill. 26(47):pii=2100044. Available at: <https://doi.org/10.2807/1560-7917.ES.2021.26.47.2100044>
- UNAIDS, 2020, *2025 AIDS Targets*. Available at: <https://aidstargets2025.unaids.org/>
- UNAIDS/UNDP, 2019, *Still not welcome: HIV-related travel restrictions*. Available at: www.unaids.org/sites/default/files/media_asset/hiv-related-travel-restrictions-explainer_en.pdf
- World Health Organization, 2022, *Chronic comorbidities & coinfections among PLHIV*. Available at: <https://www.who.int/teams/global-hiv-hepatitis-and-stis-programmes/hiv/treatment/chronic-comorbidities-and-coinfections>
- World Health Organisation, 2022, *WHO Coronavirus (COVID-19) Dashboard*. Available at: <https://covid19.who.int>

ANNEX 1. Continuum of care for people living with HIV in the countries of Europe and central Asia: number of people and targets reported by 2021

WHO Region	Country	All PLHIV	Diagnosed	Treated	Virally suppressed	90-90-90 targets			90-81-73 targets		
						% of PLHIV who are diagnosed	% of diagnosed PLHIV on ART	% on ART who are virally suppressed	% of PLHIV who are diagnosed	% of PLHIV on ART	% of PLHIV who are virally suppressed
West	Andorra										
	Austria	7 655	7 209	6 574	4 873	94%	91%	74%	94%	86%	64%
	Belgium	19 090	17 090	15 750	15 312	90%	92%	97%	90%	83%	80%
	Denmark	6 700	6 100	5800	5 700	91%	95%	98%	91%	87%	85%
	Finland	3 265	3 069	29 07	2 736	94%	95%	94%	94%	89%	84%
	France	178 700	154 600	147 500	141 400	87%	95%	96%	87%	83%	79%
	Germany	90 700	79 900	76 800	74 100	88%	96%	96%	88%	85%	82%
	Greece	16 743	13 788	11 129		82%	81%		82%	66%	
	Iceland	296	291	252	245	98%	87%	97%	98%	85%	83%
	Ireland	7 200	6 500	5 700	5 400	90%	88%	95%	90%	79%	75%
	Israel	8 039	7 448	5 087		93%	68%		93%	63%	
	Italy	137 000	126 000	119 000	102 000	92%	94%	86%	92%	87%	74%
	Liechtenstein										
	Luxembourg	1 315	1 118	999	820	85%	89%	82%	85%	76%	62%
	Malta	740	555	555		75%	100%	54%	75%	75%	
	Monaco	48	48	48	48	100%	100%	100%	100%	100%	100%
	Netherlands	23 700	21 969	20 478	19 625	93%	93%	96%	93%	86%	83%
	Norway	4 455	4 100	4 020	3 938	92%	98%	98%	92%	90%	88%
	Portugal	41 889	39 778	33 163	30 842	95%	83%	93%	95%	79%	74%
	San Marino										
	Spain	151 387	131 774	128 216	115 907	87%	97%	90%	87%	85%	77%
	Sweden	8 971	8 097	7 943	7 702	90%	98%	97%	90%	89%	86%
	Switzerland	17 100	15 850	15 600	15 400	93%	98%	99%	93%	91%	90%
	United Kingdom	105 248	98 552	96 866	93 951	94%	98%	97%	94%	92%	89%
	Sub-total	805 459	722 600	688 171	640 297	90%	95%	93%	89%	85%	79%
Centre	Albania	1 433	1 102	678	561	77%	61%	83%	77%	47%	39%
	Bosnia & Herzegovina										
	Bulgaria	3 690	3 084	1 766	1 200	84%	57%	68%	84%	48%	33%
	Croatia	1 700	1 429	1 262	1 229	84%	88%	97%	84%	74%	72%

WHO Region	Country	All PLHIV	Diagnosed	Treated	Virally suppressed	90-90-90 targets			90-81-73 targets		
						% of PLHIV who are diagnosed	% of diagnosed PLHIV on ART	% on ART who are virally suppressed	% of PLHIV who are diagnosed	% of PLHIV on ART	% of PLHIV who are virally suppressed
	Cyprus	1 293	863	598		67%	69%		67%		
	Czechia	3 503	2 948	2 690	2 625	84%	91%	98%	84%	77%	75%
	Hungary	7 205	3 615			50%			50%		
	Kosovo										
	Montenegro	392	201	196	121	51%	98%	62%	51%	50%	31%
	North Macedonia	404	263	231	195	65%	88%	84%	65%	57%	48%
	Poland	18 923	15 899	13 381		84%	84%		84%	71%	
	Romania	18 000	16 486	12 644	8 064	92%	77%	49	92%	66%	33%
	Serbia	3 341	2 911	2 172		87%	75%		87%	65%	
	Slovakia	1 041	833	650	520	80%	78%	80%	80%	62%	50%
	Slovenia	806	730	708	677	91%	97%	96%	91%	88%	84%
	Turkey										
	Sub-total	32 384	27 438	21 085	13 464	85%	77%	64%	85%	65%	42%
East	Armenia	4 771	3 193	2 305	1 898	67%	72%	82%	67%	48%	40%
	Azerbaijan	9 937	7 302	5 618	4 815	73%	77%	86%	73%	57%	48%
	Belarus	28 315	22 855	18 765	16 804	81%	82%	90%	81%	66%	60%
	Estonia	6 855	5 939	4 482		87%	75%		87%	65%	
	Georgia	8 358	6 357	5 442	5 435	76%	86%	100 %	76%	65%	65%
	Kazakhstan	35 201	27 485	20 176	16 946	78%	73%	84%	78%	57%	48%
	Kyrgyzstan	9 222	7 050	4 442	3 974	76%	63%	89%	76%	48%	33%
	Latvia		5 836								
	Lithuania	3 558	2 911	1 248	967	82%	43%	77%	82%	35%	27%
	Moldova	14 474	9 679	6 810	5 913	67%	70%	87%	67%	47%	41%
	Russia	1 000 000	794 220	615 099	587 870	79%	77%	96%	79%	62%	59%
	Tajikistan	14 246	9 459	7 960	6 850	66%	84%	86%	66%	56%	48%
	Turkmenistan										
	Ukraine	257 548	176 871	146 488	137 196	69%	83%	94%	69%	57%	53%
	Uzbekistan	57 555	43 606	31 021	17 530	76%	71%	57%	76%	54%	30%
	Sub-total	1 443 18	1 110 98	865 374	806 198	77%	78%	93%	77%	60%	56%
Total		2 281 02	1 861 02	1 574 63	1 459 95	82%	85%	92%	82%	69%	64%

ANNEX 2: COUNTRY-SPECIFIC DATA ON USE OF HRQOL TOOLS AND INDICATORS

Data collection year	ECDC Region	Country Name	Which indicators, tool or index is used to measure QoL/HRQoL	Are patient reported outcomes (PROMs) used in clinical settings	Are PROMs generic, HIV specific or both	Are PROMs collected on a regular or ad hoc basis?	Disaggregation (KP=key population)	Does monitoring compare QoL of PLHIV with the general population	What year was QoL monitoring data last collected?	Frequency of data collection
2022	EU/EEA	Austria	SOPs of the Austrian HIV cohort study group (comorbidities and comedications, other QoL measures not specified)	No			None	No	2017	One-off
2020	EU/EEA	Estonia	WHO HIV-Bref QoL instrument was used, but the last time was in 2013. These data have already been reported.	PROMS questions not asked in 2020			Gender KP: MSM, sex workers, Trans people, PWID Geographical: City specific (disaggregation by migrant status, race and ethnicity not asked in 2020)	No	2013	frequency of data collection not asked in 2020
2022	EU/EEA	Germany	Medical Outcomes Study HM Health Survey (MOS-HIV); EQ-5D; Treatment Satisfaction Questionnaire for Medication (TSQM); self-administered patient questionnaire on discrimination experience	Yes	Both generic and HIV-specific	Ad hoc	Gender KP: MSM, Migrants, PWID	No	2022	Repeated surveys in prospective cohort planned every couple of years
2020	EU/EEA	Iceland	TBC	PROMS questions not asked in 2021			Gender KP: MSM, PWID (disaggregation by migrant status, race and	No	2019	frequency of data collection not asked in 2021

Data collection year	ECDC Region	Country Name	Which indicators, tool or index is used to measure QoL/HRQoL	Are patient reported outcomes (PROMs) used in clinical settings	Are PROMs generic, HIV specific or both	Are PROMs collected on a regular or ad hoc basis?	Disaggregation (KP=key population)	Does monitoring compare QoL of PLHIV with the general population	What year was QoL monitoring data last collected?	Frequency of data collection
							ethnicity not asked in 2020)			
2022	EU/EEA	Italy	Italian 2017 guidelines (enclosed) suggest to use a standardized methodology to measure health-related QoL of PLHIV (eg WHOQOL-HIV-Bref, ISS-QOL, MOS-HIV, EQ-5D). See enclosed guidelines pages 78-81.	Yes	Both generic and HIV-specific	Ad hoc	None	No	2019	Different situations in different hospitals
2020	Non-EU	Kazakhstan	concomitant diseases, hospitalizations, treatment outcomes, mortality, survival, disability	PROMS questions not asked in 2022			Gender KP: MSM, sex workers, Trans people, PWID, prisoners Geographical: Region specific and City specific (disaggregation by migrant status, race and ethnicity not asked in 2020)	Yes	2019	frequency of data collection not asked in 2022
2022	EU/EEA	Liechtenstein	Liechtenstein patients are integrated in the Swiss HIV Cohort.	No			(Swiss Cohort study)	No	2017	(Swiss Cohort study)

Data collection year	ECDC Region	Country Name	Which indicators, tool or index is used to measure QoL/HRQoL	Are patient reported outcomes (PROMs) used in clinical settings	Are PROMs generic, HIV specific or both	Are PROMs collected on a regular or ad hoc basis?	Disaggregation (KP=key population)	Does monitoring compare QoL of PLHIV with the general population	What year was QoL monitoring data last collected?	Frequency of data collection
2022	EU/EEA	Romania	Viral load and CD4 count	Yes	HIV-specific only	Ad hoc	Gender KP: PWID, Prisoners	Yes	2021	Unknown
2022	Non-EU	Serbia	Patient Surveys	No				No	2013	One-off
2022	EU/EEA	Spain	Self-rated health question, has been included in a second generation surveillance system in PLHIV in Spain in 2019. The question is "In last 12 months, would you say that your health have been..?", with five possible responses (from very good to very bad)	No			Gender KP: MSM, PWID	Yes	2019	Second generation surveillance system in PLHIV was stopped in 2020 due to COVID-19 pandemic, and restarted in 2021 (last data available)
2022	EU/EEA	Sweden	Patient surveys, collected in the quality register InfCare. Questions are: How satisfied are you with your somatic health? and: How satisfied are you with your mental health? and "How satisfied are you with your sexual health?" "Do you have any side-effects from you hiv-medications and if so how much does that affect you?"	Yes	Both generic and HIV-specific	Regular	Gender KP:MSM, Migrants, Trans people, PWID, Race+ethncity Geographical: Region specific and city specific	No	2021	The aim is that all PWH should be invited to answer the questionnaire once annually

Data collection year	ECDC Region	Country Name	Which indicators, tool or index is used to measure QoL/HRQoL	Are patient reported outcomes (PROMs) used in clinical settings	Are PROMs generic, HIV specific or both	Are PROMs collected on a regular or ad hoc basis?	Disaggregation (KP=key population)	Does monitoring compare QoL of PLHIV with the general population	What year was QoL monitoring data last collected?	Frequency of data collection
2022	Non-EU	Ukraine	WHODAS2.0	Yes	Generic only	Ad hoc	Gender Geographical: Region specific	Yes	2020	Studies are not conducted systematically.
2022	EU/EEA	United Kingdom	EQ-5D-5L (Positive Voices Survey)	No			Gender KP:MSM, Trans people, PWID Geographical: Region specific and city specific	Yes	2017	Every three years

The evolution of HIV from a fatal to a long-term condition poses challenges for people living with HIV and for health and social care systems across the EU. This paper aims to help Members of the European Parliament and other interested stakeholders to obtain a better picture of the current situation in relation to HIV among people living with HIV in the EU, HIV-related stigma and issues which impact on health-related quality of life for people living with HIV.

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