Altering the Trajectory of HIV in Europe

CONTRACT RESEARCH REPORT
JUNE 2025

Priscila Radu
Helen Hayes
Ellie Tunnicliffe
David Mott
Grace Hampson

ohe.org

NP-GBL-HVX-PPT-250008, June 2025

JUNE 2025

Altering the Trajectory of HIV in Europe

Priscila Radu
Office of Health Economics, London

Helen Hayes
Office of Health Economics, London

Ellie Tunnicliffe
Office of Health Economics, London

David Mott
Office of Health Economics, London

Grace Hampson
Office of Health Economics, London

Please cite this report as:
Radu P., Hayes H., Tunnicliffe E., Mott D., Hampson G., 2025. Altering the Trajectory of HIV in Europe. OHE Contract Research Report, London: Office of Health Economics. Available at: https://www.ohe.org/publications/altering-the-trajectory-of-hiv-in-europe/

Corresponding Author:
Grace Hampson
ghampson@ohe.org

For further information please contact:

Grace Hampson
Associate Director, OHE

Tel +44 (0)207 747 8865
Email ghampson@ohe.org

About OHE Contract Research Reports

Many of the studies OHE performs are proprietary and the results are not released publicly. Studies of interest to a wide audience, however, may be made available, in whole or in part, with the client's permission. They may be published by OHE alone, jointly with the client, or externally in scholarly publications. Publication is at the client's discretion.

Studies published by OHE as OHE Contract Research Reports are subject to internal quality assurance and undergo external review, usually by a member of OHE's Editorial Panel. Any views expressed are those of the authors and do not necessarily reflect the views of OHE as an organisation.

Funding and Acknowledgements

This contract research report was commissioned and funded by ViiV Healthcare.

Table of Contents

OFFICE OF HEALTH ECONOMICS
CONTRACT RESEARCH

Executive Summary

Despite substantial medical advancements that have transformed HIV into a manageable chronic condition for individuals, the epidemic remains a pressing public health concern in Europe. While global HIV incidence has declined by 39% since 2010, many member states of the World Health Organisation (WHO) are witnessing a rise in new diagnoses, with certain regions in Europe disproportionately affected (UNAIDS, 2024b). Alarmingly, over half of those diagnosed in the WHO European region in 2023 were identified at a late stage, and nearly a third had already progressed to an advanced stage of the disease (ECDC and WHO, 2024). For the first time, the number of new HIV infections occurring outside sub-Saharan Africa has surpassed those within the region, signalling a troubling slowdown in progress (UNAIDS, 2024b). These trends underscore the urgent need for targeted interventions, equitable healthcare access, and renewed policy efforts to curb the epidemic's trajectory across Europe.

In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) launched a strategic framework to accelerate efforts to end the HIV epidemic by 2030. This initiative was driven by global consensus and established a series of targets designed to achieve this goal (UNAIDS, 2014). A key component of this strategy is the 95-95-95 target (updated in 2021 from 90-90-90). This approach aims to ensure that 95% of people living with HIV are aware of their status, 95% of those diagnosed receive appropriate treatment, and 95% of those on treatment achieve viral suppression (UNAIDS, 2021).

This report examines the ongoing HIV epidemic in Europe, highlighting key barriers to progress towards the UNAIDS' 2030 targets and proposing solutions. We also explore the cost of continuing on the current trajectory, which we label the 'cost of complacency'.

We conducted targeted literature reviews to explore the barriers to progress, solutions, and related costs. To validate and refine our findings, we held two rounds of interviews - first with expert stakeholders, including clinicians and policymakers, and then with patient advocates. Additionally, we convened a roundtable with experts to prioritise key barriers and solutions and held two meetings with healthcare professionals to validate projected trends, cost analyses, and the quantitative impact of proposed solutions.

The cost of complacency

While HIV treatment is cost-effective, care remains expensive across Europe, with each new case adding a substantial lifetime burden to healthcare systems. The median lifetime cost of managing HIV in high income countries is estimated at $377,820 (Tran et al., 2021). Another study estimated that if 3,000 men who have sex with men had contracted HIV in 2013, their projected lifetime healthcare costs could surpass £1 billion (Nakagawa et al., 2015). Failing to provide timely prevention and treatment exacerbates the epidemic by enabling continued transmission. Ensuring individuals achieve an undetectable viral load prevents HIV transmission, ultimately reducing diagnoses and leading to cost savings.

On the current trajectory, the 2030 UNAIDS goals will not be met. Projections indicate that without additional focus and targeted intervention, the number of people living with HIV will continue to rise, leading to increases in healthcare costs and broader societal impact. The total estimated cost of HIV care between 2025 and 2030 is estimated at €56.7bn across France, Germany, Italy, Spain and Ireland. Countries where new cases are increasing will see a significant 'cost of complacency' from a health system and societal perspective. The total estimated cost of new diagnoses between 2025 and 2030 is estimated at €4.4bn across France, Germany, Ireland, Italy, Spain, Poland and the UK.

The failure to meet UNAIDS' 2030 targets will significantly increase economic and health burdens across Europe. Beyond the financial impact, addressing these challenges through early diagnosis and comprehensive care is a critical medical necessity and public health priority.

Key barriers to progress

Significant barriers continue to hinder efforts to eliminate HIV transmission in Europe. This report highlights key barriers, which exist at multiple levels:

- **Individual barriers:** Low awareness of risk and prevention methods, mistrust in healthcare systems, and adherence challenges for treatments.
- **Societal barriers:** Stigma surrounding HIV remains a major challenge, discouraging testing and treatment uptake. Regional inequalities also affect access to care.
- **Healthcare barriers:** Limited access to testing and treatment in underserved groups, availability of medication, and healthcare provider biases contribute to gaps in testing and care.
- **Policy and research barriers:** Inconsistent surveillance, lack of government commitment and funding, and insufficient research hinder the development of effective interventions.

Solutions for addressing HIV in Europe

The potential solutions to the barriers outlined in this report are diverse, and a range of approaches will be needed to get Europe back on track. However, the following five actions are vital:

1. **Expanding access to services:** It is essential that people have easy access to HIV testing, prevention, and treatment. Increasing the availability of home testing kits and outreach programs for underserved populations, as well as offering pre-exposure prophylaxis (PrEP) in safe, stigma-free, non-medical settings (such as those led by community organisations), will improve accessibility and help to prevent HIV infections. Improved access to all elements of healthcare for people living with HIV is required, beyond initial diagnosis and medical treatment.
2. **Engaging communities:** Partnering with community organisations to develop and deliver tailored and targeted education and support programs for underserved groups, will be essential for ensuring they receive the resources and services they need, preventing them from being overlooked. These organisations are often better positioned to engage diverse communities which can be out of reach of healthcare systems and services.
3. **Combating stigma:** Stigma around HIV still exists and continues to have a far-reaching impact on people living with HIV, as well as on the rate of new diagnoses. On an individual level, stigma can prevent someone from testing and accessing care and discourage adherence to medication due to fear of disclosure. Systemically, it can influence the quality of care received by people living with HIV due to biases among healthcare professionals, and socially, it can lead to isolation, as individuals may withdraw from their communities out of fear of rejection. Public awareness campaigns to combat stigma that are co-created with affected communities, use people-first language, and are targeted at both general populations and healthcare professionals, have the potential to educate and reduce prejudice and stigma.
4. **Diversifying treatment options:** PrEP and antiretroviral therapy (ART) are highly effective in preventing new infections. However, adherence to daily pills can be challenging for some people for a wide range of reasons, leading to reduced protection and risk of antiretroviral resistance. Future ART formulations with long-acting modalities may offer important options that may better align with people's preferences and ultimately improve HIV prevention, adherence, and equity of access, contributing towards the 95-95-95 targets.
5. **Strengthening data collection:** Prioritising robust data collection across Europe is essential for accurately assessing the true burden of HIV. Incomplete or inconsistent data – whether due to gaps in evidence or irregular surveillance – hampers effective policymaking and limits the ability to design targeted, impactful interventions. Special effort must be made to

address data gaps for vulnerable groups that are less visible to the healthcare system (e.g. migrants).

A strong and sustained commitment is key to addressing the HIV epidemic in Europe. This is supported by several calls to action from various stakeholders who have voiced the need for a new EU Action Plan for HIV (HIV Outcomes, 2024). The consensus was reinforced by a group of 30 stakeholders convened in the European Parliament who urged the European Commission to address pressing issues related to the HIV threat in Europe (UNAIDS et al., 2024). Additionally, members of the WHO European Region endorsed Regional action plans to end AIDS and other transmissible diseases, (WHO European Region, 2023) while G7 leaders reaffirmed their commitment to ending HIV by 2030 (G7 leaders, 2024)

Moreover, significant geopolitical and financial changes are impacting the global HIV response and consequently pose additional considerations for achieving the goal of ending HIV in Europe. In the last six months there have been significant cuts in global HIV financing from key donors. A study recently published in *The Lancet HIV* (Brink et al., 2025) has warned that the significant reductions in global HIV funding could result in over 10 million new HIV acquisitions and nearly three million deaths by 2030, threatening decades of progress in the fight against HIV. Traditional donors are reducing health commitments without proper transition planning, creating leadership vacuums, putting pressure on the EU and its Member States to demonstrate responsible and accountable leadership.

On the current trajectory, the 2030 UNAIDS goals will not be met. However, with decisive action, increased political will, and meaningful investment in prevention, treatment, and data-driven strategies, it is still possible to alter the trajectory and get Europe back on track to achieving the goal of ending the HIV epidemic.

1. Introduction

The Human Immunodeficiency Virus (HIV) epidemic has been a global health challenge for more than 40 years, causing an estimated 88 million infections and claiming over 40 million lives (UNAIDS, 2024c). HIV is a retrovirus that is transmitted from human to human through contact with infected bodily fluids, such as blood or sexual fluids. The virus enters the human cells through receptors typically present on lymphocytes – a type of blood cell that play a crucial role in the immune system. When replicating, the virus destroys these cells, leaving the host susceptible to opportunistic infections and certain cancers. If left untreated, HIV infection can lead to Acquired Immunodeficiency Syndrome, also known as AIDS, where the immune system of the infected individual is compromised and their HIV viral load is high (Bekker et al., 2023).

Despite HIV's potential to cause significant health problems, recent advances in medicine have transformed HIV into a manageable chronic condition (Boardman et al., 2024). Antiretroviral therapy (ART), which is taken by people living with HIV, can lead to viral suppression and immune restoration. Achieving and maintaining viral suppression ensures that people living with HIV cannot transmit the virus to their sexual partners. This message was effectively promoted through the U=U global health campaign, emphasising that undetectable viral load (a viral load so low that it cannot be detected by standard laboratory tests) means HIV is sexually untransmittable (Kirby, 2024).

Many individuals who start treatment early and maintain an undetectable viral load through appropriate adherence can achieve the same life expectancy as people without HIV (Wilson and Sereti, 2013). Long-term adherence and persistence to the treatment regimen is necessary to maintain viral suppression.

Pre-exposure prophylaxis (PrEP) is taken by individuals before possible exposure (usually sexual) to protect them from infection. Post-exposure prophylaxis (PEP) is taken after a high-risk exposure to the virus. Other preventative techniques to minimise the risk of exposure include condom use and other behavioural changes (Bekker et al., 2023).

1.1 Persistent challenges

Despite significant progress in tackling the HIV epidemic in the WHO European region[1], the disease remains prevalent, with high costs of care and reduced life expectancy (Kuiper and Brady, 2023). Although globally, 39% fewer people acquired HIV in 2023 compared to 2010, this high level statistic masks regional variation; for example, in eastern Europe, the number of people acquiring HIV increased (UNAIDS, 2024b). The same report revealed that for the first time, more new infections are occurring outside sub-Saharan Africa than within the region, suggesting progress is slowing down in certain parts of the world.

In 2023, there were an estimated 1.3 million new HIV infections worldwide – over three times the 2025 target of 370,000 or fewer (UNAIDS, 2024b). In the same year, roughly 113,000 HIV diagnoses were reported in the WHO European region[1] (across 47 reporting countries). Approximately 25,000 of these diagnoses were from countries within the European Union/European Economic Area (EU/EEA) (ECDC and WHO, 2024). The diagnosis rates in the WHO European region have been increasing since 2020 (per 100,000 rates: 2023 – 12.7; 2022 12.4; 2021: 12.3; 2020 12.2). The change in behaviours and access to healthcare, including HIV testing and treatment, during the acute COVID-19 pandemic are likely to have had an impact on these diagnoses trends and although rates have remained below the 2019 rate of 15.8 per 100,000 (ECDC and WHO, 2024), the increase in diagnoses seen in some countries in recent years is concerning.

---

[1] *WHO European region: comprises 53 countries, which can be found here.*
European Union (EU): comprises 27 countries, which can be found here.
European Economic Area (EEA): The EEA includes EU countries alongside Iceland, Liechtenstein and Norway.

A recent report from the European Centre for Disease Prevention (ECDC) and the WHO (ECDC and WHO, 2024) indicates that comparing the numbers of reported new HIV diagnoses with the estimated number of new cases shows that there is a growing number of people living with undiagnosed HIV in the European region, exacerbating the need to improve surveillance of the undiagnosed population and improve access to testing (Nichols and Valk, 2021). Late diagnosis of HIV is associated with higher individual mortality, morbidity and healthcare costs (Boardman et al., 2024), and increases the risk of transmitting the virus, which therefore hinders efforts to reach public health goals. It is estimated that in the WHO European region, more than half of those diagnosed in 2023, were diagnosed late, and around a third were in an advanced stage (ECDC and WHO, 2024).

In 2023, the vast majority of reporting countries from the EU/EEA region fell short of global HIV targets. These shortfalls highlight persistent gaps in HIV testing, treatment, and management, underscoring the urgent need for stronger interventions and policy action. The trends suggest that the UNAIDS 2030 targets are unlikely to be met, which will have a significant impact on the burden of illness and costs incurred.

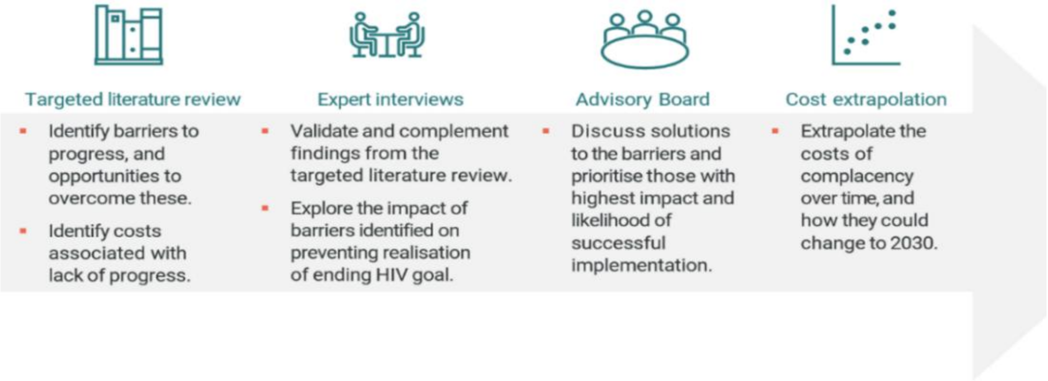
Moreover, significant geopolitical and financial changes are impacting the global HIV response and consequently pose additional considerations for achieving the goal of ending HIV in Europe. In the last six months there have been significant cuts in global HIV financing from key donors. A study recently published in *The Lancet HIV* (Brink et al., 2025) has warned that the significant reductions in global HIV funding could result in over 10 million new HIV acquisitions and nearly three million deaths by 2030, threatening decades of progress in the fight against HIV. Traditional donors are reducing health commitments without proper transition planning, creating leadership vacuums, putting pressure on the EU and its Member States to demonstrate responsible and accountable leadership.

1.2 About this report

This report aims to examine the reasons why UNAIDS 2030 targets for ending HIV in Europe are not likely to be met and to set out the cost that will be incurred as a result of the lack of progress. We explore ways in which the barriers can be overcome, including setting out how solutions and enablers could alter the trajectory of HIV in Europe.

An overview of the methods is depicted in Figure 1 and outlined in more detail in Appendix 1. The geography of interest was Europe, with specific attention paid to eight countries. Five countries were chosen as key countries in the European region (France, Germany, Italy, Spain and the UK), and the remaining three (Belgium, Ireland and Poland) were chosen because of high HIV incidence rates. Results are generalised to give an overview of the Europe-wide state of play with regards to progress towards ending HIV, with country-specific examples highlighted throughout the report.

FIGURE 1 METHODS OVERVIEW



Targeted literature review
- Identify barriers to progress, and opportunities to overcome these.
- Identify costs associated with lack of progress.

Expert interviews
- Validate and complement findings from the targeted literature review.
- Explore the impact of barriers identified on preventing realisation of ending HIV goal.

Advisory Board
- Discuss solutions to the barriers and prioritise those with highest impact and likelihood of successful implementation.

Cost extrapolation
- Extrapolate the costs of complacency over time, and how they could change to 2030.

We completed targeted literature reviews to inform the initial research, exploring the barriers and solutions to progress and identifying costs associated with lack of progress. We performed two rounds of interviews to validate and complement our findings. The first round of interviews involved expert stakeholders (including clinicians, policymakers, and payers from Spain, Portugal, Italy, Germany and the UK). The aim was to verify the relevance of our framework and that the barriers identified were complete and appropriately summarised. The second round of interviews involved seven patient advocates from Spain, Portugal, the UK and Netherlands working in the HIV field. The aim was to elicit the opinion of those working directly with people living with HIV and corroborate the relevance of our findings from the literature compared to real-world settings.

We also convened a roundtable with the experts interviewed and held sessions within two expert clinical groups comprising six healthcare professionals (HCPs) from Spain, Switzerland, Germany, the UK and the Netherlands. The aim of the roundtable was to present the barriers and solutions back to the participants and verify our alignment on the findings and finalise the results, as well as to prioritise the barriers and solutions based on magnitude of impact and ability to be overcome. The sessions focused primarily on: i) validating the projected trends and data used in the cost of complacency illustrations, and ii) validating the evidence on the quantitative impact of solutions.

2. The cost of complacency

HIGHLIGHTS

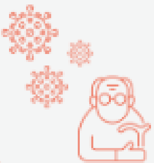
In 2023, there were an estimated **1.3 million new HIV infections**[1] worldwide - more than three times the 2025 target of 370,000 or fewer.

In the same year, **24 out of 26**[2] reporting countries from the EU/EEA fell short of the goal of 95% of PLWHIV being diagnosed.

Recent reports indicate a **growing number** of people living with **undiagnosed HIV** in the European Region.

Projected increase in cost

- Based on the linear trend between 2014-2023, the number of people living with HIV is **projected to increase**, and with that associated **healthcare system costs will also increase**.
- This is a combination of people **living longer with HIV** as well as **new HIV infections and diagnoses**.
- Continuing to tackle the HIV epidemic using the same tools and strategies is unlikely to be sufficient for meeting the UNAIDS 2030 targets.



€56.7 billion

was the total estimated cost of care between 2025 and 2030 across France, Germany, Italy, Spain and Ireland.

98,405

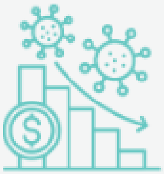
estimated new diagnoses between 2025 and 2030 across eight European countries, at an estimated additional healthcare cost of

€4.38 billion

Data gaps on cost

- There is an **evidence gap** on the wider cost and impact of HIV in Europe (non-healthcare system costs).
- New research is needed on the **societal** and **out of pocket** costs to provide a comprehensive understanding of the true cost of HIV.
- The limited available data suggests significant societal costs.

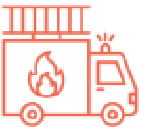
Recent uptick in diagnosis rates



- Estimated **incidence** results suggest new infections have been **steadily decreasing** across all countries.
- However recent **diagnosis** data shows a more **concerning trend** in some countries, especially in **Ireland**, the **UK** and **Poland**.

Next steps...

- There is a clear need to explore the current **barriers to progress** and the possible **solutions** to address these challenges and get us **back on track** to achieve the UNAIDS targets.



1. (UNAIDS, 2024b)
2. (ECDC, 2024)

If current efforts and available tools for tackling HIV remain unchanged, we risk falling short of global targets by 2030. There is a cost to not tackling the remaining barriers that stand in the way of eliminating new HIV infections, which we label the 'cost of complacency'.

Even if all new infections were immediately prevented, substantial costs would persist for caring for those already living with HIV. We include this baseline to provide a comprehensive economic picture of the challenge and to underscore the urgency for timely action; delays in scaling up effective interventions will drive future increases in costs as the number of people living with HIV continues to rise.

To illustrate the cost of complacency, and where we may be headed if current measures to tackle HIV are not improved, this section includes the following subsections:

1. **Costs per person living with HIV**
   A review of the evidence on the annual cost of HIV per person.

2. **Cost of complacency**
   Examination of country-specific prevalence and diagnosis trends, assigning estimated costs to future projections.

3. **New infections: Additional measures**
   Additional examination of country-specific estimates of new infections (diagnosis rates and estimated incidence).

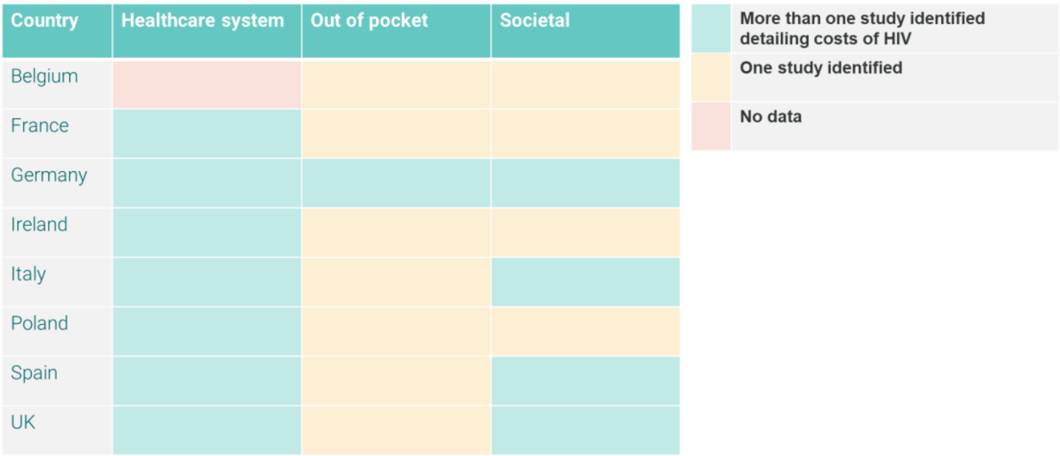
2.1 Costs per person living with HIV

Figure 2 shows the studies identified estimating the various types of costs. These include:

- **Costs to the healthcare system:** costs of treatment for people living with HIV to the healthcare system.
- **Out-of-pocket costs:** individual contributions to HIV care and treatment.
- **Societal costs:** broader societal impacts of HIV, most commonly productivity impacts due to reduced workforce engagement.

These costs were explored to demonstrate the economic burden of HIV from different perspectives. Detailed summaries of the costs for each country can be found in Appendices 2 and 3.

FIGURE 2 OVERVIEW OF AVAILABLE DATA ON THE COSTS OF HIV



Country	Healthcare system	Out of pocket	Societal
Belgium	🟥	🟨	🟨
France	🟩	🟨	🟨
Germany	🟩	🟩	🟩
Ireland	🟩	🟨	🟨
Italy	🟩	🟨	🟩
Poland	🟩	🟨	🟨
Spain	🟩	🟨	🟩
UK	🟩	🟨	🟩

🟩	More than one study identified detailing costs of HIV
🟨	One study identified
🟥	No data

Notes: In accordance with the search strategy (Appendix 1), studies older than 10 years were excluded from the results.

All costs were converted to 2023 Euros. The key findings from the literature search on the costs of HIV are provided below (see Appendix 1 for more detail on the methodology, and Appendix 3 for a full list of the costs identified).

Summary of costs identified in the literature

- Across all countries in the literature we identified, healthcare costs per person, annually, ranged from €2,637 (Poland (Zah and Toumi, 2015)) to €42,351 (Germany (Trapero-Bertran and Oliva-Moreno, 2014)).
- Pharmacological treatments, primarily antiretroviral medications, make up the largest component of medical care costs, followed by expenses for hospitalisation, outpatient and primary care consultations, and diagnostic tests (Trapero-Bertran and Oliva-Moreno, 2014).
- Societal costs per person, annually, ranged from €4,385 (Spain (Dieleman et al., 2018)) to €50,940 (UK (Trapero-Bertran and Oliva-Moreno, 2014)).
- Out-of-pocket costs per person, annually, ranged from €237 (Spain (Dieleman et al., 2018)) to €1,022 (Ireland (Dieleman et al., 2018)).
- Germany consistently reported the highest healthcare costs, while also reporting the second highest societal cost, surpassed only by the UK.
- Societal costs predominately came from one study which used a top-down costing approach (Dieleman et al., 2018) starting with broad healthcare cost data and applying assumptions to estimate costs. The results in this study were notably lower than those identified in country-specific publications which used micro-costing methodologies. Considering the country-specific studies only, societal costs were the largest of the three costs. However, there was variation in the cost components included in country-specific studies.
- Out-of-pocket costs, including transport and informal care costs borne by people living with HIV were much smaller and less frequently reported than other costs. They were not always reported separately from the societal cost, and sometimes they were converted into productivity losses and added into the total.

Cost per case of HIV varies considerably between countries

Germany reported the highest maximum average healthcare cost per case of HIV (€42,351 (Trapero-Bertran and Oliva-Moreno, 2014)), more than 15x that of Poland (€2,637 (Zah and Toumi, 2015)). Differences are driven by country specific ART eligibility criteria and reimbursement policies.

There is a lack of recent cost estimates

Few studies are available within the last five years, and often the cost data included predated this significantly. However, evidence from the expert clinical group meetings indicated that during this time there are unlikely to have been significant changes to clinical care pathways which would materially impact the cost of treatment.

Healthcare costs are the most commonly and consistently reported

Cost components from a healthcare perspective showed the least variation. They most commonly reported included cost of medications, hospitalisations, laboratory tests and diagnostic procedures.

2.2 Cost of complacency

If we do not enhance our current strategies and tools for addressing HIV, we are projected to fail to meet global targets by 2030. The consequences of inaction come at a price of new infections over the coming years, which we refer to as the 'cost of complacency.' We used illustrative projections to highlight these costs and the trajectory that might be followed if efforts are not increased.

First, we reviewed the evidence on the annual cost of HIV per person. We then examined country-specific prevalence, diagnosis and incidence trends (Table 1). We used linear projections to estimate the trajectory of new infections if the current pace is maintained. Finally, we applied healthcare system cost estimates to projections of prevalence and diagnoses to extrapolate costs. This was done to demonstrate the scale of the financial challenge if we continue on the current trajectory.

TABLE 1: PROJECTED METRICS AND SOURCES

Projected metric	Meaning	Data
Prevalence	Modelled estimates of the number of people living with HIV.	(UNAIDS, 2024a)
Cost of complacency	The number of people living with HIV, multiplied by the most recent healthcare system cost per person per year.	Various, see Table 2
Diagnosis rates	Reported number of diagnoses, per 100,000 of the population.	(ECDC and WHO, 2024)
Diagnoses	Reported number of diagnoses.	(ECDC and WHO, 2024)
Incidence	Modelled estimates of the numbers of people becoming newly infected with HIV.	(UNAIDS, 2024a)

Notes: ECDC data covers all of the countries in scope, the UNAIDs data covers France, Spain, Italy, Germany and Ireland only.

For each country, we use the *most recent* estimate of annual healthcare system costs, in the literature identified for each country, to estimate the cost of complacency (Table 2). We use healthcare costs as they are the most comparable across countries in terms of the cost components included.

TABLE 2: ANNUAL HEALTHCARE SYSTEM COST ESTIMATES PER PERSON LIVING WITH HIV (MOST RECENT LITERATURE)

	France	Germany	Ireland	Italy	Spain	United Kingdom	Poland	Belgium
EUR (2023)	16,030	20,833	12,095	13,597	9,577	13,802	2,637	No data
Source	Prodel, et al. (2021)	Vijver, et al. (2019)	O Murchu, et al. (2021)	Ferrario, et al. (2020)	López Seguí, et al. (2023)	Ong, et al. (2019)	Zah and Toumi (2015)	

Notes: Estimated healthcare system costs per person are not directly comparable as they are retrieved from various sources. However, of all costs considered, healthcare system cost components offered the highest level of comparability. All costs have been adjusted to 2023 EUR.

2.2.1 Cost of complacency: Prevalence

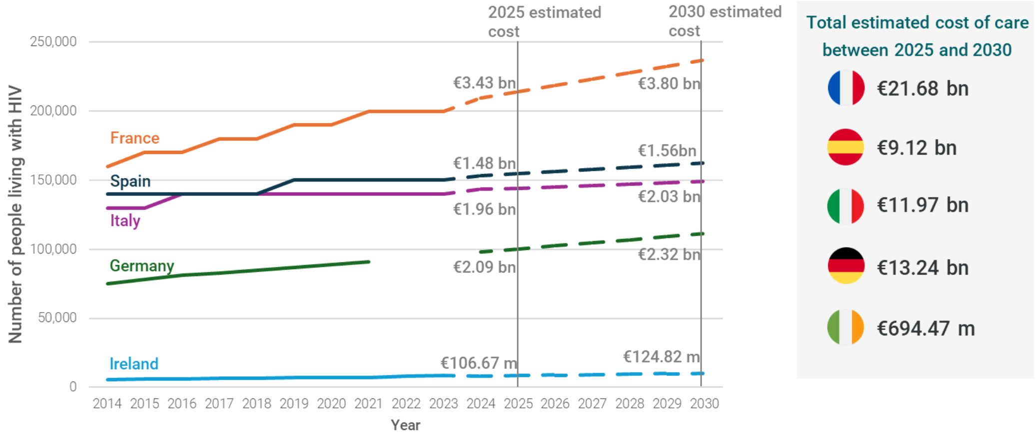
Prevalence estimates the number of people living with HIV (current cases, allowing for new cases and people dying from HIV). Prevalence is used to examine trends in the number of people living with HIV and to estimate the cost to healthcare systems over time of HIV, which we refer to as the cost of complacency.

The prevalence of people living with HIV (UNAIDS, 2024a) is projected to increase, driven by new infections, and people living longer with HIV. As such, the cost of complacency is also projected to increase (Figure 3)

Between 2025 and 2030, we estimate the cost of complacency to increase by 10.8% in France (€3.43bn to €3.8bn), 5.4% in Spain (€1.48bn to €1.56bn), 3.6% in Italy (€1.96bn to €2.03bn), 11% in Germany (€2.09bn to €2.32bn) and 17% in Ireland (€106.67m to €124.82m). The total estimated cost of care between 2025 and 2030 is calculated as the sum of the cost of complacency across these five years. Across all countries this is estimated at €56.7bn (€21.68bn, €13.24bn, €11.97bn, €9.12bn, and €694.47m in France, Germany, Italy, Spain and Ireland, respectively).

Cost projections do not account for potential future changes to costs, for example due to inflation impacting on the price of components of care, or people with HIV living longer, with increasingly complex care needs, or changing treatment options. Therefore, these are likely to be a conservative estimate of the future cost burden of HIV. For detail on the methods see Appendix 1.

FIGURE 3 PROJECTED POPULATION AND ASSOCIATED COST OF COMPLACENCY OF PEOPLE LIVING WITH HIV (ESTIMATED DIAGNOSED AND UNDIAGNOSED)



Notes: The solid line represents reported estimates (UNAIDS, 2024a). UNAIDS data does not include estimates for the UK, Poland or Belgium. The dashed line illustrates a projected trend, calculated by extending the linear trend observed between 2014 and 2023 forwards to 2030. The estimated cost of care is calculated by the annual number of people living with HIV multiplied by the annual estimated cost per person living with HIV.

Cost of complacency using reported (diagnosed) cases in the UK

The estimated prevalence of HIV for the UK, Poland, and Belgium is not included in UNAIDS figures. In countries such as the UK, data is reported based on diagnosed cases receiving care; in 2023, the number of individuals receiving HIV care in the UK was 107,949 (UKHSA, 2024). While this figure is substantial compared to estimated prevalence figures in other countries, it does not account for undiagnosed cases and is therefore not directly comparable with UNAIDS prevalence estimates presented in the Figure 3.

Based on the linear trend in this data between 2014 and 2023, there will be an estimated 110,990 cases in 2025 (with an associated cost of €1.52bn) and 122,283 estimated cases by 2030 (with an associated cost of €1.69bn). This amounts to a total estimated cost of care between 2025 and 2030 of €9.66bn for the UK.

2.2.2 Cost of complacency: New diagnoses

Diagnosis figures are an incomplete estimate of annual new infections due to surveillance gaps and undiagnosed or late diagnosed cases (i.e. they capture infections that may have occurred during previous years). However, this is useful when looking at a cost of complacency estimate for the cost of new cases, as it is only when diagnosis occurs that the cost to the healthcare system of a person living with HIV is incurred.

The number of people becoming newly diagnosed with HIV shows a concerning recent uptick (Figure 4). The potential impact of COVID-19 can be seen in the sharp drop in diagnoses in many countries in 2020 (France, the UK, Spain, Italy, Germany and Poland). Since then, we have seen a subsequent large increase in diagnoses in 2022/2023 in the UK, France, Germany, Italy, Poland, and Ireland. This recent increase in diagnoses will, to some degree, capture late diagnoses (that were missed during COVID-19). However, missed diagnoses may also have had an impact on transmission rates in vulnerable populations where individuals were not aware of their status. There may also be a number of other factors contributing to this increase such as testing rates, access to timely diagnosis, or changes in migration.

Figure 4 also presents country-level projections in diagnosis numbers, based on historical data. In an attempt to reflect the inherent uncertainty in future diagnoses, we present three linear projections based on:

- 2019-2023 data, extrapolating the recent uptick in diagnosis, adjusted for a pre-COVID baseline year,
- 2014-2023 data, extrapolating the longer-term historical trend,
- 2020-2023 data, extrapolating the post-COVID trend in diagnoses.

More detail on the selection of these three scenarios can be found in the methods in Appendix 1.

Based on the 2019-2023 projection, the UK, Poland and Ireland show the steepest future trajectory in diagnoses. Assuming trends follow a more conservative trajectory based on 2014-2023 data, there is still a projected increase in Ireland, Poland and Belgium. No country is on track to reach zero new diagnoses by 2030 based on any trajectory. This highlights the importance of intervention strategies to prevent the steeper trajectories from being realised.

FIGURE 4 PROJECTED NUMBER OF NEW HIV DIAGNOSES PER YEAR

Note: Dark grey lines present actual reported data. The three coloured projections correspond to projected trends based on an extrapolated linear trend of 2014-2023. 2019-2023 and 2020-2023.

Table 3 expresses:

- the number of new diagnosed HIV cases between 2025 and 2030,
- the healthcare cost of these diagnoses that will be incurred within this period,
- the additional lifetime costs of new infections occurring between 2025 and 2030.

These figures are calculated using the most conservative linear trend (based on 2014-2023 data), the annual healthcare costs of HIV (Table 2), and the median cost of managing HIV in high income countries (Tran et al., 2021).

The table shows that the total additional cost of new diagnosed cases between 2025 and 2030 amounts to more than €4bn across all countries. The additional lifetime costs of new infections occurring between 2025 and 2030 could reach nearly €36bn across all countries.

TABLE 3: PROJECTED LIFETIME COSTS OF NEW INFECTIONS BETWEEN 2025 AND 2030

	France	Germany	Ireland	Italy	Belgium	Spain	Poland	UK	Total
Total new diagnoses (2025-2030)	19,868	14,712	5,587	3,870	5,270	13,295	15,123	20,679	**98,405**
Additional costs (incurred in 2025-2030)	1.16bn	1.10bn	228m	242m		475m	134m	1.04bn	**4.38bn**
Additional costs (lifetime for new diagnoses within 2025-2030 period)	7.19bn	5.32bn	2.02bn	1.40bn	1.91bn	4.81bn	5.47bn	7.48bn	**35.59bn**

Notes: Median lifetime cost of managing HIV in high income countries is used for all countries (Tran et al., 2021) (377,820 2021 USD= 361,712.05 in 2023 EUR)

Adopting the more pessimistic 2019-23 and 2020-23 trends, estimated costs could reach as high as £7bn and £9bn respectively in terms of additional healthcare costs incurred between 2025-2030. This would amount to £59bn and £82bn respectively in terms of lifetime costs for infections incurred over the period 2025-2030 (full details are provided in Appendix 4). However, given disruptions with case detection during and following the COVID-19 pandemic, and the increased movement of people within and from outside the European region following this period, these later trends and figures should be interpreted with caution (ECDC and WHO, 2024).

2.3 New infections: Additional measures

Additional metrics such as diagnosis rates (per 100,000 of the population) and incidence (estimated occurrences of diagnosed and undiagnosed new infections) can also help to provide a complete picture of current and future trends in new HIV infections.

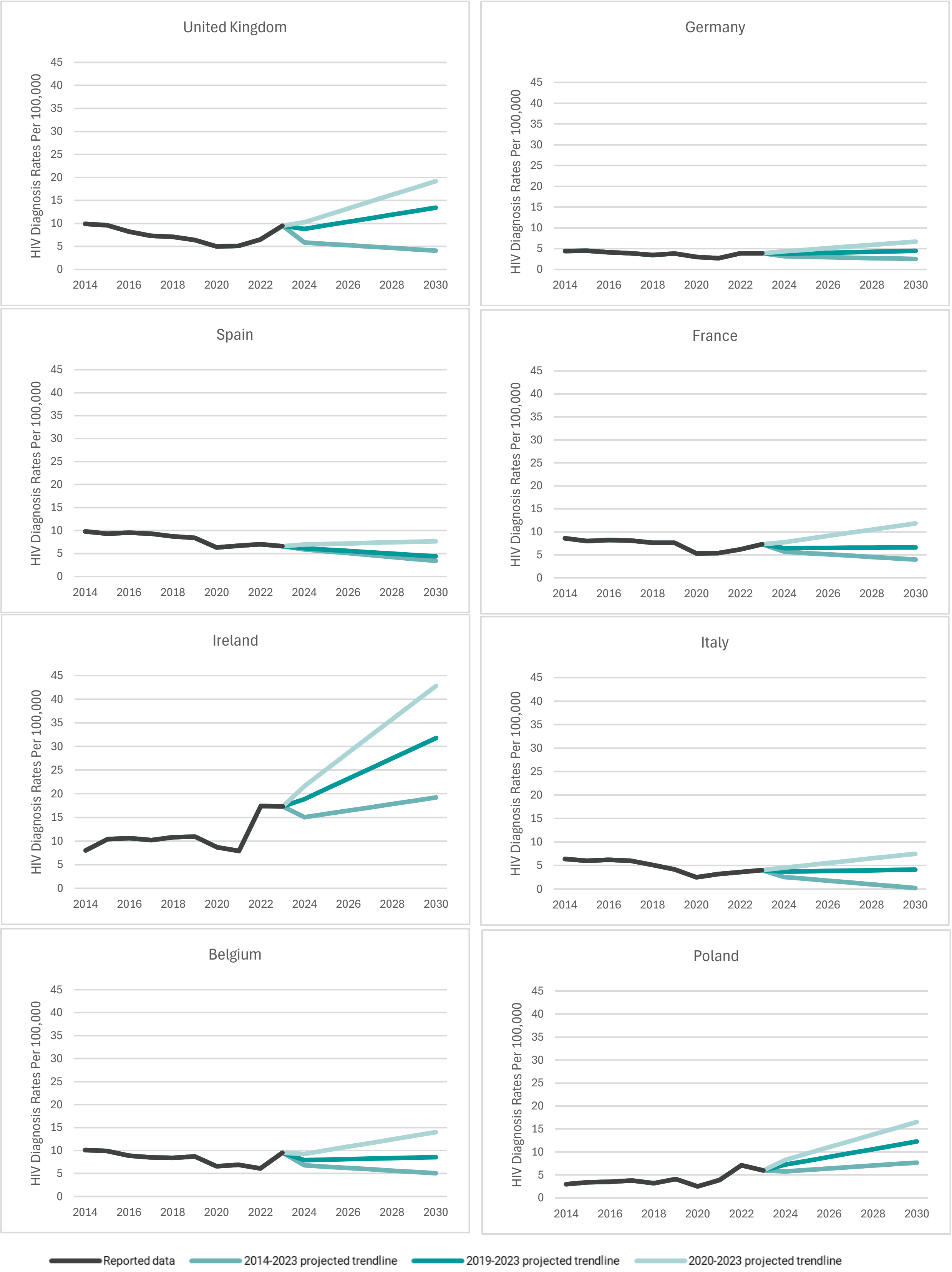
2.3.1 Projected trends in diagnosis rates

Examining projected trends in diagnosis rates, expressing numbers of diagnoses relative to the population size, allows for an easier comparison between countries to measure progress (Figure 5).

Ireland, though lowest in absolute numbers, had the highest diagnosis rates per 100,000 of the population, and exhibits a concerning recent trend of an increase in diagnosis rates. The UK and Poland have also seen a relatively high uptick in diagnosis rates in recent years (2021 to 2023). No country is on track to reach close to a zero diagnosis rate by 2030 based on any trajectory.

FIGURE 5 PROJECTED DIAGNOSIS RATES (PER 100,000 OF THE POPULATION)

Note: Dark grey lines present actual reported data. The three coloured projections correspond to projected trends based on an extrapolated linear



2.3.2 Projected trends in incidence

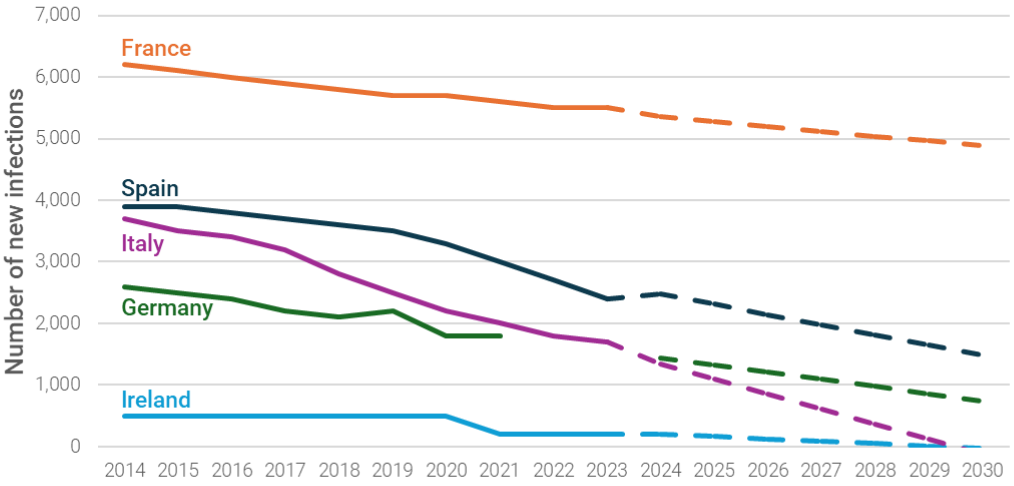
Estimated incidence measures the underlying (diagnosed and undiagnosed) number of new infections within the population, through epidemiological modelling. Modelling is required as exact numbers for incidence are inherently unknowable. While diagnosis data are available for all countries, estimated incidence data are only available for a subset of countries (France, Spain Italy, Germany, and Ireland).

Despite the concerning uptick in reported diagnoses, these modelled incidence estimates from UNAIDS (Figure 6) show a slowly decreasing trend in infection rates across key European markets between 2014 and 2023.

As set out in the introduction to this report, incidence is not decreasing quickly enough to meet existing targets. Based on projections of current trends in estimated incidence (UNAIDS, 2024a), we are not on track to see incidence at zero by 2030 in key markets across Europe, except Italy (Figure 6). These illustrative trends provide a simplified projection of where modelled UNAIDS estimates of incidence may be by 2030 if the current slope persists. This does not imply that (for example) we predict that Italy will achieve zero incidence by 2030, but rather that, if trends from the past nine years were to continue, this could be their reality.

Even though modelled infection rates are in gradual decline, the observed rising diagnosis rates presents immediate challenges for healthcare systems through increased treatment costs and demand on services. Furthermore, while widely used by global health authorities such as UNAIDS, ECDC and WHO, these models have limitations and may not fully capture recent changes in transmission patterns in certain populations. We are yet to see if the recent surge in diagnoses captures a backlog of previously undetected cases, changes in testing or migration, or a genuine increase in transmission that will be reflected in future incidence modelling estimates.

FIGURE 6 PROJECTED INCIDENCE



Notes: The solid line represents reported estimates (UNAIDS, 2024a). The dashed line illustrates a projected trend, calculated by extending the linear trend observed between 2014 and 2023 forwards to 2030. UNAIDS data does not include estimates for the UK, Poland or Belgium. For detail on the methods see Appendix 1.

3. Barriers and solutions

HIGHLIGHTS

Barriers

Barriers occur at **individual**, **societal**, **healthcare**, and **policy** levels, affecting different **stages** of the HIV care pathway and **at-risk groups**.

- Healthcare barriers include limited access to **diagnosis**, **treatment**, and **preventative** medicine, especially outside medical settings.
- **Poor data collection** hinders tracking of HIV burden, disproportionately overlooking groups like migrants.
- **Low awareness** of HIV **risk**, services, and **non-medical prevention strategies** remains a key challenge.
- **Stigma** is a major societal barrier, difficult to quantify, complicating efforts to address it.

Limited **community involvement** restricts access to HIV education, prevention, and treatment; outreach should be more targeted and relatable.

Solutions

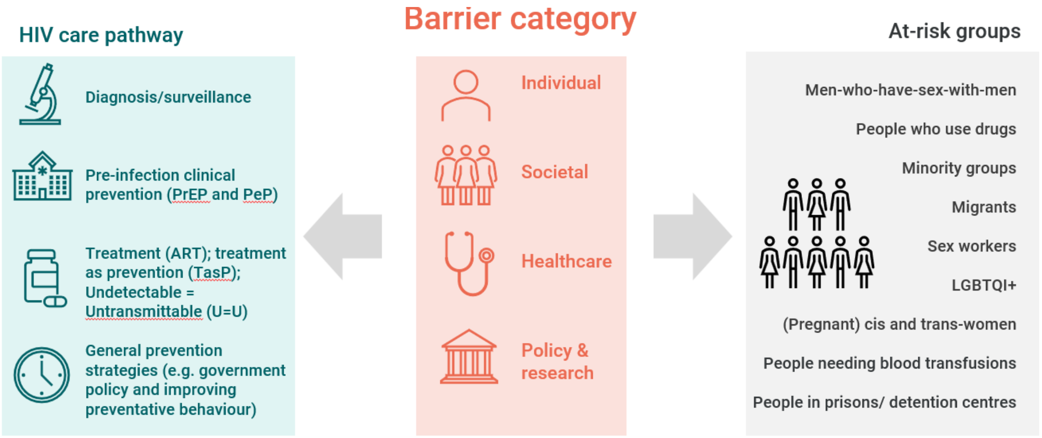
- Expanding diagnosis and treatment **beyond clinical settings** (e.g., offering PrEP in communities) can improve uptake.
- **Diversifying treatment options**, including long-acting modalities, can ease the burden of HIV management.
- Increasing access to **varied HIV testing methods**, such as home kits and community testing.
- Strengthening collaboration with **at-risk communities** and providing clear, educational messaging.
- Enhancing stigma-related data collection and **promoting targeted campaigns** to reduce misconceptions.
- **Standardizing data collection** and sharing platforms across countries to improve tracking and response.

3.1 Barriers framework overview

We first categorise the barriers by the levels at which they take place: individual, societal, healthcare and policy. We then sub-group these barriers based on the stage within the HIV care pathway that they affect, i.e., general prevention strategies, pre-clinical prevention, diagnosis and treatment stages. Lastly, we identify the groups that are most at risk of being disproportionately affected by a given barrier, compared to the general population at risk[2]. This provides the basis of the barriers framework which is depicted in Figure 7. A full list of the barriers identified and considered is outlined in Figure 8.

The barriers discussed in this report were chosen because of their impact on meeting the UNAIDS 2030 targets of eliminating HIV transmission in Europe by 2030. They were initially selected from the evidence found in the literature, followed by validation through expert interviews (see detail in Section 1.1). The interviews clarified the significance of each of the barriers on reaching the goal of ending the HIV threat in Europe and filled in gaps in the knowledge, based on their own expertise.

FIGURE 7 BARRIERS FRAMEWORK



Individual barriers refer to personal factors or challenges that limit someone from effectively engaging in behaviours or accessing services designed to reduce their risk of HIV or for HIV treatment.

The **societal barriers** relate to challenges driven by societal norms and expectations.

The **healthcare barriers** relate to challenges driven by shortcomings in the current healthcare systems, including in guidelines, staff training and access to medication. Healthcare barriers revolve around the availability of, and access to, diagnosis and treatment or preventative medicine, both in general, but also specifically outside of clinical or medicalised settings.

The **policy and research barriers** relate to challenges driven by limited resources in the current political and academic systems.

---

[2] *Minority groups, as defined by the European Commission: A non-dominant group which is usually numerically less than the majority population of a State or region regarding their ethnic, religious or linguistic characteristics and who (if only implicitly) maintain solidarity with their own culture, traditions, religion or language [Link].*

3.2 Solutions framework

Having pinpointed the barriers considered crucial to driving the stagnation in progress towards the 2030 UNAIDS goal of eliminating HIV, we sought to identify potential solutions to these challenges. We identified the solutions from the available evidence in the literature. Initially, we indirectly gathered evidence on the potential solutions from those proposed to the barriers identified when performing our initial targeted literature review (TLR). We also investigated solutions directly by interrogating how specific barriers are tackled in certain regions. Similarly to the barriers, the solutions that we found were validated by a group of experts during a roundtable[3]. The roundtable participants provided their insights on the importance of these solutions and their potential to bring us closer to the elimination of HIV in Europe. They also proposed suggestions to fill in the gaps in the available literature based on their expertise.

Some of the solutions spanned across the barriers categories and were applicable to more than one barrier. An example of this was the introduction of opt-out testing in areas of high HIV prevalence, which could be done in response to barriers in healthcare, policy and research and individual categories. As such, the solutions did not fit neatly in the categories proposed for the barriers. Therefore, we categorised the solutions based on the following criteria:

Awareness and education

Data collection and surveillance

Access to healthcare services

Community support services

Our analysis identified a substantial number of barriers, along with an even greater number of potential solutions to address them. However, previous modelling work indicates that implementing these solutions in isolation would require an impractically large scale-up to achieve zero transmission (Massey et al., 2023). Therefore, we recommend a comprehensive, multi-faceted policy approach that simultaneously targets prevention, screening, and treatment to meet the ambitious goal of ending the HIV epidemic. While we present solutions in response to specific barriers, we emphasise that an integrated strategy is the most effective path to achieving these objectives.

---

[3] *Some members of the roundtable who were not able to attend the session were interviewed separately afterwards.*

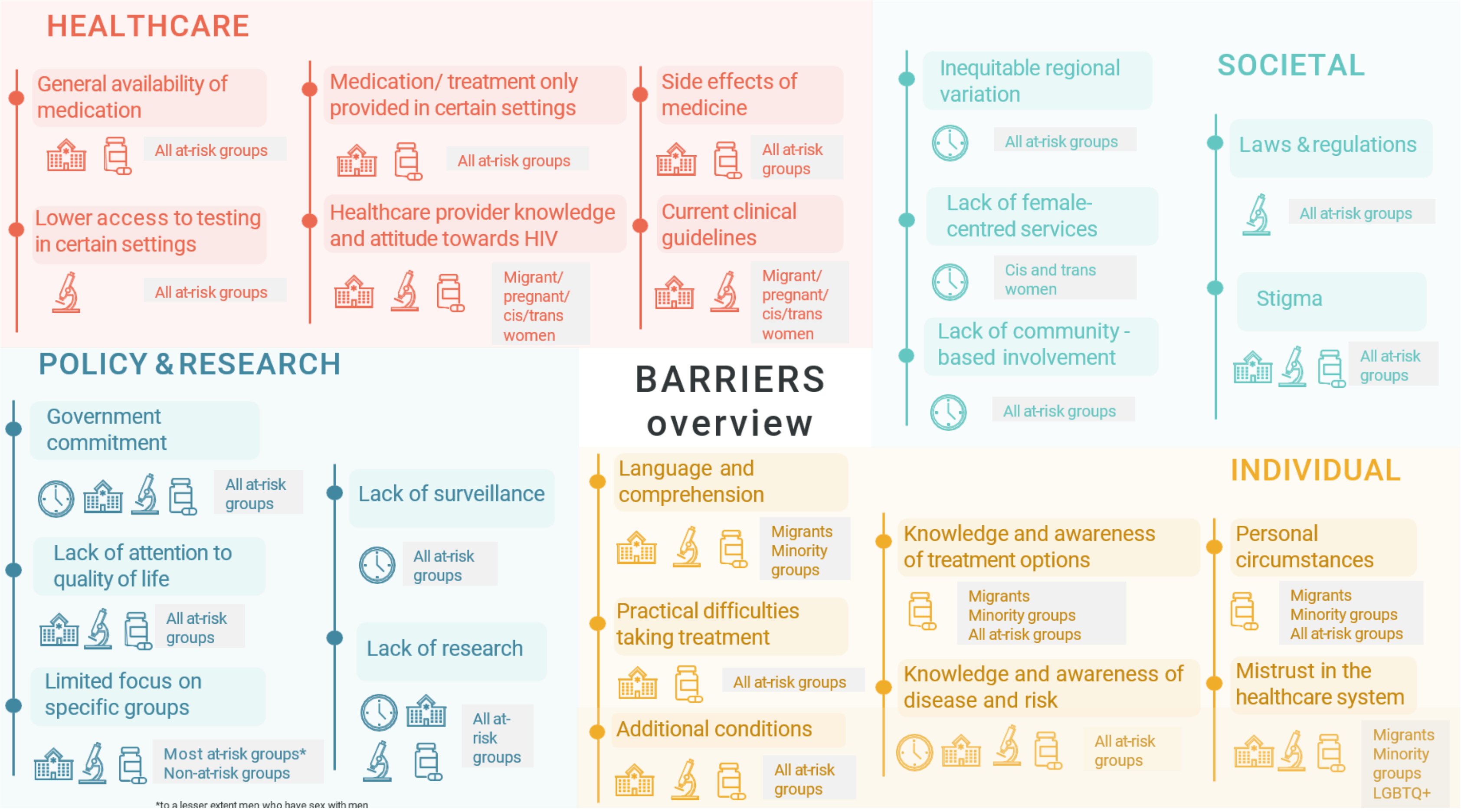


FIGURE 8 BARRIERS OVERVIEW

3.3 Individual barriers

Individual barriers refer to personal factors or challenges that limit someone from effectively engaging in behaviours or accessing services designed to reduce their risk of HIV or for HIV treatment. A summary of these barriers in presented in Table 4 and a more detailed explanation of the barriers, with proposed solutions to address these barriers are explored in this section.

The individual barriers generally impact a person's interaction with the diagnosis and treatment stages of the care pathway, although some individual factors impact general prevention strategies. Many individual barriers are particularly prevalent in certain high-risk groups, such as migrants, minority ethnic groups and LGBTQI+ individuals. Individual barriers were perceived as generally having a high level of impact by interviewees. Some barriers were viewed as being relatively easy to address, while others were seen as requiring complex solutions. Solutions to individual barriers generally entail patient education and increasing awareness on good management and treatment adherence.

Key takeaways

Barriers

- The main barriers are individual knowledge of disease, including low perceived risk, and awareness of available services to address concerns (Owusu et al., 2023; Whelan et al., 2023).
- Language barriers and mistrust in healthcare services are barriers experienced by specific underserved groups, including migrants and people from other minorities (Owusu et al., 2023; Celum and Baeten, 2020; Kuiper and Brady, 2023).
- Personal circumstances, such as socioeconomic status and personal beliefs, can prevent people from starting or adhering to treatment (Glendinning et al., 2019).
- Other practical barriers such as remembering to take pills daily and physical repulsion to medication were noted (Van Landeghem et al., 2023; de los Rios et al., 2020; Glendinning et al., 2019).

Solutions

- Provide sexual-education programmes in school to promote a culture of safe practice and understanding (KPMG, 2019; Kuiper and Brady, 2023).
- Increase research and development of modalities which are long-acting to improve adherence (Celum and Baeten, 2020; Sherman, 2024).
- Increase collaboration with communities (especially those comprising at-risk groups) and provide educational material to inform and tackle misconceptions surrounding spread, management and treatment of HIV (Boardman et al., 2024).
- Determine effective interventions for people with mental illness living with HIV including medication and improving social welfare to minimise the compounding effects of mental health (Gooden et al., 2022).

TABLE 4 INDIVIDUAL BARRIERS

BARRIER	HIV CARE PATHWAY IMPACTED	AT-RISK GROUPS	SOLUTIONS
Language and comprehension e.g., incl. explicit consent for HIV testing	▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	Migrants Minority groups	▪ Integrating translation and interpretation services. ▪ Simplifying consent procedures and removal of the need for written consent, replacing it with verbal consent.
Mistrust in the healthcare system e.g., distrust of new medicines	▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	Migrants Minority groups LGBTQI+	▪ Addressing feelings of mistrust that may arise from communication barriers in migrant or minority groups. ▪ Introducing peer-led community support and community-based services to encourage access to healthcare services.
Knowledge and awareness e.g., about the disease and how it is spread; low perceived risk	▪ General prevention strategies ▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	All at-risk groups	▪ Community involvement and collaboration with healthcare services to increase awareness and de-stigmatise HIV. ▪ Awareness campaigns aimed at all populations aiming to reduce the focus on specific communities and increasing awareness amongst those that underestimate their own risk. ▪ Opt-out testing in high-prevalence areas. ▪ Including additional blood-borne diseases testing to HIV testing.
Knowledge and awareness e.g., about treatment options	▪ Treatment	All at-risk groups In particular, Migrants and Minority groups	▪ Patient education on benefits of good HIV management and consequence of poor adherence to treatment. ▪ Clarifying the rights of migrants to access healthcare, specifically sexual health and HIV services.
Practical difficulties in taking treatment e.g., adherence to medication schedule, size, taste of pills	▪ Pre-infection clinical prevention ▪ Treatment	All at-risk groups	▪ Diversifying treatment options for ART and increased use of long-acting modalities. ▪ Patient education on benefits of good HIV management.
Personal circumstances e.g. religious beliefs	▪ Treatment	All at-risk groups In particular, Migrants and Minority groups	▪ Communicate the rationale of treatment adherence in a way that makes sense to individuals and does not conflict with their existing beliefs. ▪ Offer subsidies (e.g., bus fares) to support people accessing care.
Additional conditions e.g. mental health	▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	All at-risk groups	▪ Apply a holistic approach to care to ensure personalised medical attention is targeting the needs of the individual. ▪ Determining effective interventions for people with mental illness living with HIV including medication and improving social welfare.

3.4 Societal barriers

The societal barriers relate to challenges driven by societal norms and expectations. A summary of these barriers in presented in Table 5, and a more detailed explanation of the barriers, alongside proposed solutions to minimise the effects of these barriers are explored in the rest of this subchapter.

The societal barriers identified fall into two broad categories – those that affect everyone equally and those that affect specific groups of people in a disproportionate way. As such, some of the barriers have been perceived as moderately impactful by the interviewees, while others have been perceived as having a great effect. The solutions to these barriers are thought to be reliant on society's willingness to change its attitudes towards issues surrounding HIV. The feasibility of making significant strides in achieving these solutions depends on the dedication of the members of society and their power to convince decisionmakers to take action towards achieving HIV targets.

Key takeaways

Barriers

- A key societal barrier prominent in the literature and spanning across the barrier categories was stigma (Kuiper and Brady, 2023; Boardman et al., 2024; Glendinning et al., 2019; Vaughan, Power and Sixsmith, 2020; de los Rios et al., 2020; Shirley-Beavan et al., 2020; Noori et al., 2021).
- Stigma is hard to quantify and measure, adding an additional level of complexity to strategies for addressing it.
- Laws and regulations surrounding HIV transmission can lead individuals to avoid seeking diagnosis (European HIV Legal Forum, 2023; Owusu et al., 2023).
- Social exclusion and stigma are particularly harmful for women who use drugs, leading them to avoid harm-reduction services (Shirley-Beavan et al., 2020).
- Inequitable regional variation and limited community-based involvement are additional barriers to helping mitigate barriers to accessing HIV services for local communities (Anderson, 2019; Deblonde et al., 2018).

Solutions

- Increase data collection and reporting on stigma to promote understanding trends, populations at risk and need for action (Kuiper and Brady, 2023, DHSC, 2021).
- Eliminate legal matters surrounding the need for written consent for HIV testing, making verbal consent acceptable (Kuiper and Brady, 2023) or introducing opt-out testing in locations with high prevalence (DHSC, 2021).
- Promote public campaigns and community-specific outreach programmes to inform and reduce misconceptions and stigma around HIV (Kuiper and Brady, 2023).
- Increase funding for, and empower community-based services to play a bigger part in, supporting access to HIV services for local communities.

TABLE 5 SOCIETAL BARRIERS AND SOLUTIONS

BARRIER	HIV CARE PATHWAY IMPACTED	AT-RISK GROUPS	SOLUTIONS
Stigma e.g., influencing likelihood of accessing diagnosis or treatment	▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	All at-risk groups	▪ Prioritising the collection of data on stigma levels and discrimination experienced by people living with HIV and using tools such as the stigma index to quantify these. ▪ Incorporating HIV awareness education in healthcare and school settings. ▪ Running campaigns to train healthcare staff on stigma and discrimination. ▪ Using people-first language, emphasising the person before their disability.
Laws and regulations e.g., criminalisation of HIV	▪ Diagnosis	All at-risk groups	▪ Advocating for the decriminalisation of HIV and HIV-related phenomena, such as drug use or sex work. ▪ Ensuring that the media is trained to use accurate, judgement-free language around people living with HIV when reporting on these cases. ▪ Raising awareness among the general public on latest scientific developments and concepts such as 'U equals U'.
Inequitable regional variation e.g., urban vs rural	▪ General prevention strategies	All at-risk groups	▪ Examining current inequalities and tracking progress. ▪ Angling policy focus towards lower priority areas.
Lack of holistic women's health services e.g., for harm reduction, health and social services	▪ General prevention strategies	Cis and trans-women	▪ Reducing the stigma and structural violence experienced by cis and transgender women and gender non-conforming people who use drugs.
Lack of community-based involvement e.g., local groups advocating for specific communities	▪ General prevention strategies	All at-risk groups	▪ Increasing funding and diversifying financing to support the work that HIV advocacy groups undertake, beyond specific projects.

3.5 Healthcare barriers

The healthcare barriers relate to challenges driven by shortcomings in current healthcare systems, including in guidelines, staff training and access to medication. A summary of these barriers is presented in Table 6, and a more detailed explanation of the barrier, alongside proposed solutions to minimise the effects of these barriers are described in this subchapter.

Healthcare barriers were perceived as particularly impactful by the interviewees, generally affecting the majority of the population, unlike other categories that have a greater impact on specific groups. The solutions to these barriers are likely to be reliant on healthcare professionals' attitudes to change and increased interest and financial commitment from decision makers to facilitate these changes.

Key takeaways

Barriers

- Healthcare barriers revolve around availability of and access to diagnosis and treatment/or preventative medicine (Paternoster, 2024; Kuiper and Brady, 2023).
- Restricting diagnosis and treatment services to medicalised settings can disproportionately affect certain groups with lower access to healthcare (Hayes et al., 2019; EMA, 2024; Van Landeghem et al., 2023; Tribaudeau and Eyvrard, 2024; ECDC and WHO, 2023).
- Provider knowledge and clinical guidelines (Whelan et al., 2023) can also prevent specific groups, specifically those not at high risk, from receiving appropriate care (Deblonde et al., 2018; Rodriguez-Rincon et al., 2020; Vaughan, Power and Sixsmith, 2020).
- Physical properties of the treatment, including side-effects, can affect treatment/prevention adherence (de los Rios et al., 2020).

Solutions

- Encouraging governments to look beyond medicalised settings to offer diagnosis and treatment, e.g., by offering PrEP through community-based organisations (Kuiper and Brady, 2023; KPMG, 2019).
- Expanding the availability and variety of HIV testing methods, such as improving access and awareness of home testing kits (Croxford et al., 2020; Kuiper and Brady, 2023).
- Providing tailored education programmes for healthcare professionals to advance clinical understanding and minimise stigma (Kuiper and Brady, 2023).
- The dialogue between patients and HCPs should be improved to try and minimise the impact of medication side effects, such as through the provision of tailored advice and complementary medication that can help to alleviate side effects (Glendinning et al., 2019).

TABLE 6 HEALTHCARE BARRIERS AND SOLUTIONS

BARRIER	HIV CARE PATHWAY IMPACTED	AT-RISK GROUPS	SOLUTIONS
General availability of medication e.g., availability of PrEP/PEP, drug shortages	▪ Pre-infection clinical prevention ▪ Treatment	All at-risk groups	▪ Securing long term supplies of PrEP to maintain stocks. ▪ Early intervention from the authorities to mitigate and prevent shortages. ▪ Minimising additional factors that prevent access to medication. ▪ Improving availability of, and appropriate referral to, treatment programmes.
Medication/treatment only provided in certain settings e.g., medicalised/prescribed by doctors only	▪ Pre-infection clinical prevention ▪ Treatment	All at-risk groups	▪ Enabling the expansion of PrEP access from specialised clinics to general practices, pharmacies and the community. ▪ Raising awareness amongst policymakers that access and availability are not interchangeable and why they need to be treated as different issues.
Lower access to testing in certain settings e.g., testing offered in medicalised settings	▪ Diagnosis	All at-risk groups	▪ Licensing home-testing kits more widely through Europe. ▪ Introducing HIV testing in non-traditional settings, such as prisons, addiction and misuse centres, and even at work. ▪ Normalising the act of getting tested through public health campaigns. ▪ Introducing opt-out testing in areas of high prevalence.
Healthcare provider knowledge and attitudes towards HIV e.g., certain groups being less likely to be considered for diagnosis/treatment	▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	Migrant/ pregnant/ cis and trans-women	▪ Educating HCPs on HIV transmission and infection control as part of mandatory training and through conference attendance. ▪ Instructing HCPs to offer HIV testing based on presentation, regardless of other factors and using HIV score tools, such as the DENVER HIV risk score tool, to calculate HIV risk. ▪ Routine offering of HIV testing for patients presenting with STIs. ▪ Adding electronic testing prompts in primary care settings.
Current clinical guidelines e.g., overlooking women in benefitting from PrEP	▪ Pre-infection clinical prevention ▪ Diagnosis	Migrant/ pregnant/ cis and trans-women	▪ Broadening of guidelines to include those who might be overlooked to address this inequality. ▪ Educating HCPs to offer HIV testing based on presentation, regardless of other factors and range of available choices for treatment and prevention. ▪ Introducing quotas to ensure accurate and relevant representation in early clinical trials for HIV prevention and treatment.
Side effects of medicine e.g. experienced adverse effects outweigh promise of longer-term health	▪ Pre-infection clinical prevention ▪ Treatment	All at-risk groups	▪ Improving dialogue between patients and HCPs to minimise side effects. ▪ Pharmaceutical efforts to increase access to treatment options associated with fewer side effects.

3.6 Policy and research barriers

The policy and research barriers relate to challenges driven by limited resources in the current political and academic systems. A summary of these barriers in presented in Table 7, and a more detailed explanation of the barriers, alongside some proposed solutions to minimise the effects of these barriers are explored in the rest of the section.

Policy and research barriers have been perceived as moderately impactful by the interviewees. While they generally affect a significant proportion of the people at risk of contracting HIV, their impact is less apparent at the individual level. The solutions to these barriers are thought to be reliant on decisionmakers' willingness to increase their interest and financial commitment towards the cause.

Key takeaways

Barriers

- Lack of data is a major hurdle because it prevents a comprehensive and up-to-date understanding of the disease landscape (Kuiper and Brady, 2023; Laar et al., 2019). Information on wellbeing, stigma, and quality of life is hard to estimate from limited data.
- Limited data on routes of transmission is exacerbated by lack of research into upcoming trends, such as chemsex (KPMG, 2019a).
- Lack of attention to the quality of life of people living with HIV after diagnosis could lead to lower treatment adherence, unsuppressed viral loads and the possibility of illness and transmission of HIV (Cairns, 2023).
- Government commitment is varied across Europe and HIV is not seen as a priority at the EU-level (Kuiper and Brady, 2023).
- Some less-at-risk groups are overlooked in policy and research outputs (de los Rios et al., 2020; KPMG, 2019b; Whelan et al., 2023).

Solutions

- Ensure adequate and continuous financial support is provided at the European level to cover costs for research and innovation in HIV (Kuiper and Brady, 2023).
- Prioritise data collection for vulnerable groups (Celum and Baeten, 2020) and work to recognise and minimise health inequalities (DHSC, 2021).
- Establish dedicated data-sharing platforms to exchange figures, statistics and other information between countries and promote interoperability of data sources by standardising data collection and reporting across countries (Kuiper and Brady, 2023).
- A strong and sustained commitment is essential to tackling the HIV epidemic in Europe, as emphasized by calls for a new EU Action Plan (HIV Outcomes, 2024), WHO regional efforts (WHO European Region, 2023), and G7 leaders (2024) reaffirming their support for ending HIV by 2030. While current trends indicate the 2030 UNAIDS goals will not be met, decisive action, political will, and strategic investment can still shift the trajectory toward success.

TABLE 7 POLICY AND RESEARCH BARRIERS

BARRIER	HIV CARE PATHWAY IMPACTED	AT-RISK GROUPS	SOLUTIONS
Lack of surveillance e.g., data on those affected by HIV	▪ General prevention strategies	All at-risk groups	▪ Standardising data collection and reporting within and between countries. ▪ Increasing the level of interoperability, collaboration and data sharing. ▪ Sharing successful strategies for data collection. ▪ Introducing country comparison studies.
Government commitment e.g., lack of funding, low policy priority	▪ General prevention strategies ▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	All at-risk groups	▪ Leveraging the influence and authority of the EU to drive positive change in attitudes towards the need for ending HIV by introducing a EU strategy. ▪ Devising a dedicated budget established by the European Commission to tackle the HIV epidemic. ▪ Encouraging communication between European countries on raising awareness and sharing successful strategies on reducing the burden of HIV. ▪ Ensuring constituents are raising awareness of HIV to their representatives.
Lack of research e.g., into preventative behaviour, pharmaceutical development, data monitoring	▪ General prevention strategies ▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	All at-risk groups	▪ Introducing better incentives for researchers to get involved, for example through increasing grant funding in this area. ▪ Ensuring that HIV remains a priority through awareness, advocacy and multilateral engagement. ▪ Prioritising data collection for vulnerable groups.
Limited focus on specific groups e.g., some at-risk and lower risk groups overlooked in policy and research output	▪ Pre-infection clinical prevention ▪ Diagnosis	Most at-risk groups* Not-at-risk groups	▪ Using an ‘equity approach’ to healthcare (focusing on specific groups that may struggle with access to healthcare) to ensure targeted interventions reach those who need it most.
Lack of attention to quality of life e.g., global response neglecting people living with HIV	▪ Pre-infection clinical prevention ▪ Diagnosis ▪ Treatment	All at-risk groups	▪ Creating incentive models focusing on generating value, on one hand avoiding new infections, and on the other hand, ensuring continued healthcare beyond diagnosis and initial treatment to maximise quality of life. ▪ Encouraging HCPs to inform patients about all available choices for HIV management.

**To a lesser extent men who have sex with men*

4. Prioritising solutions

HIGHLIGHTS

Barriers and solutions were assessed based on **magnitude of impact** and **feasibility**, focusing on the most pressing and achievable issues ("the arrow of attention").

Barriers within the arrow of attention included:

On an individual level, **knowledge** and **awareness** of HIV and the **risk of infection**.

On the healthcare level, **HCP knowledge** of HIV and those at risk and the fact that testing and treatment are only available in **medicalised settings**.

On a societal level, the impact of **stigma** and limited **community-based involvement** are featured as most important.

Regarding policy and research, limited **government commitment** and inconsistency in **surveillance** within and between countries.

Solutions within the arrow of attention included:

Awareness and **education**, including on the benefits of good disease management and consequence of poor treatment **adherence** and **stigma minimisation**.

In terms to access to community services, the experts suggested that community involvement and an **equity approach** were needed.

In terms of access to healthcare services, the importance of **testing** and its availability in the **simplest form**, and **diversifying treatment options**.

Regarding data collection & surveillance, introducing better **incentives for research** and **standardising data collection**, specifically on stigma.

We prioritised the barriers and solutions on two dimensions: magnitude of impact and feasibility (Figure 9), allowing us to focus on what we call "the arrow of attention". This highlights the barriers and solutions where the most impactful issues meet the most feasible solutions. The two-way approach was designed to enable decision makers to prioritise addressing the most pressing challenges and inform them of the most achievable solutions, therefore fighting HIV on two fronts.

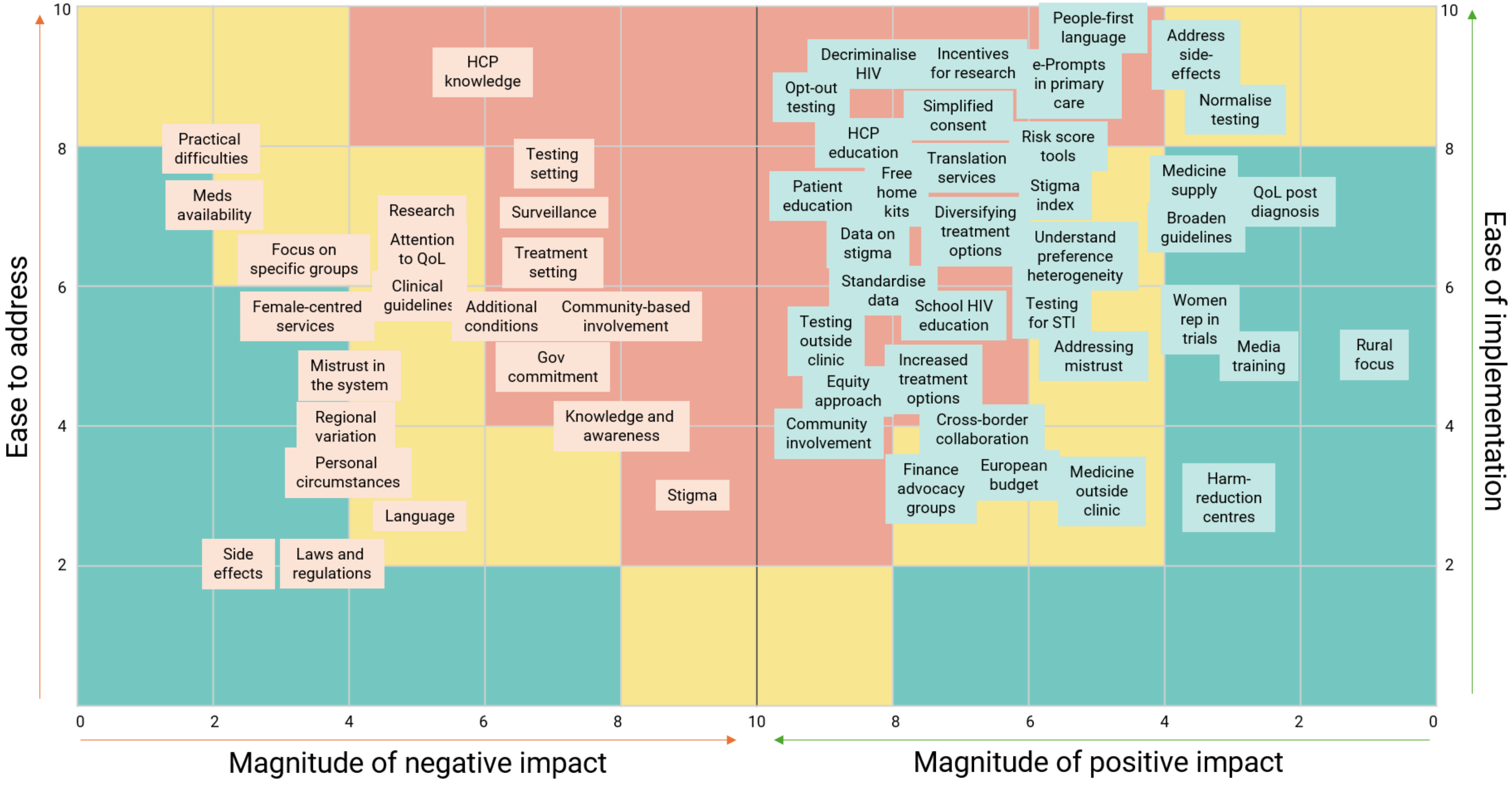
We established the ranking based on evidence from the TLRs and expert opinion. The barriers were ranked during the interviews, where experts were asked to score each barrier on a scale from one to ten in terms of how easily it could be addressed and how big its negative impact would be. The approach to ranking the solutions was slightly different to that of ranking the barriers, because of the high number of proposed solutions. To simplify the prioritisation exercise, the solutions were initially ranked within their barrier categories. To get a sense of importance of all solutions relative to each other, the participants were subsequently asked to rank the highest solutions across categories.

Barriers within the arrow of attention spanned across the four categories. Stigma emerged as the most challenging and detrimental barrier to overcome, due to its pervasive negative effects on nearly every aspect of HIV care. It discourages testing, delays treatment, reinforces discrimination, and perpetuates misinformation - ultimately contributing to further transmission and worsening health outcomes. The persistence of stigma is attributed to its deep-rooted presence in societal norms, fuelled by longstanding biases and misconceptions. Other barriers identified included: on an individual level, lack of knowledge and awareness of HIV and its transmission risk; on the healthcare level, gaps in HCP knowledge about HIV and key at-risk populations, compounded by the fact that testing and treatment are often confined to clinical settings; on a societal level, the limited involvement of community-based organisations and initiatives in HIV awareness and care; and on a policy and research level, the insufficient government commitment and inconsistencies in surveillance and data reporting within and between countries.

The solutions presented within the arrow of attention reinforced the urgent need to address these crucial issues. Among the most impactful and feasible solutions are those directly aimed at combatting stigma, including decriminalisation of HIV and HIV-related phenomena, the introduction of opt-out testing in areas of high HIV prevalence and the provision of education for HCPs. These solutions offer hope, demonstrating that meaningful steps can be taken to tackle the most pressing barrier to HIV care. Further solutions identified include enhancing awareness and education, particularly on the benefits of effective disease management, the consequences of poor treatment adherence, and strategies to minimise stigma. In terms of healthcare access, the focus was on simplifying testing procedures and diversifying treatment options to increase availability. The need for greater community involvement and an equity-based approach to improve access to services was also highlighted. Regarding data collection and surveillance, introducing stronger incentives for research and standardizing data collection, with a specific focus on stigma were highlighted.

While a broad range of potential solutions exists, only a limited number have available, quantifiable data that can be directly linked to HIV incidence. The advisory board discussions emphasised that improvements to testing represent a key enabler of progress. However, a gap was identified in the literature regarding the impact of enhanced testing on new HIV infections. Data on another key element – stigma – is widely recognised as incomplete, and its complex, multifaceted effects make it challenging to quantify in terms of its impact on incidence reduction. This has constrained our ability to conduct a comprehensive quantitative analysis of the effectiveness of key identified solutions on reducing HIV infections. Nevertheless, diversifying treatment options emerged as another promising solution within the arrow of attention, prompting further exploration into how innovation in preventative modalities, such as long-acting injectables, may contribute to reducing HIV incidence.

FIGURE 9 ARROW OF ATTENTION



[4]

---

[4] *0 = Hard to address/implement or low impact. 10 = Easy to address/implement or high impact. Left axis (pink boxes) = barriers; right axis (green boxes) = solutions.*

5. Key insights

Europe now faces a pivotal moment in its HIV response. The projections within this report demonstrate we are not on track to meet the UNAIDS 2030 goal of zero new infections: 98,405 people are estimated to be newly diagnosed with HIV across France, Germany, Ireland, Italy, Belgium, Spain, Poland and the UK between 2025 and 2030, based on historical trends.

The convergence of declining global HIV funding, weakened multilateral coordination, increased migration pressures, and a slowdown in innovation threatens to reverse decades of progress. As traditional donors retreat, the EU and its Member States must step up with renewed leadership, strategic investment, and a commitment to equity and innovation. By acting decisively, through meaningful funding, stronger partnerships, and a revitalised focus on prevention and care, Europe can safeguard its public health security and get back on track to end HIV as a public health threat by 2030.

The gravity of the task has pushed us to think beyond conventional approaches and develop innovative solutions to strengthen the collaborative HIV response within this report. The potential solutions are diverse, and a range of approaches will be needed to get Europe back on track. However, the following five actions are vital and should be prioritised by policymakers:

1. **Expanding access to services:** It is essential that people have easy access to HIV testing, prevention, and treatment. Increasing the availability of home testing kits and outreach programs for underserved populations, as well as offering PrEP in non-medical settings (e.g., checkpoints), will improve accessibility and help to slow down the rate of new HIV infections. Adequate access to all elements of healthcare for people living with HIV is required, beyond initial diagnosis and medical treatment.
2. **Engaging communities:** Partnering with community organisations to develop and deliver tailored education and support programs for key at-risk groups will be essential for ensuring they receive the resources and services they need, preventing them from being overlooked.
3. **Combating stigma:** Stigma around HIV still exists and continues to have an impact on people living with HIV, as well as on the rate of new diagnoses. Public awareness campaigns to combat stigma that are co-created with affected communities, use people-first language, and are targeted at both general populations and healthcare professionals have the potential to educate and reduce prejudice and stigma.
4. **Diversifying treatment options:** Daily oral PrEP and ART remain highly effective in preventing HIV transmission. Expanding the range of innovative treatment and prevention options can better align with individuals' diverse needs and preferences, supporting improved adherence and helping to further reduce transmission and improve outcomes.
5. **Strengthening data collection:** Prioritising robust data collection across Europe is essential for accurately assessing the true burden of HIV. Incomplete or inconsistent data – whether due to gaps in evidence or irregular surveillance – hampers effective policymaking and limits the ability to design targeted, impactful interventions. Special effort must be made to address data gaps for vulnerable groups that are less visible to the healthcare system (e.g. migrants).

References

Anderson, J., 2019. An assessment of HIV policy and recommendations to improve the lives of people living with, and at risk of HIV. Summary of findings from England, France, Germany, Italy and Spain.

Bekker, L.-G., Beyrer, C., Mgodi, N., Lewin, S.R., Delany-Moretlwe, S., Taiwo, B., Masters, M.C. and Lazarus, J.V., 2023. HIV infection. *Nature Reviews Disease Primers*, 9(1), pp.1–21. 10.1038/s41572-023-00452-3.

Boardman, E., Boffito, M., Chadwick, D.R., Cheserem, E., Kabagambe, S., Kasadha, B. and Elliott, C., 2024. Tackling late HIV diagnosis: Lessons from the UK in the COVID-19 era. *International Journal of STD & AIDS*, 35(4), pp.244–253. 10.1177/09564624231202287.

Brink, D.T., Martin-Hughes, R., Bowring, A.L., Wulan, N., Burke, K., Tidhar, T., Dalal, S. and Scott, N., 2025. Impact of an international HIV funding crisis on HIV infections and mortality in low-income and middle-income countries: a modelling study. *The Lancet HIV*, p.S2352301825000748. 10.1016/S2352-3018(25)00074-8.

Cairns, G., 2023. *More people with HIV in England have dropped out of care than remain undiagnosed*. [online] aidsmap.com. Available at: https://www.aidsmap.com/news/may-2023/more-people-hiv-england-have-dropped-out-care-remain-undiagnosed [Accessed 30 Aug. 2024].

Celum, C. and Baeten, J., 2020. PrEP for HIV Prevention: Evidence, Global Scale-up, and Emerging Options. *Cell Host & Microbe*, 27(4), pp.502–506. 10.1016/j.chom.2020.03.020.

Deblonde, J., Van Beckhoven, D., Loos, J., Boffin, N., Sasse, A., Nöstlinger, C., Supervie, V., Apers, H., Deblonde, J., Ķīvīte, A., Loos, J., Marty, L., Nöstlinger, C., Castro, D.R., Supervie, V., Van Beckhoven, D., and HERMETIC Study Group, 2018. HIV testing within general practices in Europe: a mixed-methods systematic review. *BMC Public Health*, 18(1), p.1191. 10.1186/s12889-018-6107-0.

Denison-Johnston, S., 2022. Why Including Women in HIV Research Matters - EGPAF. *Elizabeth Glaser Pediatric AIDS Foundation*. Available at: https://www.pedaids.org/2022/04/19/why-including-women-in-hiv-research-matters/ [Accessed 12 Aug. 2024].

DHSC, 2021. *Towards Zero - An action plan towards ending HIV transmission, AIDS and HIV-related deaths in England - 2022 to 2025*. [online] GOV.UK. Available at: https://www.gov.uk/government/publications/towards-zero-the-hiv-action-plan-for-england-2022-to-2025/towards-zero-an-action-plan-towards-ending-hiv-transmission-aids-and-hiv-related-deaths-in-england-2022-to-2025 [Accessed 30 Jul. 2024].

Dieleman, J.L., Haakenstad, A., Micah, A., Moses, M., Abbafati, C., Acharya, P., Adhikari, T.B., Adou, A.K., Kiadaliri, A.A., Alam, K., Alizadeh-Navaei, R., Alkerwi, A., Ammar, W., Antonio, C.A.T., Aremu, O., Asgedom, S.W., Atey, T.M., Avila-Burgos, L., Awasthi, A., Ayer, R., Badali, H., Banach, M., Banstola, A., Barac, A., Belachew, A.B., Birungi, C., Bragazzi, N.L., Breitborde, N.J.K., Cahuana-Hurtado, L., Car, J., Catalá-López, F., Chapin, A., Dandona, L., Dandona, R., Daryani, A., Dharmaratne, S.D., Dubey, M., Edessa, D., Eldrenkamp, E., Eshrati, B., Faro, A., Feigl, A.B., Fenny, A.P., Fischer, F., Foigt, N., Foreman, K.J., Fullman, N., Ghimire, M., Goli, S., Hailu, A.D., Hamidi, S., Harb, H.L., Hay, S.I., Hendrie, D., Ikilezi, G., Javanbakht, M., John, D., Jonas, J.B., Kaldjian, A., Kasaeian, A., Kates, J., Khalil, I.A., Khang, Y.-H., Khubchandani, J., Kim, Y.J., Kinge, J.M., Kosen, S., Krohn, K.J., Kumar, G.A., Lam, H., Listl, S., Razek, H.M.A.E., Razek, M.M.A.E., Majeed, A., Malekzadeh, R., Malta, D.C., Mensah, G.A., Meretoja, A., Miller, T.R., Mirrakhimov, E.M., Mlashu, F.W., Mohammed, E., Mohammed, S., Naghavi, M., Nangia, V., Ngalesoni, F.N., Nguyen, C.T., Nguyen, T.H., Niriayo, Y., Noroozi, M., Owolabi, M.O., Pereira, D.M., Qorbani, M., Rafay, A., Rafiei, A., Rahimi-Movaghar, V., Rai, R.K., Ram, U., Ranabhat, C.L., Ray, S.E., Reiner, R.C., Sadat, N., Sajadi, H.S., Santos, J.V., Sarker, A.R., Sartorius, B., Satpathy, M., Savic, M., Schneider, M., Sepanlou, S.G., Shaikh, M.A., Sharif, M., She, J., Sheikh, A., Sisay, M., Soneji, S., Soofi, M., Tadesse, H., Tao, T., Templin, T., Tesema, A.G., Thapa, S., Thomson, A.J., Tobe-Gai, R., Topor-Madry, R., Tran, B.X., Tran, K.B., Tran, T.T., Undurraga, E.A., Vasankari, T., Violante, F.S., Wijeratne, T., Xu, G., Yonemoto, N., Younis, M.Z., Yu, C., Zaki, M.E.S., Zhou, L., Zlavog, B. and Murray, C.J.L., 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015. *The Lancet*, 391(10132), pp.1799–1829. 10.1016/S0140-6736(18)30698-6.

ECDC, 2010. *HIV testing : increasing uptake and effectiveness in the European Union : evidence synthesis for guidance on HIV testing*. [online] LU: Publications Office. Available at: https://data.europa.eu/doi/10.2900/35250 [Accessed 8 Jul. 2024].

ECDC, 2017. *HIV treatment, care and support: monitoring implementation of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia : 2017 progress report.* [online] LU: Publications Office. Available at: https://data.europa.eu/doi/10.2900/94617 [Accessed 5 Jul. 2024].

ECDC, 2024. *Continuum of HIV care: monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia : 2023 progress report.* [online] LU: Publications Office. Available at: https://data.europa.eu/doi/10.2900/039534 [Accessed 15 Aug. 2024].

ECDC and WHO, 2023. *HIV/AIDS surveillance in Europe 2023: 2022 data.* [online] LU: Publications Office. Available at: https://www.ecdc.europa.eu/sites/default/files/documents/HIV-AIDS_surveillance_in_Europe_2023_%28_2022_data_%29_0.pdf [Accessed 16 May 2024].

ECDC and WHO, 2024. *HIV/AIDS surveillance in Europe 2024 : 2023 data*. [online] SE: European Centre for Disease Prevention and Control. Available at: https://data.europa.eu/doi/10.2900/3113714 [Accessed 29 Jan. 2025].

EMA, 2024. *Truvada | European Medicines Agency*. [online] Available at: https://www.ema.europa.eu/en/medicines/human/EPAR/truvada#authorisation-details [Accessed 5 Jul. 2024].

European Commission, 2020. *Sexuality education across the European Union: an overview*.

European HIV Legal Forum, 2023. *HIV criminalisation in the EU*. [online] Available at: https://www.nat.org.uk/sites/default/files/publications/HIV%20criminalisation%20in%20the%20EU.pdf [Accessed 5 Jun. 2024].

G7 leaders, 2024. *Apulia G7 Leaders' Communiqué*. [online] Available at: https://www.consilium.europa.eu/media/fttjqncg/apulia-g7-leaders-communique.pdf [Accessed 27 Mar. 2025].

Glendinning, E., Spiers, J., Smith, J.A., Anderson, J., Campbell, L.J., Cooper, V., Horne, R., Anderson, J., Campbell, L.J., Chalder, T., Collins, S., Cooper, V., Glendinning, E., Harfield, S., Horne, R., King, K., Leake Date, H., McCrone, P., Mosweu, I., Michie, S., Nelson, M., Perry, N., Sabin, C., Smith, J.A., Sseruma, W., Walker, S., and the SUPA Group, 2019. A Qualitative Study to Identify Perceptual Barriers to Antiretroviral Therapy (ART) Uptake and Adherence in HIV Positive People from UK Black African and Caribbean Communities. *AIDS and Behavior*, 23(9), pp.2514–2521. 10.1007/s10461-019-02670-x.

GNP+, 2024. *Country Reports*. [online] People Living with HIV Stigma Index. Available at: https://www.stigmaindex.org/country-reports/ [Accessed 9 Sep. 2024].

Gooden, T.E., Gardner, M., Wang, J., Chandan, J.S., Beane, A., Haniffa, R., Taylor, S., Greenfield, S., Manaseki-Holland, S., Thomas, G.N. and Nirantharakumar, K., 2022. The risk of mental illness in people living with HIV in the UK: a propensity score-matched cohort study. *The Lancet HIV*, 9(3), pp.e172–e181. 10.1016/S2352-3018(21)00319-2.

Hayes, R., Schmidt, A.J., Pharris, A., Azad, Y., Brown, A.E., Weatherburn, P., Hickson, F., Delpech, V., Noori, T. and Network, the E.D.D.M., 2019. Estimating the 'PrEP Gap': how implementation and access to PrEP differ between countries in Europe and Central Asia in 2019. *Eurosurveillance*, 24(41), p.1900598. 10.2807/1560-7917.ES.2019.24.41.1900598.

HIV Outcomes, 2024. *Recommit to ending the AIDS epidemic by 2030: the need for a new EU Action Plan on HIV/AIDS*. [online] Available at: https://hivoutcomes.eu/wp-content/uploads/2024/07/HIV-Outcomes_Call-to-Action_2024.pdf [Accessed 27 Mar. 2025].

Kirby, T., 2024. Bruce Richman: building the U=U movement for HIV prevention. *The Lancet*, 403(10421), p.18. 10.1016/S0140-6736(23)02699-5.

KPMG, 2019a. An assessment of HIV policy and recommendations to improve the lives of people living with, and at risk of HIV. Summary of findings from England, France, Germany, Italy and Spain.

KPMG, 2019b. *Ending the HIV epidemic in Spain*. [online] Available at: https://assets.kpmg.com/content/dam/kpmg/uk/pdf/2019/03/ending-the-hiv-epidemic-spanish-report.pdf [Accessed 14 May 2024].

Kuiper, E. and Brady, D., 2023. *Ending the HIV epidemic in Europe*. [online] Available at: https://www.epc.eu/content/PDF/2023/HIV_DP_Final.pdf [Accessed 18 Apr. 2024].

Laar, M.J. van de, Bosman, A., Pharris, A., Andersson, E., Assoumou, L., Ay, E., Bannert, N., Bartmeyer, B., Brady, M., Chaix, M.-L., Descamps, D., Dauwe, K., Fonager, J., Hauser, A., Lunar, M., Mezei, M., Neary, M., Poljak, M., Sighem, A. van, Verhofstede, C., Amato-Gauci, A.J. and Broberg, E.K., 2019. Piloting a surveillance system for HIV drug resistance in the European Union. *Eurosurveillance*, 24(19), p.1800390. 10.2807/1560-7917.ES.2019.24.19.1800390.

Massey, K., Vardanega, V., Chaponda, M., Eddowes, L.A. and Hearmon, N., 2023. Investigating zero transmission of HIV in the MSM population: a UK modelling case study. *Archives of Public Health*, 81, p.201. 10.1186/s13690-023-01178-0.

Nakagawa, F., Miners, A., Smith, C.J., Simmons, R., Lodwick, R.K., Cambiano, V., Lundgren, J.D., Delpech, V. and Phillips, A.N., 2015. Projected Lifetime Healthcare Costs Associated with HIV Infection. *PLOS ONE*, 10(4), p.e0125018. 10.1371/journal.pone.0125018.

Nichols, B.E. and Valk, M. van der, 2021. Barriers to eliminating HIV transmission in England by 2030. *The Lancet Public Health*, 6(10), pp.e699–e700. 10.1016/S2468-2667(21)00161-4.

Noori, T., Hargreaves, S., Greenaway, C., van der Werf, M., Driedger, M., Morton, R.L., Hui, C., Requena-Mendez, A., Agbata, E., Myran, D.T., Pareek, M., Campos-Matos, I., Nielsen, R.T., Semenza, J., Nellums, L.B. and Pottie, K., 2021. Strengthening screening for infectious diseases and vaccination among migrants in Europe: What is needed to close the implementation gaps? *Travel Medicine and Infectious Disease*, 39, p.101715. 10.1016/j.tmaid.2020.101715.

Owusu, M.W., Krankowska, D.C., Lourida, P. and Weis, N., 2023. Late HIV diagnosis among migrant women living in Europe — a systematic review of barriers to HIV testing. *IJID Regions*, 7, pp.206–215. 10.1016/j.ijregi.2023.03.006.

Paternoster, T., 2024. *How did Germany run low on potentially life-saving HIV medication?* [online] euronews. Available at: https://www.euronews.com/health/2024/04/13/how-did-germany-run-low-on-potentially-life-saving-hiv-medication [Accessed 23 Jul. 2024].

de los Rios, P., Okoli, C., Punekar, Y., Allan, B., Muchenje, M., Castellanos, E., Richman, B., Corbelli, G.M., Hardy, W.D., Young, B. and Van de Velde, N., 2020. Prevalence, determinants, and impact of suboptimal adherence to HIV medication in 25 countries. *Preventive Medicine*, 139, p.106182. 10.1016/j.ypmed.2020.106182.

Rodriguez-Rincon, D., Hocking, L., Parks, S., J Amato-Gauci, A. and Semenza, J., 2020. Barriers for the MSM Population to Access Testing for HIV in France, Poland, the UK and Across Europe: a Qualitative Study. *jaid*. [online] 10.17303/jaid.2020.7.101.

Sherman, E.M., Agwu, A.L., Ambrosioni, J., Behrens, G.M.N., Chu, C., Collins, L.F., Jimenez, H.R., Koren, D.E., McGorman, L., Nguyen, N.N., Nicol, M.R., Pandit, N.S., Pierre, N., Scarsi, K.K., Spinner, G.F., Tseng, A., Young, J.D. and Badowski, M.E., 2024. Consensus recommendations for use of long-acting antiretroviral medications in the treatment and prevention of HIV-1: Endorsed by the American Academy of HIV Medicine, American College of Clinical Pharmacy, Canadian HIV and Viral Hepatitis Pharmacists Network, European AIDS Clinical Society, and Society of Infectious Diseases Pharmacists. *Pharmacotherapy*, 44(7), pp.494–538. 10.1002/phar.2922.

Shirley-Beavan, S., Roig, A., Burke-Shyne, N., Daniels, C. and Csak, R., 2020. Women and barriers to harm reduction services: a literature review and initial findings from a qualitative study in Barcelona, Spain. *Harm Reduction Journal*, 17(1), p.78. 10.1186/s12954-020-00429-5.

Tran, H., Saleem, K., Lim, M., Chow, E.P.F., Fairley, C.K., Terris-Prestholt, F. and Ong, J.J., 2021. Global estimates for the lifetime cost of managing HIV. *AIDS*, 35(8), p.1273. 10.1097/QAD.0000000000002887.

Trapero-Bertran, M. and Oliva-Moreno, J., 2014. Economic impact of HIV/AIDS: a systematic review in five European countries. *Health Economics Review*, 4, p.15. 10.1186/s13561-014-0015-5.

Tribaudeau, L. and Eyvrard, F., 2024. Disparities in approaches to ART access in Europe. *The Lancet HIV*, 11(3), p.e140. 10.1016/S2352-3018(23)00334-X.

UKHSA, 2024. *HIV: annual data*. [online] GOV.UK. Available at: https://www.gov.uk/government/statistics/hiv-annual-data-tables [Accessed 18 Mar. 2025].

UNAIDS, 2014. *Fast-track - ending the HIV epidemic by 2030*. [online] Available at: https://www.unaids.org/sites/default/files/media_asset/JC2686_WAD2014report_en.pdf [Accessed 27 Feb. 2025].

UNAIDS, 2015. The critical role of communities in reaching global targets to end the AIDS epidemic.

UNAIDS, 2021. Ending inequalities and getting on track to end AIDS by 2030 — A summary of the commitments and targets within the United Nations General Assembly's 2021 Political Declaration on HIV and AIDS.

UNAIDS, 2024a. *HIV estimates with uncertainty bounds 1990-Present*. [online] Available at: https://www.unaids.org/en/resources/documents/2024/HIV_estimates_with_uncertainty_bounds_1990-present [Accessed 12 Feb. 2025].

UNAIDS, 2024b. *The Urgency of Now: AIDS at a Crossroads*. [online] Available at: https://www.unaids.org/sites/default/files/media_asset/2024-unaids-global-aids-update_en.pdf .

UNAIDS, 2024c. *UNAIDS_FactSheet_en*. [online] Available at: https://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf [Accessed 7 Feb. 2025].

UNAIDS, WHO Regional Office for Europe, Spanish Ministry of Health, Africa Advocacy Foundation, AIDeS (France), AIDS Action Europe, AIDSfonds, Alliance for Public Health (Ukraine), Asociacion Stop Sida (Spain), EuroNPUD, ESWA, ExAequo Checkpoint (Belgium), GAT Portugal, Global Fund to Fight AIDS, Tuberculosis and Malaria, ILGA Europe, IAPAC, PICUM, Polish Scientific AIDS Society, ARAS, Sophia Forum, TB Europe Coalition, TGEU, UNITE Parliamentarians Network for Global Health, ViiV Healthcare, Andriukaitis, V. and Angel, M., 2024. *Consensus Statement on actions needed from the EU to achieve ending AIDS and HIV as a public health threat by 2030*. [online] Available at: https://viivhealthcare.com/content/dam/cf-viiv/viivhealthcare/en_GB/pdf/consensus-statement-on-actions-needed-from-the-eu-to-achieve-ending-aids-and-hiv.pdf [Accessed 27 Mar. 2025].

Van Landeghem, E., Dielen, S., Semaan, A., Rotsaert, A., Vanhamel, J., Masquillier, C., Wouters, E., Wouters, K., Vuylsteke, B., Reyniers, T. and Nöstlinger, C., 2023. Insights into barriers and facilitators in PrEP uptake and use among migrant men and transwomen who have sex with men in Belgium. *BMC Public Health*, 23, p.712. 10.1186/s12889-023-15540-y.

Vaughan, E., Power, M. and Sixsmith, J., 2020. *Experiences of stigma in healthcare settings by people living with HIV in Ireland: a qualitative study*. [online] Available at: https://www.tandfonline.com/doi/epdf/10.1080/09540121.2020.1781761?needAccess=true [Accessed 14 May 2024].

Whelan, I., Strachan, S., Apea, V., Orkin, C. and Paparini, S., 2023. Barriers and facilitators to HIV pre-exposure prophylaxis for cisgender and transgender women in the UK. *The Lancet HIV*, 10(7), pp.e472–e481. 10.1016/S2352-3018(23)00080-2.

WHO European Region, 2023. *Regional action plans for ending AIDS and the epidemics of viral hepatitis and sexually transmitted infections 2022–2030*. [online] Available at: https://iris.who.int/bitstream/handle/10665/369243/9789289058957-eng.pdf?sequence=7 [Accessed 27 Mar. 2025].

Wilson, E.M.P. and Sereti, I., 2013. Immune restoration after antiretroviral therapy: the pitfalls of hasty or incomplete repairs. *Immunological Reviews*, 254(1), pp.343–354. 10.1111/imr.12064.

Zah, V. and Toumi, M., 2015. COMPARISON OF ECONOMIC AND HEALTH IMPLICATIONS FROM EARLIER DETECTION OF HIV INFECTION IN THE UNITED KINGDOM AND POLAND. (4).

Appendix 1: Methods

Targeted Literature Review
The objectives of the targeted literature review (TLR) were to identify i) current barriers and ii) solutions to progress towards eliminating HIV in Europe. To capture literature and analysis from different research angles, we first reviewed articles published since 2019 (i.e., covering the most recent five years) in journals recorded within the PubMed and Google Scholar databases. In addition to identifying peer-reviewed journal articles, we identified relevant grey literature, such as key reports and policy texts. We focused on country and international-level sources, including (but not limited to) the websites of the following key organisations:

- Joint United Nations Programme on HIV/AIDS (UNAIDS)
- Global HIV Prevention Coalition resource hub
- European AIDS Treatment Group
- European Centre for Disease Prevention and Control
- European Policy Centre

Screening
Titles and abstracts (or executive summaries) of studies identified were screened by a single researcher for inclusion against agreed criteria detailed in the scope.

Snowballing
After identifying relevant reports and articles, we applied the snowballing technique. This involves reviewing the reference and citation lists of these resources to identify further relevant resources.

Stopping rule
We identified saturation points through the snowballing process to determine the appropriate time to conclude our initial search.

Interviews
Expert interviews
The first round of interviews aimed to validate our initial findings from the TLR, verify and substantiate our barriers framework, and rank the barriers based on magnitude of impact and feasibility to address them. These interviews were conducted in the early phase of the study to ensure our understanding of the challenge aligns with expert opinion on the matter. We conducted five interviews with experts from the following five countries: Spain, Portugal, Italy, Germany and the UK. The profiles of their experts included: policy maker, ex-payer and patient advocate.

Patient advocate interviews
The second round of interviews aimed to elicit the opinion of patient advocates on the barriers and solutions found through the literature review, expert interviews and roundtable. The direct involvement of the patient advocate with people living with HIV and communities enabled us to corroborate the relevance of our findings from the literature compared to what is happening in real life. Patient advocates were presented with our findings in their near-complete form and were asked to provide their opinion regarding their accuracy. We interviewed seven patient advocates from four countries: Spain, Portugal, the UK and Netherlands.

Roundtable
Participants in the roundtable were the same as the experts interviewed at the beginning of the project. The aim of the roundtable was to present the barriers and solutions back to the participants and verify our alignment on the findings and finalise the results. We also asked the participants to rank the solutions based on magnitude of impact and feasibility of implementation. We asked them to prioritise the most impactful solutions as an indication of what experts think should be prioritised by decision-makers. Participants who were not able to attend were interviewed separately.

Expert clinical group

The expert clinical group comprised two meetings with six healthcare professionals (HCPs) from Spain, Switzerland, Germany, the UK, and the Netherlands. The first aim of the expert clinical group meetings was to validate the projected trends and data used in the cost of complacency illustrations. The second aim was to validate the evidence on the quantitative impact of solutions which were prioritised during the roundtable.

Costs of HIV

We performed a second TLR exploring the evidence for the current annual cost of HIV per person in the countries of interest over the last 10 years. This time-period was chosen to capture multiple cost estimates per country for comparison and validation, despite a lack of recent data. Results are shown in Appendix 2 & 3. Prices were converted to 2023 EUR.

Extrapolating trends

Additionally, we examined the number of people living with, and becoming newly infected with HIV, looking at country-specific prevalence, incidence and diagnosis trends between 2014 and 2023. Data on prevalence and incidence were sourced from UNAIDS (2024a). Data on diagnoses and diagnosis rates were sourced from ECDC and WHO (2024). ECDC data covers all of the countries in scope, the UNAIDs data covers France, Spain, Italy, Germany and Ireland only.

For prevalence and incidence trends, we produced illustrative projections of country-specific trends, calculated by extending the linear trend observed between 2014 and 2023, forwards to 2030. Results are presented graphically. The longer-term trend was chosen due to the relatively stable and linear nature of the reported trends over this period.

For diagnoses, we produced three scenarios of illustrative projections for each country, calculated by extending the linear trend observed between 2014 and 2023, 2019 and 2023, and 2020 and 2023 forwards to 2030. Results are presented graphically.

- The extrapolated trend for 2014 to 2023 was chosen to reflect a predicted trend following longer term historical data and for consistency with the prevalence and incidence extrapolations.
- The extrapolated trend for 2019 to 2023 focuses more on contemporary trends, capturing the recent acceleration in diagnosis rates, whilst anchoring the linear trend to a baseline, pre-COVID level.
- The extrapolated trend for 2020 to 2023 presents an extreme scenario whereby the recent (2020 onwards) uptick in trends would be projected to continue to 2030.

Cost of complacency

For prevalence projections, we applied cost estimates to obtain the future estimated costs incurred by healthcare systems if Europe continues on the current trend. We multiplied the number of projected people living with HIV by the most recent annual healthcare system cost estimate per person to arrive at these figures.

Appendix 2: Country-level costs of HIV

This appendix provides detailed summaries of the evidence identified on the cost of HIV identified in the literature, by country, which is used to illustrate the cost of complacency.

Appendix 2.1: Belgium

	Healthcare system	Out-of-pocket	Societal
Minimum estimate *(if >1 study identified)*			
Estimate *(if 1 study identified)*	-	€377[1]	€11,411[1]
Maximum estimate *(if >1 study identified)*			

Notes: Annual costs, 2023 EUR. Data on costs are examples only, retrieved from literature searches on publications in the last 10 years.

1. Dieleman, J.L., et al, 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015

There is a lack of recent data in Belgium on the healthcare system cost of caring for people living with HIV. One study in 2018 estimates the out-of-pocket expenses per year to be 377 euros, and wider societal costs to be 11,411 euros.

There is no data from a healthcare system perspective since 2001 (which was excluded from our literature search due to the 10-year limit).

Appendix 2.2: France

	Healthcare system	Out-of-pocket	Societal
Minimum estimate *(if >1 study identified)*	€16,030[3]		
Estimate *(if 1 study identified)*		€589[1]	€16,818[1]
Maximum estimate *(if >1 study identified)*	€23,452[2]		

Notes: Annual costs, 2023 EUR. Data on costs are examples only, retrieved from literature searches on publications in the last 10 years.

1. *Dieleman, J.L., et al, 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015.*
2. *Durand-Zaleski, I., et al., 2018. Costs and benefits of on-demand HIV preexposure prophylaxis in MSM.*
3. *Prodel, M., et al., 2021. Costs and mortality associated with HIV: a machine learning analysis of the French national health insurance database.*

Annual healthcare system costs for a person living with HIV in France ranged between 16,030 and 23,452 euros. One study estimated annual out-of-pocket costs to be 589 euros, and another estimated societal costs at 16,818 euros.

Data availability was a commonly cited limitation in French studies.

There was little data on resource use for people living with HIV discharged to nursing homes so costs here will be underestimated, especially considering resource use tended to increase with age.

Some cost estimates were based on regional databases because national data was not available, but the results are likely to be generalisable.

Appendix 2.3: Germany

	Healthcare system	Out-of-pocket	Societal
Minimum estimate *(if >1 study identified)*	€20,833[5]	€269[4]	€28,472[4]
Estimate *(if 1 study identified)*			
Maximum estimate *(if >1 study identified)*	€42,351[3]	€521[1]	€31,738[2]

Notes: Annual costs, 2023 EUR. Data on costs are examples only, retrieved from literature searches on publications in the last 10 years.

1. *Dieleman, J.L., et al, 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015.*
2. *Kuhlmann, A.; et al., 2015. Cost of Illness of HIV Patients under Anteretroviral Therapy in Germany – Results of the 48-Week Interim Analysis of the Prospective Multicentre Observational Study 'CORSAR'.*
3. *Trapero-Bertran, M. And Oliva-Moreno, J., 2014. Economic impact of HIV/AIDS: a systematic review in five European countries.*
4. *Treskova, M., et al., 2016. Analysis of contemporary HIV/AIDS health care costs in Germany.*
5. *Vijver, D.A.M.C. van de, et al., 2019. Cost-effectiveness and budget effect of pre-exposure prophylaxis for HIV-1 prevention in Germany from 2018 to 2058..*

Estimated annual healthcare system costs in Germany for a person living with HIV ranged between 20,833 and 42,351 euros. Out-of-pocket costs ranged between 269 and 521 euros. Societal costs ranged between 28,472 and 31,738 euros.

In Germany, healthcare costs are relatively high because they refer to those incurred to statutory health insurance and include sick pay (an indirect cost which would not be included in the healthcare system perspective in the UK for example).

Costs from a societal perspective were very similar across different studies and included productivity losses but excluded other costs like informal care.

Appendix 2.4: Ireland

	Healthcare system	Out-of-pocket	Societal
Minimum estimate *(if >1 study identified)*	€12,095[3]		
Estimate *(if 1 study identified)*		€1,022[1]	€14,817[1]
Maximum estimate *(if >1 study identified)*	€13,950[2]		

Notes: Annual costs, 2023 EUR. Data on costs are examples only, retrieved from literature searches on publications in the last 10 years.

1. *Dieleman, J.L., et al, 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015.*
2. *Brennan, A., et al., 2015. Resource utilisation and cost of ambulatory HIV care in a regional HIV centre in Ireland: a micro-costing study.*
3. *O Murchu, E., et al., 2021. Cost-Effectiveness Analysis of a National Pre-Exposure Prophylaxis (prep) Program in Ireland*

Estimated annual healthcare system costs in Ireland for a person living with HIV ranged between 12,095 and 13,950 euros. One study estimates the out-of-pocket expenses per year to be 1,022 euros, and wider societal costs to be 14,817 euros.

UK epidemiological data was used in some studies due to lack of Irish data.

In Ireland, most HIV-related care is provided in an outpatient setting so the usage (and cost) of other hospital services were not included, even though a minority of patients do use a substantial amount of other services.

Appendix 2.5: Italy

	Healthcare system	Out-of-pocket	Societal
Minimum estimate *(if >1 study identified)*	€8,230[2]	€419[1]	€4,819[1]
Estimate *(if 1 study identified)*			
Maximum estimate *(if >1 study identified)*	€15,847[4]	€874[3]	€9,971[2]

Notes: Annual costs, 2023 EUR. Data on costs are examples only, retrieved from literature searches on publications in the last 10 years.

1. *Dieleman, J.L., et al, 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015.*
2. *Trapero-Bertran, M. And Oliva-Moreno, J., 2014. Economic impact of HIV/AIDS: a systematic review in five European countries.*
3. *Ferrario, L., et al., 2020. The impact of prep: results from a multicenter Health Technology Assessment into the Italian setting.*
4. *Colombo, G.L., et al., 2013. Cost analysis of initial highly active antiretroviral therapy regimens for managing human immunodeficiency virus-infected patients according to clinical practice in a hospital setting.*

Estimated annual healthcare system costs in Italy for a person living with HIV ranged between 8,230 and 15,847 euros. Out-of-pocket costs ranged between 419 and 874 euros. Societal costs ranged between 4,819 and 9,971 euros.

There is considerable heterogeneity across studies, driven by differences in which costs were included.

Productivity losses were included in patients' out-of-pocket expenses in some cases, but in societal costs in others. The full breakdown was not provided to separate different cost components.

Not all treatment options available for HIV patients were considered in all analyses which limits their comparability.

Appendix 2.6: Poland

	Healthcare system	Out-of-pocket	Societal
Minimum estimate *(if >1 study identified)*			
Estimate *(if 1 study identified)*	€2,637[2]	€255[1]	€25,487[1]
Maximum estimate *(if >1 study identified)*			

Notes: Annual costs, 2023 EUR. Data on costs are examples only, retrieved from literature searches on publications in the last 10 years.

1. *Dieleman, J.L., et al, 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015.*
2. *Zah, V. And Toumi, M., 2015. Comparison of economic and health implications from earlier detection of HIV infection in the United Kingdom and Poland.*

Estimated annual healthcare system costs in Ireland for a person living with HIV in one study was estimated at 2,637. Another study estimated the out-of-pocket expenses per year to be 255 euros, and wider societal costs to be 25,487 euros.

Healthcare system costs in Poland were considerably lower than in other European countries because at the time of this study, a fixed annual reimbursement policy for HIV care was in place. Costs above the reimbursement threshold were considered out-of-pocket expenses (but these were not reported).

Appendix 2.7: Spain

	Healthcare system	Out-of-pocket	Societal
Minimum estimate *(if >1 study identified)*	€9,395[2]		
Estimate *(if 1 study identified)*		€237[1]	€25,487[1]
Maximum estimate *(if >1 study identified)*	€14,892[3]		

Notes: Annual costs, 2023 EUR. Data on costs are examples only, retrieved from literature searches on publications in the last 10 years.

1. *Dieleman, J.L., et al, 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015.*
2. *Reyes-Urueña, J., et al., 2018. Can we afford to offer pre-exposure prophylaxis to MSM in Catalonia? Cost-effectiveness analysis and budget impact assessment.*
3. *Trapero-Bertran, M. And Oliva-Moreno, J., 2014. Economic impact of HIV/AIDS: a systematic review in five European countries.*

Annual healthcare system costs in Spain for a person living with HIV ranged between 9,395 and 14,892 euros. One study estimated annual out-of-pocket costs to be 237 euros, and another estimated societal costs at 25,487 euros.

Drug prices and healthcare costs can vary significantly across regions in Spain. The minimum cost to the healthcare system reported here is for the Catalonia region specifically, and the authors stated this would be an underestimate for the nation as a whole.

The maximum healthcare system cost provided is an estimate based on nine different studies and may be more representative of the national cost.

Appendix 2.8: UK

	Healthcare system	Out-of-pocket	Societal
Minimum estimate *(if >1 study identified)*	€8,047[2]		€11,366[1]
Estimate *(if 1 study identified)*		€659[1]	
Maximum estimate *(if >1 study identified)*	€36,171[3]		€50,940[3]

Notes: Annual costs, 2023 EUR. Data on costs are examples only, retrieved from literature searches on publications in the last 10 years.

1. *Dieleman, J.L., et al, 2018. Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015.*
2. *Zah, V. And Toumi, M., 2015. Comparison of economic and health implications from earlier detection of hiv infection in the United Kingdom and Poland.*
3. *Trapero-Bertran, M. And Oliva-Moreno, J., 2014. Economic impact of HIV/AIDS: a systematic review in five European countries.*

Estimated annual healthcare system costs in the UK for a person living with HIV ranged between 8,047 and 36,171 euros. One study estimated the out-of-pocket expenses per year to be 659 euros. Wider societal costs ranged between 11,366 and 50,940 euros.

Studies in the UK include disease-phase information, which is lacking in many other European studies. This provides a more accurate cost estimate because resource use varies considerably at different stages of disease progression.

Appendix 3: Costs of HIV full tables

Appendix 3.1: Summary of healthcare system costs across countries

Healthcare System Costs	Reference	Year	Original currency		EUR	2023 EUR
Belgium (no data)	-	-	-	-	-	-
France	Trapero-Betran, 2014	2010	EUR	14,821.00	14,821.00	18,382.09
	Durand-zeleski et al. 2018	2016	EUR	20,000.00	20,000.00	23,451.70
	Prodel et al. 2021	2019	EUR	14,223.00	14,223.00	16,029.66
Germany	Trapero-Betran, 2014	2010	EUR	32,110.00	32,110.00	42,350.67
	Mostardt et al.2013	2008	EUR	23,298.00	23,298.00	31,164.64
	Treskova et al. 2016	2012	EUR	20,802.55	20,802.55	26,349.97
	Kuhlmann et al. 2015	2011	EUR	22,563.00	22,563.00	29,153.90
	Van de Vijver et al. 2019	2016	EUR	17,015.93	17,015.93	20,833.09
Ireland	O murchu et al. 2021	2017	EUR	10,200.00	10,200.00	12,094.61
	Brennan et al. 2015	2012	EUR	11,676.00	11,676.00	13,949.64
Italy	Trapero-Betran, 2014	2010	EUR	6,399.00	6,399.00	8,230.22
	Colombo et al 2013	2011	EUR	8,551.00	8,551.00	10,700.52
	Foglia et al. 2013	2011	EUR	8,548.00	8,548.00	10,696.77
	Angeletti et al. 2014	2011	EUR	10,077.00	10,077.00	12,610.12
	Colombo et al 2013	2012	EUR	11,734.00	11,734.00	14,250.25
	Ferrario et al. 2020	2019	EUR	11,694.86	11,694.86	13,597.11
	Colombo et al 2013	2012	EUR	13,048.39	13,048.39	15,846.50
Poland	Zah and Toumi, 2015	2013	PLN	7,629.98	1,817.74	2,636.98
Spain	Trapero-Betran, 2014	2010	EUR	11,638.00	11,638.00	14,891.69
	Reyes-Uruena et al. 2018	2015	EUR	7,820.79	7,820.79	9,395.46
	Lopez Segui et al 2023	2021	EUR	8,534.00	8,534.00	9,576.80
United Kingdom	Long et al, 2014	2012	GBP	7,793.00	9,610.67	12,877.62
	Trapero-Betran, 2014	2010	EUR	25,340.00	25,340.00	36,170.54
	Ong et al 2019	2017	GBP	9,743.67	11,114.41	13,802.25
	Zah and Toumi, 2015	2013	GBP	5,216.82	6,142.79	8,046.51

Appendix 3.2: Summary of societal costs across countries

Societal Costs	Reference	Year	Original Currency	EUR	2023 EUR
Belgium	Dieleman et al. 2018	2017	10,581.30	9,366.47	11,410.71
France	Dieleman et al. 2018	2017	16,370.30	14,490.84	16,818.13
Germany	Mostardt et al. 2013	2008	23,298.39	23,298.39	31,165.17
	Dieleman et al. 2018	2017	8,722.10	7,720.72	9,312.14
	Treskova et al. 2016	2012	22,477.57	22,477.57	28,471.66
	Kuhlmann et al. 2015	2011	24,563.00	24,563.00	31,738.12
Ireland	Dieleman et al. 2018	2017	14,117.00	12,496.24	14,817.36
Italy	Trapero-Betran, 2014	2010	7,752.56	7,752.56	9,971.13
	Dieleman et al. 2018	2017	4,601.90	4,073.56	4,819.30
Poland	Dieleman et al. 2018	2017	19,960.00	17,668.41	25,487.28
Spain	Trapero-Betran, 2014	2010	17,299.18	17,299.18	22,135.59
	Reyes-Uruena et al. 2018	2015	13,481.97	13,481.97	16,196.48
	Lopez Segui et al 2023	2021	8,976.20	8,976.20	10,073.03
	Dieleman et al. 2018	2017	4,195.40	3,713.73	4,384.75
United Kingdom	Trapero-Betran, 2014	2010	35,687.24	35,687.24	50,940.28
	Dieleman et al. 2018	2017	10,340.00	9,152.87	11,366.35

Appendix 3.3: Summary of out-of-pocket costs across countries

Out of Pocket Costs	Reference	Year	Original currency		EUR	2023 EUR
Belgium	Dieleman et al., 2018	2017	USD	349.18	309.09	376.55
France	Dieleman et al., 2018	2017	USD	572.96	507.18	588.63
Germany	Treskova et al., 2016	2012	EUR	212.23	212.23	268.83
	Dieleman et al., 2018	2017	USD	488.44	432.36	521.48
	Kuhlmann et al., 2015	2011	EUR	216.00	216.00	279.10
Ireland	Dieleman et al., 2018	2017	USD	974.07	862.24	1,022.40
Italy	Dieleman et al., 2018	2017	USD	400.37	354.40	419.28
	Ferrario et al., 2020	2019	EUR	751.94	751.94	874.25
Poland	Dieleman et al., 2018	2017	USD	199.60	176.68	254.87
Spain	Dieleman et al., 2018	2017	USD	226.55	200.54	236.78
United Kingdom	Dieleman et al., 2018	2017	USD	599.72	530.87	659.25

Appendix 4: Projected costs of new diagnoses (all trends)

PROJECTED LIFETIME COSTS OF NEW INFECTIONS BETWEEN 2025 AND 2030

	France	Germany	Ireland	Italy	Belgium	Spain	Poland	UK	Total
2014-2023 trend									
Total new diagnoses (2025-2030)	19,868	14,712	5,587	3,870	5,270	13,295	15,123	20,679	**98,405**
Additional costs (incurred in 2025-2030)	1.16bn	1.10bn	228m	242m		475m	134m	1.04bn	**4.38bn**
Additional costs (lifetime for new diagnoses within 2025-2030 period)	7.19bn	5.32bn	2.02bn	1.40bn	1.91bn	4.81bn	5.47bn	7.48bn	**35.59bn**
2019-2023 trend									
Total new diagnoses (2025-2030)	27,286	21,975	8,474	13,817	7,796	15,377	21,853	46,821	163,399
Additional costs (incurred in 2025-2030)	1.52bn	1.56bn	333.28m	649.25m	0.00m	534.85m	188.29m	2.13bn	6.92bn
Additional costs (lifetime for new diagnoses within 2025-2030 period)	9.87bn	7.95bn	3.07bn	5.00bn	2.82bn	5.56bn	7.90bn	16.94bn	59.10bn
2020-2023 trend									
Total new diagnoses (2025-2030)	41,891	29,829	10,823	22,116	10,370	21,842	28,163	62,806	227,840
Additional costs (incurred in 2025-2030)	2.22bn	2.05bn	417.67m	984.38m	0.00m	718.71m	237.71m	2.79bn	9.41bn
Additional costs (lifetime for new diagnoses within 2025-2030 period)	15.15bn	10.79bn	3.91bn	8.00bn	3.75bn	7.90bn	10.19bn	22.72bn	82.41bn

Notes: Median lifetime cost of managing HIV in high income countries is used for all countries (Tran et al., 2021) (377,820 2021 USD= 361,712.05 in 2023 EUR)

Appendix 5: Barriers and solutions

Appendix 5.1: Individual barriers and solutions

Language and comprehension

Definition	HIV care pathway impacted	At-risk groups
The impact of individuals not understanding or speaking the same language as their healthcare provider on HIV testing and treatment.	▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	Migrants Minority groups

BARRIER

Some individuals with HIV or at risk of contracting HIV may face barriers to accessing HIV testing and treatment due to not understanding or speaking the same language as their healthcare provider. This communication barrier has been specifically highlighted in migrant populations (Kuiper and Brady, 2023), where it was seen to hinder access to healthcare services, including HIV testing (Owusu et al., 2023). Furthermore, comprehension can also pose a challenge to communication even if the same language is spoken by the patient and healthcare provider (HCP). A communication barrier example which currently exists is the need for explicit written consent for HIV testing (Kuiper and Brady, 2023). This can pose a challenge to those who are not able to write. As migrant populations are one of the key populations facing barriers to HIV prevention and care in Europe, it is important that these obstacles are addressed.

SOLUTIONS

Proper integration of translation and interpretation services within sexual health clinics has been highlighted as a potential solution to reduce communication barriers (Owusu et al., 2023). The ECDC and WHO suggest simplifying consent procedures for HIV testing, to remove the need for written consent for HIV testing, and replace this with verbal consent (ECDC, 2010; Kuiper and Brady, 2023).

Mistrust in the healthcare system

Definition	HIV care pathway impacted	At-risk groups
Individuals' mistrust in the healthcare system and how this impacts seeking of medical care, including diagnosis and management of disease.	▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	Migrants Minority groups LGBTQI+

BARRIER

Some individuals may have mistrust in the healthcare system, either driven by individual experiences, knowledge of others, or knowledge of discrimination experienced by certain communities. This is particularly common in migrant, minority and LGBTQI+ groups. Mistrust in the healthcare system, and concerns of being stereotyped may contribute to reduced accessing of healthcare resources (Owusu et al., 2023), including diagnosis and management of HIV. For example, low PrEP use by young African women in trials was associated with scepticism about a new medication being *tested* *on them* (Celum and Baeten, 2020). In another study, black women voiced concerns on their general mistrust of the healthcare system, driven by previous experiences of institutional racism (Whelan et al., 2023). One study highlighted that 22% of migrant women said that they do not trust their GP (Owusu et al., 2023). Interviews suggested that LGBTQI+ communities are also likely to have trust issues linked to healthcare services because of previously faced institutional discrimination.

SOLUTIONS
Building trust in the healthcare system among certain individuals and communities is a challenging task. It requires a deep understanding of the specific communities and the reasons behind their mistrust to effectively address it. One potential solution to achieve progress in this barrier would be to address feelings of mistrust that may arise from communication barriers in migrant or minority groups. Here, integration of translation and interpretation services within sexual health clinics has been highlighted as a potential solution to increase trust (Owusu et al., 2023). Peer-led community support and community-based services could be a gateway for specific communities to encourage them to access healthcare services. However, this does not address some of the more complex and deeper causes of feelings of mistrust in certain communities.

Knowledge and awareness about the disease and how it is spread

Definition	HIV care pathway impacted	At-risk groups
How individuals' knowledge and awareness of the disease impacts their willingness to participate in testing and seek treatment.	▪ General prevention strategies ▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups

BARRIER
An individual's knowledge and awareness of the disease and how it is spread can create barriers at multiple stages of the HIV care pathway and for potentially all at-risk groups. One key component of this barrier was low perceived risk of HIV, which is particularly the case among women and some heterosexual individuals (Owusu et al., 2023; Whelan et al., 2023). Low perceived risk may reduce healthcare-seeking behaviour, therefore decreasing the likelihood of testing and seeking treatment for these populations. General lack of knowledge about HIV was also highlighted, including limited knowledge regarding symptoms associated with the condition, ways of transmission, and types of behaviours conducive to increased risk of HIV transmission (Rodriguez-Rincon et al., 2020). Sexual health education is not mandated in schools in many countries such as Spain and Italy, leading to potentially missed opportunities of education on HIV characteristics (European Commission, 2020).

SOLUTIONS
Community involvement and collaboration with healthcare services to increase awareness and de-stigmatise HIV may provide a successful strategy in removing gaps in information which inhibit access (Rodriguez-Rincon et al., 2020). The UK government aims to increase awareness and uptake by delivering the annual "HIV testing week" (DHSC, 2021). Similar such awareness campaigns aimed at all populations could be highly impactful in reducing the focus on specific communities (thereby increasing awareness amongst those that underestimate their own risk). In certain areas with high prevalence, opt-out testing in locations may be a be a viable solution (DHSC, 2021) and including additional blood-borne diseases testing to HIV testing could help minimise stigmatisation and maximise effectiveness. There are numerous ways to increase knowledge and awareness of HIV, but the challenge lies in effectively targeting the right communities and ensuring that this increased knowledge leads to changes in behaviour or engagement with healthcare services for the solution to be truly successful.

Knowledge and awareness about treatment options

Definition	HIV care pathway impacted	At-risk groups
How individuals' knowledge and awareness of the treatment options impacts their uptake and adherence to treatment.	▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups In particular, Migrants Minority groups

BARRIER
Knowledge and awareness about the types and delivery of treatment options may impact an individual's likelihood to both seek treatment and adhere to that treatment once it is offered. For example, one study reported low levels of awareness of PrEP in the UK, highlighting that 80% of participants had not heard of the therapy before (Whelan et al., 2023). The interviews suggested that migrant populations are specifically affected by this barrier as they are often not familiar with their healthcare rights and can fear hurdles in settlement applications if their HIV status is disclosed.

SOLUTIONS
Patient education on benefits of good disease management and the consequences of poor adherence to treatment have been highlighted as a successful tool to encourage treatment adherence. For example, people living with HIV who had been told by their healthcare provider about "U=U" were 33% less likely to report poor adherence to treatment (de los Rios et al., 2020). Clarifying the rights of migrants to access healthcare, specifically sexual health and HIV services is fundamental to improving detection in these groups.

Practical difficulties in taking treatment

Definition	HIV care pathway impacted	At-risk groups
Individuals' practical difficulties in taking treatment and how this impacts adherence.	▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups

BARRIER
Some individuals report practical difficulties in taking treatment, for example their consistency towards medication schedules, or issues with the size or taste of pills. This barrier to maintaining adherence to medication is impacting the success of pre-infection clinical prevention, or TasP. Women tend to have lower treatment adherence than men, which may be driven by numerous interpersonal factors making a treatment schedule more difficult to adhere to, for example being caregivers or being responsible for childbearing duties (de los Rios, 2020). Additionally, aspects such as remembering to take a pill daily and discrete storage of medication were highlighted as issues for all populations (Van Landeghem et al., 2023), alongside elements of physical repulsion including difficulties in swallowing the pills dues to their taste and size (Glendinning et al., 2019).

SOLUTIONS
Diversifying treatment options for ART could reduce this barrier by simplifying the treatment regimen and making it less burdensome on individuals living with HIV (de los Rios et al., 2020; DHSC, 2021; Sherman et al., 2024). Patient education on benefits of good disease management and consequence of poor adherence were also highlighted as a successful tool to encourage treatment adherence (de los Rios et al., 2020).

Personal circumstances

Definition	HIV care pathway impacted	At-risk groups
The interference of personal circumstances, including socioeconomic status and personal beliefs on testing and treatment adherence.	▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups In particular, Migrants Minority groups

BARRIER
There are a multitude of complex interactions of personal circumstances, including elements such as education, religion, and other personal beliefs which may impact testing and treatment adherence. A qualitative study from Glendinning (2019) identified perceptions of barriers that can limit an individuals uptake and adherence to treatment. These included conflicting views on taking ART if not feeling unwell and a lack of understanding of the importance of prevention rather than symptom management (especially when symptoms were not present yet); misconception around the fatality of the disease, generally informed by colloquial experiences of HIV-related deaths; and religious or supranatural beliefs. The interviews also highlighted the difficulty of people living in multi-person households who may want to conceal their HIV-positive status, resulting in difficulties for storing of and adhering to treatment. Interviews also highlight the importance of financial hardship and homelessness on being able to access HIV services, such as affordability of public transport.

SOLUTIONS
The interviews presented mixed responses towards how easily this barrier could be overcome, highlighting the diversity in the underlying causes that may contribute to it. The general solution is to communicate the rationale of treatment adherence in a way that makes sense to individuals living with HIV and does not conflict with their existing beliefs (Glendinning et al., 2019). However, some personal circumstances, for example relating to religion, may require a more sensitive approach. The interviews suggested subsidies to be offered (e.g., bus fares) to support people accessing care.

Additional conditions

Definition	HIV care pathway impacted	At-risk groups
The interference of additional conditions, such as comorbidities and mental health on testing and treatment adherence.	▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups

BARRIER
The challenges of additional co-morbidities, including challenges with mental health, have been brought up in interviews as an additional barrier to people living with HIV. This issue has the potential to prevent people from being aware of, and accessing the specific care they need. Mental illness is among the most common co-morbidity in people living with HIV, which is associated with non-adherence to medication and reduced retention in care (Gooden et al., 2022).

SOLUTION
A holistic approach to care was recommended to ensure personalised medical attention is targeting the needs of the individuals living with HIV. Additionally, determining effective interventions for people with mental illness living with HIV including medication and improving social welfare are crucial to minimise the compounding effects of mental health (Gooden et al., 2022).

Appendix 5.2: Societal barriers and solutions

Stigma

Definition	HIV care pathway impacted	At-risk groups
The impact of stigma on individuals seeking medical care for HIV diagnosis and treatment.	▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups

BARRIER

Stigma is highlighted as a crucial barrier, affecting numerous aspects of HIV transmission between individuals, including testing, treatment, and prevention alongside general well-being of those at risk-of, or living with HIV (Kuiper and Brady, 2023; Boardman et al., 2024). Reluctance to seek care (Kuiper and Brady, 2023), concerns about attending HIV clinics (Glendinning et al., 2019), and reduced treatment adherence (de los Rios et al., 2020) were all attributed to stigma. The impact of stigma was emphasised in all interviews, highlighting the influence that societal prejudice has on people living with HIV. While stigma can span beyond general societal prejudice, including as enacted by some healthcare practitioners (Vaughan, Power and Sixsmith, 2020), the interviews revealed that the stigma anticipated by people living with HIV was likely to be more important. Despite stigma being a universal barrier faced by all people living with HIV, it was distinctly highlighted in women who use drugs in Spain (Shirley-Beavan et al., 2020) and minority groups across Europe (Glendinning et al., 2019; Noori et al., 2021).

SOLUTIONS

Ending stigma could be arguably one of the most difficult barriers to overcome because it involves a fundamental shift in mentality for the whole population, which is unlikely to be achieved easily. Nevertheless, there are solutions which could minimise the impact of stigma, including prioritising the collection of data on stigma levels and discrimination experienced by people living with HIV (DHSC, 2021) and using tools such as the stigma index to quantify these (GNP+, 2024). Incorporating HIV awareness education in healthcare and school settings would also help boost understanding of HIV and reduce ignorance surrounding the subject, with the aim of minimising prejudice and stigma (Kuiper and Brady, 2023). Running campaigns to train healthcare staff on stigma and discrimination and how to reduce this within the healthcare settings and beyond is another critical tool to raise awareness of the issue (Boardman et al., 2024; Kuiper and Brady, 2023). Additionally, interviews highlighted the importance of using people-first language, emphasising the person before their disability, for example “people living with HIV” rather than “HIV patients”.

Lack of holistic women’s health services

Definition	HIV care pathway impacted	At-risk groups
The general of lack of holistic women’s health services and harm reduction centres.	▪ General prevention strategies	Cis and trans-women

BARRIER

There are few harm reduction centers designed specifically for cis and transgender women (or gender non-conforming people), resulting in poorly integrated services to address the needs of these populations, notably sexual and reproductive health services, services for people who have experienced gender-based violence, and childcare. This reinforces inequalities in access to services which can contribute to HIV prevention and treatment (Shirley-Beavan et al., 2020).

SOLUTIONS
Certain centres aim to address this barrier by reducing the stigma and structural violence experienced by cis and transgender women and gender non-conforming people who use drugs. The goal is for them to be considered as part of the community rather than a challenge to the community, to mitigate the perception of failure and avoid re-victimisation (Shirley-Beavan et al., 2020). While this is a known issue, more research is necessary to highlight its impact and arrive at solutions.

Laws and regulations

Definition	HIV care pathway impacted	At-risk groups
The impact of laws and regulations on individuals seeking HIV diagnosis, as well as the criminalisation of exposure and transmission for those people living with HIV.	▪ Diagnosis	All at-risk groups

BARRIER
Exposure and transmission of HIV can be criminalised in various European countries, in particular when this is judged to be deliberate or the person living with HIV has not disclosed their HIV status to their sexual partner. There is no evidence to suggest that criminalisation laws prevent new infections, rather they harm prevention efforts by increasing stigma and deterring individuals in key population from testing and knowing their status (European HIV Legal Forum, 2023). Additionally, legal issues surrounding access to healthcare for migrants and non-citizens can limit these groups' engagement with the healthcare system, therefore reducing diagnosis and treatment (Owusu et al., 2023). The interviews highlighted harsh criminalisation of HIV-related activities as a barrier, such as sex-work or drug use, particularly in countries such as Poland.

SOLUTIONS
Advocating for the decriminalisation of HIV would be the first and most important step to raise awareness on the issue and encourage decision makers to bring it up in discussion. Decriminalising HIV-related phenomena, such as drug use or sex work could also help encourage those living with HIV to come forward and seek medical help. Additionally, ensuring that the media is trained to use accurate, judgement-free language around people living with HIV when reporting on these cases would be beneficial to minimise stigma and engender change in this area. Lastly, raising awareness among the general public on latest scientific developments and concepts such as 'U equals U' and treatment as prevention would heighten general knowledge around HIV and hopefully minimise prejudice and stigma stemming from ignorance on the subject (European HIV Legal Forum, 2023).

Inequitable regional variation

Definition	HIV care pathway impacted	At-risk groups
The differences in resource, awareness and access between rural and urban settings, even within the same country.	▪ General prevention strategies	All at-risk groups

BARRIER
The striking difference in resources, awareness and access to testing and care between rural and urban areas fosters regional inequity (Anderson, 2019; Deblonde et al., 2018). The interviews revealed that specialist units to tackle the diagnosis and treatment of HIV (with Spain as an example) are generally set up in urban locations, exacerbating geographical inequalities, and that healthcare

practitioners located in rural areas may have less experience with people living with HIV than their urban counterparts. They also suggested that staff shortages, particularly infectious disease or HIV specialists are more prevalent outside of big cities, further exacerbating the problem.

SOLUTIONS
The interviews suggested that current inequalities must be examined, and progress tracked. This could take the form of comparing changes in HIV diagnoses in urban areas and rural areas and measuring the difference between these. Angling policy focus towards these lower priority areas should be at the forefront of decisionmakers' minds to close the gap between rural and urban communities and minimise regional variation in HIV care.

Lack of community-based involvement

Definition	HIV care pathway impacted	At-risk groups
The absence of the perspectives of people living with HIV from the discussion.	▪ General prevention strategies	All at-risk groups

BARRIER
The interviews revealed that there is a lack of community-based organisational involvement in the discussion around HIV and in helping to mitigate some of the barriers, such as offering PrEP in more localised settings. The participants highlighted that funding is often an issue for existing advocacy groups because financing is generally project-specific, limiting the freedom of these organisations to explore other barriers. Additionally, the interviews revealed that doctors and nurses are reluctant to allow communities to get involved in diagnosis, prevention and treatment because they do not want to "share the power" of performing these tasks and therefore risk "diluting their status". This view was mainly supported by attitudes to the profession in some parts of Europe, where hierarchy in the medical profession is upheld more strictly. Only a limited number of countries includes the voice of people living with HIV and patient advocacy groups in health technology assessment (HTA) of new medicines, exacerbating the variation of the degree of community voice involvement in reimbursement decisions for HIV medicines.

SOLUTIONS
Community-based involvement could ensure that the actions taken to curb the HIV epidemic are relevant to specific groups and that strategies to increase uptake of diagnosis and preventative methods are delivered to the right settings. Community-based services have been proven to complement the work of public health systems, successfully reaching out to marginalised populations that are sometimes underserved. Community action has the potential to translate into tangible results, change social attitudes, promote equal access and mobilise political leadership (UNAIDS, 2015), which is why it is crucial to enable it to materialise throughout Europe. The interviews suggested that increasing funding and diversifying financing to support the work that HIV advocacy groups undertake, beyond specific projects, could ensure that they can become true advocates for people living with HIV, focusing on a multitude of barriers and challenges in the field. Peer-led support would drive trust and provide models for good use of HIV services.

Appendix 5.3: Healthcare barriers and solutions

General availability of medication

Definition	HIV care pathway impacted	At-risk groups
The heterogeneity in the availability of medicines across the EU, including PrEP/PEP and ART, as well as the challenge of drug shortages.	▪ Pre-infection clinical prevention (PrEP and PEP) ▪ Treatment (ART) and treatment as prevention (TasP)	All at risk groups

BARRIER

While general availability of HIV drugs is usually not a critical barrier in European countries, countries like Germany, Belgium, Sweden, and Spain have recently reported shortages of PrEP medication (Paternoster, 2024). Other EU countries, including Italy, Portugal and Ireland reported discontinuation of PrEP programmes (Kuiper and Brady, 2023). Germany has recently reported shortages of PrEP as a result of bottlenecks in the supply of medication. These were likely caused as a result of a new regulation, based on WHO guidelines, demanding that the threshold for a specific impurity found in the active ingredient of HIV medication was lowered, leading to fewer suppliers being able to provide medicines to Europe (Paternoster, 2024). Individuals have reported being advised by their doctors to space out their doses to minimise the impact of the shortage, with the risk of lowering the level of protection provided by the medicine (Paternoster, 2024). A study based on findings from the ECDC estimated that around 500,000 men who have sex with men in the EU would use PrEP, but do not have access to it (Hayes et al., 2019). Availability of PrEP is paramount to limiting transmission of HIV, however, a 2019 study highlighted that only 14 European and Central Asian countries provide reimbursed PrEP. This was echoed by experts during the interviews and roundtable, who highlighted that although available "on paper", PrEP is not used as widely as thought in Europe. Barriers preventing those diagnosed from accessing treatments were found to be mostly related to system and service delivery, including inappropriate referral to treatment programmes, availability of treatment programmes, and integration with other services (ECDC, 2017).

SOLUTIONS

Securing long term supplies of PrEP has been suggested as a solution to maintain stocks and uphold the trust of those needing the medication. The article reporting this issue also highlighted the delayed response of the Ministry of Health in Germany to the crisis, having been warned about it in advance (Paternoster, 2024). As such, early intervention from the authorities could be a useful tool to mitigate shortages and prevent their occurrence in the future. Furthermore, minimising additional factors that prevent people from accessing medication can increase the uptake. This includes improving availability of, and appropriate referral to, treatment programmes (DHSC, 2021; ECDC, 2017).

Medication/treatment only provided in certain settings

Definition	HIV care pathway impacted	At-risk groups
The fact that medication is restricted to specific settings, which can hinder its accessibility.	▪ Pre-infection clinical prevention (PrEP and PEP) ▪ Treatment (ART) and treatment as prevention (TasP)	All at risk groups

BARRIER

In the EU, HIV medication can only be prescribed by a doctor (EMA, 2024), therefore people living with HIV would need access to the healthcare system in order to benefit from HIV medication. In many countries, they would also need health insurance to access these services. Specifically, in

Belgium, PrEP can only be reimbursed for people who have health insurance coverage, limiting the access for those who do not, and disproportionately affecting specific groups (Van Landeghem et al., 2023). As such, those that are less engaged with the healthcare systems are particularly affected by this barrier. Additionally, people who live far away from a hospital or surgery could also be at a disadvantage. A recent report looking at disparities in approaches of access to ART in Europe highlights that almost 50% of people diagnosed with HIV lack access to treatment close to their home through community pharmacies, as treatment is only offered in medicalised settings (Tribaudeau and Eyvrard, 2024). The interviews emphasised that policymakers are often focusing on general availability of treatments, but not always on accessibility by those who need them.

SOLUTIONS

The most impactful solution to this barrier would be enabling the expansion of PrEP access from specialised clinics to general practices, pharmacies and the community (Whelan et al., 2023; DHSC, 2021). The UK Action Plan towards ending HIV has highlighted efforts to explore the acceptability of delivering PrEP in different settings including drug and alcohol services, pharmacies and prisons (DHSC, 2021). The interviewees suggested shifting the question from *“Is PrEP available in your region?”* to *“Does everybody who should be using PrEP have access to it?”* to raise awareness amongst policymakers of the difference between how access and availability are not interchangeable and why they need to be treated as different issues.

Lower access to testing in certain settings

Definition	HIV care pathway impacted	At-risk groups
The fact that testing is restricted to specific settings, limiting access.	▪ Diagnosis (leading to prevention for self and others)	All at risk groups

BARRIER

Similar to medication only being provided in medicalised settings, the settings in which testing is offered can also be limited and act as a barrier. Restrictions on who can administer an HIV test (e.g., limiting this to doctors) and where this can be done (e.g., limiting this to healthcare settings) can hinder general access to testing, specifically for those groups that may not have access to primary care, such as migrants (ECDC and WHO, 2023). This can lead to delays in testing and late diagnosis. For example, in 2023, the proportion of people diagnosed late was above 60% in Italy (ECDC and WHO, 2023). Although self-testing is available in some countries, the sale of at-home kits can often be limited to pharmacies only, as opposed to online or other accessible shops (KPMG, 2019a). In addition to the restrictions imposed by limiting the venues providing HIV testing, the interviews revealed that even in medicalised settings, HIV testing is not always included in routine checks by clinicians. Lack of testing can lead to people being carriers of HIV without their knowledge, and possibly unknowingly spreading it to others by not taking preventative measures. These people would be unaware of their HIV status, therefore not taking medication to supress their viral load, which could have repercussions for their health. This has the potential to turn into a vicious cycle of people living with HIV unknowingly.

SOLUTIONS

Empowering individuals to take ownership of their health and providing them with the tools to do so could yield significant benefits in tackling this barrier, such as by licensing home-testing kits more widely through Europe. A good example of this is how home testing is available in many parts of the UK for no charge (Boardman et al., 2024). HIV testing performed in non-traditional settings, such as prisons, addiction and misuse centres, and even at work could improve testing rates and encourage people hindered by stigma to partake (DHSC, 2021). Public health campaigns could also improve testing by normalising the act of getting tested if you suspect that you might have been at risk (Boardman et al., 2024). In certain areas with high prevalence, opt-out testing in locations may be a viable solution (DHSC, 2021). Nevertheless, it is crucial to ensure that expanding HIV testing and diagnosis is directly related to expanding immediate access to services for HIV treatment.

Healthcare provider knowledge and attitudes towards HIV

Definition	HIV care pathway impacted	At-risk groups
The influence of healthcare provider knowledge and attitudes towards HIV on testing, treatment recommendation, and treatment adherence.	▪ Pre-infection clinical prevention (PrEP and PEP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	All at risk groups

BARRIER
HCP knowledge is essential for timely diagnosis and appropriate referral. A recent study exploring HIV testing practices in general practice in countries in Europe reported that GPs are not always fully aware of specific details surrounding the HIV epidemic nor testing guidelines in their country (Deblonde et al., 2018). Poor testing rates may also be attributed to healthcare providers' misinterpretation and preconception of who might be at risk of HIV (Boardman et al., 2024), and general lack of knowledge about characteristics of illness, guidelines and management of disease post diagnosis (Rodriguez-Rincon et al., 2020). Enacted stigma (defined as "explicit experiences of discrimination") by healthcare practitioners or other administrative staff was reported as an issue in Ireland (Vaughan, Power and Sixsmith, 2020) and during the interviews. Furthermore, GPs were reported to rarely discuss sexual behaviours during routine appointments, and to feel uncomfortable to offer HIV tests proactively during routine consultations (Deblonde et al., 2018). The interviews suggested that there have been cases where women who self-identified as needing or benefiting from PrEP were turned away by HCPs and that younger doctors were lacking awareness of the history of HIV/AIDS.

SOLUTIONS
The driving solution to this barrier involves education for HCPs on HIV transmission and infection control as part of mandatory training (DHSC, 2021) and instructing HCPs to offer HIV testing based on presentation, regardless of other factors (Boardman et al., 2024). Routine offering of HIV testing for patients presenting with STIs, as indicator diseases, can be an effective strategy (Deblonde et al., 2018). The addition of electronic testing prompts in primary care settings increased initial testing notably (Boardman et al., 2024). Furthermore, practical solutions, such as using HIV score tools, for example, the DENVER HIV risk score tool, to calculate HIV risk could be useful for clinicians to decide who to offer an HIV test to (Deblonde et al., 2018). Educational campaigns and promotion of up-to-date information through conferences and relevant medical sources was also highlighted as a way to promote best practice amongst HCPs (Boardman et al., 2024).

Side effects of medicine

Definition	HIV care pathway impacted	At-risk groups
The impact of immediate side effects on individuals' adherence to treatment.	▪ Pre-infection clinical prevention (PrEP and PEP) ▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups

BARRIER
Side effects are a reality for most medical treatments, and their extent is dependent on the chemical makeup of the drug as well as the individual's reactivity to the active substance. Nevertheless, this aspect of the treatment must not be ignored as it can contribute to the barriers preventing people from starting on and adhering to PrEP, getting diagnosed or taking other HIV medication. Individuals suffering gastro-intestinal side effects from ART were more likely to have reduced adherence compared to their counterparts who experienced no adverse effects (de los Rios et al., 2020). The interviews revealed that some countries do not have access to the most advanced medication with fewer side effects because of funding issues and medicines pricing.

SOLUTIONS

One of the key solutions to limit the impact of side-effects is by improving dialogue between patients and HCPs to explore ways of minimising side effects, including potentially through providing tailored advice and additional medicines to manage adverse events (Glendinning et al., 2019). HCPs should ensure that individuals' understanding of the importance of longer-term health and viral load suppression (Glendinning et al., 2019), and that the risk of not adhering to treatment and exposing themselves to HIV could be more harmful to them than the side effects of the drugs. The interviews suggested that efforts to increase access to treatment options that are associated with fewer side effects are important to improve uptake and adherence in an equitable way.

Current clinical guidelines

Definition	HIV care pathway impacted	At-risk groups
The risk of overlooking women specifically in HIV testing and treatment due to incomplete guidelines.	▪ Pre-infection clinical prevention (PrEP and PEP) ▪ Diagnosis	Migrant/ pregnant/ cis and trans-women

BARRIER

Clinical guidelines in European countries are generally relevant and comprehensive when it comes to HIV diagnosis and treatment. However, there are still some gaps in the procedure, mainly pertaining to the low perceived risk of HIV in women and lack of attention to longer-term effects of medicines. It has been reported that women are offered HIV testing at lower rates than heterosexual and men who have sex with men in sexual health clinics, likely attributable to misconceptions about low perceived risk of contracting HIV in women (Whelan et al., 2023). Furthermore, women have been intentionally excluded or under-represented in clinical trials, resulting in gaps in data to support use of PrEP in this group (Whelan et al., 2023). Limited evidence resulting from this could impact this group's inclusion in guidelines for using PrEP. The interviews also highlighted that first line therapies for HIV are rarely associated with quality of life, and longer-term effects of medicines, which are not expanded on in the guidelines. This can lead to low adherence to treatment for individuals, resulting in reduced viral suppression and the possibility of transmission to others.

SOLUTIONS

The key solution to this barrier would be the broadening of guidelines to include those who might be overlooked, specifically women. Additionally, education for healthcare providers to offer HIV testing based on presentation, regardless of other factors, such as gender, could help minimise the instances of specific groups of people being left out (Boardman et al., 2024). Introduction of quotas to ensure accurate and relevant representation of women in early clinical trials for HIV prevention and treatment would also be beneficial to minimise the female underrepresentation in HIV research (Denison-Johnston, 2022). To address the issue of how clinical guidelines may not consider the quality of life of people on first-line treatment, the interviewees suggested that promoting a mentality of *"living is more than just surviving"* among HCPs could be beneficial. They highlighted the importance of considering this aspect for encouraging treatment adherence.

Appendix 5.4: Policy and research barriers and solutions

Lack of surveillance

Definition	HIV care pathway impacted	At-risk groups
How lack of data and surveillance hinders efforts to implement effective HIV strategies.	▪ General prevention strategies	All at-risk groups

BARRIER
Accurate data collection and surveillance capabilities are vital for understanding the epidemiology of any condition, especially of those that are transmissible between humans. Gaps in datasets can obscure the real size of the problem and reduce the ability of decision makers to track progress or stagnation (Kuiper and Brady, 2023). The past decade has seen unprecedented migration from outside of, and across European countries, exacerbating the need for good data. Countries adopt different surveillance methods, which can hinder interoperability and comparison between countries and can impede accurate interpretation of trends and patterns (Laar et al., 2019). The interviews also suggested that some communities, such as Latin-American, may be underrepresented because the ethnic groupings are overly simplified in surveys (e.g. classified as *"other"* in demographic questions in surveys). This can mean that certain minority groups who may not share the same cultural habits and customs are clustered together resulting in misrepresentation. The interviews also highlighted the magnitude of loss to follow-up, which results from people previously diagnosed with HIV who discontinue their care.

SOLUTIONS
Standardising data collection and reporting within and between European countries could increase the level of interoperability and collaboration between countries. Increasing cross-border data sharing could leverage available data and drive implementation of relevant and effective strategies to end HIV (Kuiper and Brady, 2023). The interviews suggested that the UK has one of the most robust and accurate datasets concerning individuals with HIV. Sharing the knowledge and method of building similar models for data collection in other countries would be a great stepping stone towards crossing this barrier. The interviews also suggested that introducing country comparison studies could apply some pressure among peers and encourage them to stick to and deliver HIV targets. This is already achieved to some extent by reports showcasing the situation in the whole European region.

Government commitment

Definition	HIV care pathway impacted	At-risk groups
How limited government commitment to the issue could result in lower policy efforts to address the problem.	▪ General prevention strategies ▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups

BARRIER
Government commitment is arguably one of the most crucial aspects of achieving a unified response across an entire country, and region. Relevant authorities decide on budgets and priorities leading to financial decisions which ultimately underpin the countries capabilities to respond to a crisis. Here, we are not arguing that governments are not acknowledging that HIV is a problem, but rather that the level of commitment needed to achieve eradication is not reached. The levels of commitment and funding are highly variable in Europe. In general, HIV is not seen as a priority at EU-level, limiting drive to achieve HIV targets (Kuiper and Brady, 2023). Although encouraging to see recent improvements in HIV, this has caused an overall sense of complacency (KPMG, 2019a),

potentially hindering further progress. Furthermore, the current political climate, including austerity and increased *"populist views"*, is not conducive to prioritising meeting HIV targets (KPMG, 2019a).

SOLUTIONS

A key solution would be to leverage the influence and authority of the European Union to drive positive change in attitudes towards the need for ending HIV within the member countries and beyond. Solutions that could be driven at European level, include devising a dedicated budget established by the European Commission to tackle the HIV epidemic (Kuiper and Brady, 2023). This way, the budget could be allocated equitably to countries with greater need for support. Encouraging communication between European countries in raising awareness and sharing successful strategies on reducing the burden of HIV would also be beneficial (Kuiper and Brady, 2023). The interviews highlighted that ensuring constituents are raising awareness of HIV to their representatives, especially in countries where HIV affects marginalised groups disproportionately could be beneficial.

Lack of attention to quality of life

Definition	HIV care pathway impacted	At-risk groups
The fact that the global response focuses on testing and prevention of HIV but neglects the quality of life of people living with HIV.	▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups

BARRIER

The interviews highlighted that funding for HIV prevention/treatment is primarily focused on avoiding additional diagnoses and improving survival, rather than improving quality of life (QoL). Additionally, in the UK, experts suggest that estimates for those who have dropped out of care after receiving initial viral suppressive treatment is underestimated. The most common reasons people drop out of care are related to lack of resource, for example to get to the clinic, substance abuse and mental health issues (Cairns, 2023). Neglecting the QoL of people living with HIV after diagnosis could lead to lower treatment adherence, unsuppressed viral loads and the possibility of illness and transmission of HIV. The interviews highlighted that the population living with HIV is aging and therefore has additional conditions which need to be addressed besides HIV. Understanding these comorbidities and interactions is crucial to ensure a satisfactory QoL for people living with HIV.

SOLUTIONS

The interviews suggested creating incentive models for policymakers focusing on generating value, which means on one hand avoiding new infections, but on the other hand, creating financial incentives to make sure that people diagnosed with HIV are getting treatment and maintain a suppressed viral load.

Lack of research

Definition	HIV care pathway impacted	At-risk groups
The lack of research on preventative behaviour, additional treatments, and surveillance strategies.	▪ General prevention strategies ▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	All at-risk groups

BARRIER

Here, we look at research extending beyond finding new treatments for people living with HIV, such as identifying epidemiological trends, emerging behaviours and other conditions conducive to increased HIV transmission. Lack of research has been associated with delays to understanding transmission routes throughout the EU, which is a crucial factor in the spread of the disease (Kuiper and Brady, 2023). Here, the barrier goes beyond the limited data and surveillance described above, but also into the analysis of this data and information sharing between countries. Pharmaceutical developments have also been hindered by limited research, such as in the case of evaluating safety and efficacy of PrEP in pregnant women (Celum and Baeten, 2020). The interviews also revealed that people living with HIV are often excluded from other clinical trials, such as for oncology or diabetes. This is another case of specific groups being actively excluded from research, resulting in those groups being misrepresented or leading to medicines not being licensed for those populations. Current research does not explore the ramifications of emerging trends, such as *chemsex* (KPMG, 2019b). Understanding people's behaviours is crucial to establishing measures to curb risky conduct and reducing their potential exposure to HIV.

SOLUTIONS

The most general solution to increase research on this topic would be to introduce better incentives for researchers to get involved, for example through increasing grant funding in this area. The interviews revealed that research funding relates to current trends, so ensuring that HIV remains a priority through awareness, advocacy and multilateral engagement is essential. Data collection for vulnerable groups, such as pregnant women, should be prioritised, especially in contexts where HIV risk and fertility are both at a high level (Celum and Baeten, 2020).

Limited focus on specific groups

Definition	HIV care pathway impacted	At-risk groups
The fact that some at-risk groups and some non-at-risk groups may be overlooked in policy and research outputs.	▪ Pre-infection clinical prevention (PrEP and PeP) ▪ Diagnosis ▪ Treatment (ART) and treatment as prevention (TasP)	Most at-risk groups* Not-at-risk groups

BARRIER

While it is well documented that HIV affects individuals disproportionately, there is evidence pointing out that some groups which are not perceived to be at high risk of contracting the disease can also be overlooked. A study reported that combining the adherence levels of men who have sex with women with those of men who have sex with men has masked the lower adherence in the former group (de los Rios et al., 2020). Another study highlighted that public health focus in the media and promotion activities on preventative therapies for HIV have been aimed at gay and bisexual men (Whelan et al., 2023). While this does not represent a problem in itself, making sure that campaigns are aimed at groups who are less at risk can raise awareness and limit exposure in these groups too. A Spanish study has highlighted that interventions at a national level are sparse and generally focused on men who have sex with men (KPMG, 2019b). The interviews brought to our attention the "invisible" minority communities which are unique in their character, but are often grouped with other culturally different groups, because of socioeconomic similarities, leading to outreach to these groups being inadequate (e.g. Latin-American communities).

SOLUTIONS

The solution here is based on understanding that while campaigns designed to target specific groups are not harmful, lack of acknowledgement that HIV does not discriminate based on race, gender or sexual orientation can be misleading and may paint the wrong picture for certain groups of people who are already wrongly perceiving their risk as low. Constant reminders of ways in which to minimise risk against contracting HIV could be a more useful strategy. An 'equity approach' to healthcare (focusing on specific groups that may struggle with access to healthcare) was suggested as a solution to ensure targeted interventions reach those who need it most (de los Rios et al., 2020).

*To a lesser extent men who have sex with men

CONTRACT RESEARCH REPORT
JUNE 2025

About us

With over 60 years of expertise, the Office of Health Economics (OHE) is the world's oldest independent health economics research organisation. Every day we work to improve health care through pioneering and innovative research, analysis, and education.

As a global thought leader and publisher in the economics of health, health care, and life sciences, we partner with Universities, Government, health systems and the pharmaceutical industry to research and respond to global health challenges.

As a government-recognised Independent Research Organisation and not-for-profit, our international reputation for the quality and independence of our research is at the forefront of all we do. OHE provides independent and pioneering resources, research and analyses in health economics, health policy and health statistics. Our work informs decision-making about health care and pharmaceutical issues at a global level.

All of our work is available for free online at www.ohe.org.

Areas of expertise

- Evaluation of health policy
- The economics of health care systems
- Health technology assessment (HTA) methodology and approaches
- HTA's impact on decision making, health care spending and the delivery of care
- Pricing and reimbursement for biologics and pharmaceuticals, including value-based pricing, risk sharing and biosimilars market competition
- The costs of treating, or failing to treat, specific diseases and conditions
- Drivers of, and incentives for, the uptake of pharmaceuticals and prescription medicines
- Competition and incentives for improving the quality and efficiency of health care
- Incentives, disincentives, regulation and the costs of R&D for pharmaceuticals and innovation in medicine
- Capturing preferences using patient-reported outcomes measures (PROMs) and time trade-off (TTO) methodology
- Roles of the private and charity sectors in health care and research
- Health and health care statistics

ohe.org

The Office of Health Economics A Company Limited by Guarantee of Registered No.09848965
OHE Consulting Ltd Registered Company No.09853113
OHE is a Charity Registration No.1170829
Registered Office 2nd Floor Goldings House, Hay's Galleria, 2 Hay's Lane, London, SE1 2HB