Ending the Epidemic

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

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Ending the Epidemic
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Executive summary

The HIV epidemic in Western Europe today is unrecognizable from a few decades ago. It’s no longer characterized by the devastating AIDS-related deaths of the 1980s and early 1990s. More and more people are on anti-retroviral therapy (ART) and are virally suppressed [1]. Life expectancy is close to normal and they cannot pass the infection on to others.

But the epidemic has not ended – only changed. The HIV response in England, France, Germany, Spain, and Italy (the Europe5) is now facing new challenges, like providing long-term care or equally serving new at-risk populations. Policy, though, is yet to change. To meet these challenges, it must evolve.

The chance to end the epidemic is within our grasp, but urgent action is needed from the Europe5 focused on the most significant challenges:

- **Lack of visibility of HIV:** All the progress achieved by the HIV response - such as nearly achieving UNAID’s treatment targets (‘90-90-90’) [1] – has allowed complacency to creep in. The visibility HIV once had has waned and HIV is fading from the public agenda.

- **Failing to stop new infections and high rates of late diagnoses:** The number of new HIV infections has broadly stabilised, even marginally decreased. But it has not yet significantly dropped, or stopped altogether, in any of the Europe5. Plus, high rates of diagnoses are considered ‘late’ [2] (CD4<350 cells/mm³) – contributing to higher and higher mortality and morbidity.

- **Serving sub-populations unequally:** Changing epidemiology and risk patterns are creating new populations [3] who are vulnerable to HIV infection. Services are not equally focused on all these populations, often missing those hardest to reach – creating inequalities in care.

- **Keeping pace with long-term health beyond viral suppression:** More people are living with HIV than ever before. But even though they live longer, quality of life can be poor, due to injury from infection, the burden of comorbidities and challenges associated with mental health. These needs continue to go largely unmet.

- **Buckling under Europe’s socio-economic and political pressures:** Austerity, the rise in populism, and numerous other events in Europe have heaped more pressure on the HIV response. With reduced funding, maintaining the HIV care continuum is even more challenging.

In this report, compiled by KPMG LLP (UK), a Steering Group [4] of HIV experts from across the Europe5 have addressed these challenges head on. Going country by country, the report puts the current policy landscape under a microscope. It breaks down how effective local policy is across the HIV care continuum: Awareness, Prevention, Testing and Screening, HIV specific Clinical Treatment and Long-term Holistic Care. At each stage of the continuum, the current focus of policy is compared with what happens in practice, with opinion from the Steering Group.

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1. The UNAIDS 90-90-90 targets set in 2014 are targets for the treatment of people with HIV – 90% of people with HIV will know their status, 90% of people diagnosed with HIV will be receiving ongoing antiretroviral therapy, and 90% of people with HIV on treatment will be virally suppressed by 2020. These targets are based on the assertion that it is not possible to end the HIV epidemic without treating all of those with HIV that need it [1].

2. A ‘late’ diagnosis is one which is made at a point in time after which HIV treatment should have been started. Currently, a CD4 cell count below 350 cells/mm³ at time of diagnosis is considered ‘late’ [1].

3. See Methodology section, Figure 5 for a list of high risk populations.

4. See Methodology section, Table 1.
and other expert contributors included. Areas of strength and those that need improvement are identified, and clear recommendations made – both at a European level and also specific to each country.

To see some of the expert contributors to the report (in addition to the Steering Group), please go to Appendix 1.

The Steering Group of this report have put forward a number of recommendations to improve the lives of those living with, and at risk of, HIV:
Country-specific recommendations are also available in later chapters

Develop combined strategies for prevention, with appropriate implementation plans, that reflect the current reality of HIV

1. Re-evaluate the current approach to prevention, using the latest available science-based evidence.
2. Include emerging trends into prevention strategies.

Define policies that support the long-term health of people living with HIV

5. Integrate HIV into long-term health policy.
6. Develop education and training to facilitate person-centred long-term care in the community.

Address low rates of testing and high rates of late diagnosis

3. Embed repeat testing in all high risk populations.
4. Improve the offer and uptake of testing across all settings of care.

Find, highlight, and spread examples of good practice

7. Assess and integrate effective ‘local’ practices into policy - do not reinvent the wheel.

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1. See Methodology section for list of high risk populations

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The HIV epidemic is changing. Globally, there has been a marked decrease in the number of new HIV infections from 2.8 million in 2000 to 1.8 million in 2017, and AIDS-related deaths from 1.5 million in 2000 to 0.9 million in 2017. Today, there are 36.9 million people living with HIV worldwide, of whom 21.7 million – almost 60% – are on anti-retroviral therapy (ART) \(^1\). This is great progress. Just a few decades ago, HIV was spreading unchecked and often equalled a death sentence. To date it has claimed the lives of 39 million people \(^2\).

The Europe5 countries have been at the forefront of this change. Investment in care and the considerable effort from public, private and civil society have contributed to positive outcomes. Today, an estimated 0.67m people are living with HIV in the Europe5, increasing from 0.59m (or 14%) since 2010 \(^1\) (Figure 1a). In parallel, and contributing to this increase, there has been a steady increase in the number of people living with HIV who are on ART. For example, between 2010-2017, the number of people living with HIV receiving ART increased from 70% to 81% (France), 65% to 74% (Germany) and 65% to 82% (Spain) \(^1\). Finally, the number of AIDS-related deaths are consistently declining, with an overall 55% decrease in annual deaths observed across the Europe5 between 2008 and 2015 \(^3\). Europe5 have also made progress against international targets, such as the UNAIDS 90-90-90 treatment targets, collectively achieving 86%-92%-92% (see Figure 2). This equates to 79% (0.53m) of all people living with HIV in the region on ART and a total of 73% (0.48m) being virally suppressed.

ART has allowed for much greater longevity of life and the ability to stop or minimise onward transmission of the infection, as people on ART with viral suppression, i.e., undetectable viral loads, do not transmit the infection. This success has created a large cohort of people who are, for the first time, ageing with HIV. Ageing with a long-term illness affects quality of life. Patients face higher risk of co-morbidities and greater challenges to their mental health. Also, while the number of new infections across the Europe5 have stabilised (Figure 1b), they are yet to meaningfully decrease. In fact, new subpopulations are emerging who are at risk of HIV as a result of behavioural and demographic changes. Young people, heterosexuals, newly-arrived migrants and those engaging in risky behaviours are increasingly at risk (see below for details).

While the epidemic has transformed from what it was only a few decades ago, this evolution does not make it any less complicated – only different.

Tackling the new and continuing challenges of the epidemic requires a fundamental change in the way in which HIV is viewed. No longer an ‘acute’ event with viral suppression as the ultimate goal, it must now be viewed in terms of long-term health management. Policies across much of the Europe5 are yet to make this change. But policy must evolve. And the reward for success could be significant: ending the epidemic once and for all.
Figure 1a. HIV prevalence rate (%) by country (adults)

Note: Data for France, Germany, Italy and Spain from UNAIDS HIV prevalence data 2017 [1]. Data for UK from HIV in the UK, 2016 Report [2] see country reports for details.

Figure 1b: HIV incidence rate (per 100,000 residents) by country (adults)

Note: Data for France is from UNAIDS HIV incidence data 2017.

Figure 2. Europe5 aggregate 90-90-90 (estimated)

86% Aware of their HIV status

92% On HIV treatment

92% Virally supressed

Notes: Aggregate 90-90-90 for Europe5 estimated using most recent figures available for each country – see country reports for 90-90-90 data by country.
Key challenges facing the HIV response:

Lack of visibility of HIV

Decades of investment in HIV services and care have resulted in a number of positive outcomes in the Europe5, including a drop in AIDS-related deaths and progress towards the UNAIDS 90-90-90 treatment targets. This indicates the majority of people living with HIV are on ART and virally suppressed.

While these achievements must be celebrated, the success of the HIV response has created a sense of complacency - there is evidence that HIV is falling off the public agenda. The intense focus on the UN 90-90-90 treatment targets (i.e., on securing long-term viral suppression) has reduced focus on other indicators of the epidemic, such as long-term condition management, infection control and the quality of life of people living with HIV, such as stigma. More work is required to address these indicators, ensure wider recognition of the epidemic and to change the rhetoric.

While achieving 90-90-90 is a crucial and necessary milestone, at best it indicates 73% of the total numbers of people living with HIV are virally suppressed, which the Steering Group considers to be too low an ambition for countries with the resources of the Europe5.

Failing to stop new infections and high rates of late diagnoses

The current failure to stop new infections altogether, combined with large populations who remain undiagnosed, are features of the current HIV epidemic across all the Europe5. While a small decline in incidence has been reported in England, Spain and Germany, France and Italy indicate only a broadly stabilised number of new infections per year. Significant undiagnosed populations exist in all countries, e.g., 13,000 in England (2016), 11,400 in Germany (2017) and 14,000 in Italy (2012) and this needs to be addressed.

High rates of late diagnosis (i.e., CD4<350cells/mm³ at time of diagnosis) also persist in all the Europe5. For example, in 2017, 43% of all new diagnoses in England / UK, 56% of all new diagnoses in Italy, and 47.8% of all new diagnoses in Spain fell into this category.

Early diagnosis of HIV is crucial for ensuring a better quality of life and minimising onward transmission, making addressing the rate of late diagnosis a critical component of the HIV response.

Current challenges in prevention, timely diagnosis and links to care are evidenced by the as yet failure of most of the Europe5 to reach the 1st of the UNAIDS 90-90-90 targets, i.e., 90% of people living with HIV knowing their HIV status. England/UK is the only exception, where 92% of people living with HIV are diagnosed, 98% of those are on treatment, and 97% of those have an undetectable viral load.

Serving sub-populations unequally

Certain populations may be more vulnerable to HIV infection. For example, people who engage in high risk behaviours such as injecting drugs or engaging in chemsex. Also, those who may be marginalised, such as men-who-have sex with men (MSM) or transgender people. Those who face cultural or financial barriers, such as ethnic minority women. Or those who may fear interacting with HIV services, such as newly arrived migrants or sex workers. For a full list of high risk populations, see the Methodology section, Figure 5. These populations also suffer from intersecting self and social stigmas, be they cultural, social or religious, which may deter engagement with care.

Decades of effort by public and civil society have resulted in improvements among certain subpopulations. A good example is the decline in the number of new infections in MSM in central London over time, or the broadly stabilising number of new infections among MSM in Germany. However, others continue to display worse indicators, indicating they may be underserved in terms of focus or availability of accessible services. For example, in Spain the rate of late diagnosis in women is 50.6%, compared to 47.2% in men, and in England the rate of late diagnosis is higher at 69% in black African men compared to the average (43%).

Engaging effectively with these underserved groups requires targeted programmes specifically designed to provide information and support to these populations, coupled with education of the wider population to help eradicate persistent stigma.

1. Chemsex is the practice of consuming drugs recreationally in order to facilitate sexual activity – typically this refers to one or a combination of three drugs: methamphetamine (crystal meth), mephedrone (M-cat), and GHB/GBL (G). Consumption of these drugs reduces inhibitions and therefore increases risky behaviours, whilst also exacerbating an individual’s mental health.

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Keeping pace with long-term health beyond viral suppression

With the availability of effective therapy, people living with HIV who are diagnosed in time and who have access to care can expect a near normal life expectancy. This means there’s an increasing number of people who are ageing with HIV. The complications associated with ageing emerge more frequently and at younger ages amongst people with HIV. This is from a combination of injury from HIV infection such as persistently heightened inflammation, long-term treatment toxicity, impact of risky behaviours such as smoking or illicit drug use, and the burden of age-related comorbidities such as cardiovascular disease and liver cirrhosis [16]. Adding to this issue is the higher incidence of depression and anxiety that has been documented in people living with HIV, linked to real and perceived stigma, HIV-related bereavements and survivor guilt, particularly among those who have lived for the longest time with HIV [17].

International and national bodies, including the World Health Organisation (WHO), are calling for specialised person-centred long-term care for people living with HIV, ensuring long-term care beyond viral suppression is available [18]. The WHO defines its vision as “zero new HIV infections, zero HIV-related deaths and zero HIV-related discrimination in a world where people living with HIV are able to live long and healthy lives” [19]. However, it is clear that national policies and practice are yet to effectively address this. HIV continues to be viewed as an “acute” event, with effort focused on testing and treatment, often with sustained viral suppression as the ultimate outcome. Care is primarily delivered through hospital-based specialists and multidisciplinary teams which may not be the most effective and sustainable model as people living with HIV age. Long-term health and wellbeing have different requirements. Collaboration is needed between primary and secondary care, and between specialties such as infectious disease, mental health or other non-communicable conditions, which often does not happen effectively. This results in delays, costs, and distress.

Buckling under Europe’s socio-economic and political pressures

Recent events in Europe, including economic austerity and the rise of populist political views, have created a particularly challenging environment for those living with, affected by and working within HIV. This has been exacerbated by further geo-political events, such as the migrant crisis which started in 2015.

The impact has been felt across all the Europe5. For example, in England, severe austerity measures have seen the diminishing of the National and Local Authority funding available for HIV and related services. Surveys indicate that ~47% of local authorities planned to reduce spending on sexual health in their 2018-19 budgets [20]. In cases where new funding is required, policies of austerity mean that funds are unlikely to be forthcoming. For example, the 2017 national plan for HIV/AIDS for Italy remains unfunded to date of this report.

There are also wider laws and policies that affect people living with HIV and their quality of life. Among these are free, non-discriminatory access to healthcare, legal protection against stigma and discrimination, and non-discriminatory laws and regulations in sex work and drug use (see country chapters for details). Prosecution of certain behaviours (e.g., reckless transmission) is another legal aspect that may impact people living with HIV. However, an examination of this was considered out of scope for this report and therefore not covered.
This chapter outlines the Steering Groups’ assessment of current HIV policy across England, France, Germany, Italy and Spain, broken down by stages of the HIV care continuum. A set of recommendations for improving the lives of those with, and at risk of HIV relevant for all Europe5, are outlined in the next chapter.

Tackling new and emerging challenges of the epidemic requires policies that are comprehensive, well funded and effectively implemented.

France, Germany, Spain and Italy have recently published or updated their national-level strategies and policies on HIV/AIDS, either as standalone or in combination with their policy on sexual health or infectious diseases.

England’s mix of service specifications, public body recommendations, and clinical guidelines form the basis of the national response to HIV. Each of these policies cover the stages of the HIV care continuum with varying degrees of comprehensiveness.

Going step by step across the HIV care continuum of Awareness, Prevention, Testing and Screening, HIV-specific Clinical Treatment, and Long-term Holistic Health, the Steering Group of this report assessed the effectiveness of the existing policy. They considered the ability of policy to both maintain the existing high standards of care where available, as well as to tackle the new and emerging challenges of the epidemic. Figure 3 provides a summary of their assessment, and further analysis is available in the country chapters.
Figure 3. The Steering Groups assessment of HIV policy across the Europe5

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A summary of the Steering Groups’ assessment of HIV policy is provided below. For country-specific details please see individual country chapters.

3.1 HIV specific clinical treatment is generally provided to a high standard, although areas for improvement exist

Policy and guidelines are in place and largely effective in the clinical treatment of people living with HIV across the Europe5 countries. Guidelines from all five countries recommend initiation of ART regardless of CD4 count (see country reports), recognised to reduce the risk of serious AIDS events and mortality in people living with HIV. Time to initiation of treatment however, may vary. Good practice examples have been piloted, such as Dean Street Clinic in Soho, London, UK, where treatment is initiated within 48 hours of diagnosis (see Figure 4). Once initiated on ART, people living with HIV are closely monitored, at 3, 6 and 12 month intervals depending on clinical need, adherence and rates of viral suppression. As mentioned above, the success in clinical treatment is exemplified in the progress towards the UNAIDS 90-90-90 targets.

Areas for improvement remain. While national level data on time to treatment initiation is scarce, anecdotal evidence indicates it may still take several weeks to months from diagnosis - however, further data is required to develop a true picture. Equal access to newly approved medicines is also not yet available across all countries. Rapid and comprehensive access to newly approved medicine is available in France and Germany. Policy exists in all others, however, various challenges may introduce delays or inequalities in access. These include lengthy, multi-step processes or restrictions or caps on medication due to budget constraints. The latter may be particularly true where there is a devolution of power and responsibility to autonomous regions or provinces, giving rise to discrepancies in medicine access.

3.2 While policy covers the early stages of the HIV care continuum, it is often limited in scope and underfunded in practice, resulting in inconsistent implementation

Awareness

Policy in many of the Europe5 countries recognises the importance of interventions that can raise awareness of HIV and tackle stigma, and in some cases targets high risk populations using effective channels, such as culturally-sensitive awareness programmes for migrants. Germany demonstrates this particularly well, with large-scale national, regional and local interventions delivered through state-departments or non-governmental organisations (NGOs) based on the target sub-population (e.g., social-media based campaigns targeting youth) [21]. Good practice examples are also available in other Europe5 countries, including innovative YouTube-based campaigns targeting youth in Italy, and “Do-It London”, a large-scale awareness campaign in England.

“We are currently running STD awareness campaigns for young people with funny pictures and puns so people can laugh and enjoy it. I’ve had patients coming in to get tested because of this and probably wouldn’t have done so without this initiative”

HIV HCP, Germany

However, in practice, there are significant regional variations in the effectiveness of awareness interventions. Quite often, the implementation of policy is devolved through autonomous regions or provinces or separate government bodies, and as a result significant regional variations occur. For example, in England, the 353 local authorities/councils are responsible for developing and delivering public health activities, whilst being supported by Public Health England (PHE).

“You find any attempt by PHE to artificially impose a national framework for uniformity across England onto what is a localised picture, ends up in duplication in some areas and absolute gaps in others”

HIV policymaker, UK

Furthermore, although policy often notes the importance of targeting a wide range of high risk populations, in practice implementation is almost always focused on one (or a subset) of these populations. For example, most interventions in France and Spain focus on the MSM populations, with others such as youth or migrants often being missed out. As a result, many high risk and highly vulnerable sub-populations such as newly arrived migrants, migrant women or ethnic minorities, may not receive adequate attention.
Essentially, campaigns have reduced significantly with only certain populations, such as MSM, being targeted. These do not reach young people nor certain vulnerable populations such as immigrants.”

HIV policy expert, France

Prevention

Comprehensive combined prevention strategies are rare in the Europe5 countries, even though the importance of a multi-faceted approach - such as bringing together behavioural, biomedical and harm reduction - is widely recognised. For example, while Pre-exposure Prophylaxis (PrEP) is freely available through the health system in France, and will be available in Germany from September 2019, it is not routinely available in Italy and Spain. In England, an implementation trial for 26,000 people is underway. However, its availability through the National Health Service (NHS) following completion of the trial is not yet guaranteed. Many questions still remain among policy makers and HIV clinicians over the use of PrEP, including concern over unintended consequences - such as increasing rates of other STIs - and pricing and reimbursement. Moralistic and ideological stances over its use are also found, all of which have slowed, and continue to slow the development of PrEP policies.

“PrEP is not implemented at all – it’s just mentioned in guidelines. We are far from using PrEP.”

HIV policymaker, Italy

Testing and screening

Testing and screening policies are generally well developed but implementation can be ineffective. To varying degrees, testing is available across the Europe5 countries through primary care, secondary care, public health, sexual health clinics, and NGOs. Successes have been noted in innovative approaches, such as self-testing vending machines in Brighton, England, or routine testing offered at community drug clinics (see Figure 4).

However, barriers continue to exist, limiting the effectiveness of offer and uptake of testing. These include, among others, a lack of convenient testing sites, which provide anonymous, free and inclusive environments. Requirements around opting-in and parental consent could further deter regular testing. Finally, gaps in health care professional (HCP) knowledge on testing guidelines and processes result in missed testing and screening opportunities in primary and secondary care.

“The GP is a challenging area. They often don’t classify the symptoms correctly and don’t do an HIV test, so quite frequently, patients come to treatment too late. GP’s need more awareness on patient symptoms”

Patient group representative, Germany

Rapid referral and links to care is a challenge in certain countries, and particularly within more vulnerable populations like newly arrived migrants. For example, in Spain, the current requirement to have a GP referral in order to see an HIV specialist, combined with long waiting times, is thought to cause delays, distress and may even lead to loss of individuals from follow-up.

3.3 A fundamental change is required to address long-term holistic health for people living with HIV

The provision of person-centred, long-term holistic care for best health outcomes will require a fundamental change in the way in which care for people with HIV is organised and delivered. The prevention and management of comorbidities as well as mental health support and non-clinical services such as counselling, behavioural advice, and peer mentoring need specific focus and effort. Recognising the growing importance of this topic, initiatives such as HIV Outcomes are underway, aiming (among

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other things), to ensure holistic health and well being of people living with HIV are central to the overall response [20]. However, comprehensive support for long-term health and wellbeing remains a key policy gap today, as the shift in thinking to recognise and treat HIV as a long-term condition (beyond viral suppression) is yet to happen.

While policy and guidelines generally exist for the treatment of comorbidities such as non-communicable chronic conditions, they are often stand-alone and only specific to HIV. They are not yet well integrated with wider policy on long-term or chronic condition management within health systems. Furthermore, while the current model of care relies heavily on hospital-based specialists and provides a very high quality service, it often suffers from issues related to links between different specialties, with long waits for appointments or referral loops.

"While access to co-morbidity care is good, sometimes the organisation of care is complicated. For example, if you need to see another specialist you may have to wait months for an appointment."

HIV clinician and policy expert, France

Provision of clinical and non-clinical support varies significantly too. All Europe5 countries acknowledge severe funding and capacity constraints in the provision of mental health services in the wider population, but this critically impacts people living with HIV where the prevalence of psychiatric and psychological issues is higher. Wider provision of other supportive for people living with HIV, such as peer support and counselling, is also varied among the Europe5. In Germany, provision is covered in policy and delivered through state funded projects with NGOs, whilst in Italy it is covered in policy but limited to certain issues (for example, policy covers counselling for negative HIV tests). In England, there is no specific policy for non-clinical supportive services, resulting in reliance on NGOs to fill the gap.

“London does better in terms of support services. There are whole areas, e.g., rural areas, that have very few services around support.” HIV policymaker, UK
4.1 Develop combined prevention strategies, with appropriate implementation plans, that reflect the current reality of HIV

The Steering Group for this report recommends a common framework for prevention activities based on the current epidemiology of HIV, taking into consideration sub-populations most at risk, recent trends in transmission modes, and evidence-based interventions with proven effectiveness.

**Recommendation 1**

**Re-evaluate prevention approaches using latest available evidence**

Much of the current approach to prevention focuses on traditional interventions, such as promoting the use of condoms. While this is important, policy does not yet reflect the latest science-based evidence, including biomedical interventions like PrEP to reduce the risk of infection, and targeted, effective campaigns such as Undetectable = Untransmittable (U=U). These developments must be taken into consideration and used to shape policy to deliver impactful messaging and effective prevention approaches.

**Recommendation 2**

**Integrate emerging trends into prevention strategies**

Current HIV strategies and policies do not yet fully reflect changing patterns of risk within the key sub-populations at higher risk of contracting HIV - chemsex, for example. Greater understanding is required and targeted, effective interventions that are integrated with the wider prevention strategies need to be developed.
4.2 Address low rates of testing and high rates of late diagnosis

Despite continued efforts, late-stage diagnosis of HIV and undiagnosed HIV continue to persist across the Europe5, contributing to onward transmission and a greater burden on the individual and public health. While policy and guidelines on testing often exist (see country reports), their implementation remains poor for a number of reasons: lack of knowledge among HCPs (e.g., indicator condition testing), fear of perceived stigma, requirements around consent / opt-in, and lack of inclusive, accessible testing sites (e.g., community-based). The Steering Group sees an urgent need to increase testing, particularly among the populations that are most at risk or hardest to reach.

Recommendation 3

Embed repeat testing in high risk populations

While recommendations for repeat testing exist, studies indicate these are not well implemented - even within high risk populations [23]. Guidelines for repeat testing in priority groups should be developed and implemented, together with education and awareness programmes for the public as well as HCPs.

Recommendation 4

Improve the offer and uptake of testing across all settings of care

Multiple missed opportunities for HIV testing are well documented [24], indicating a priority area to be addressed. Interventions to address this by removing the conditions of opt-in should be considered where appropriate, together with greater education and awareness of HCPs. Innovative approaches like testing in social setting (see Figure 3. Good practice examples) or home sampling, should also be evaluated and implemented.
4.3 Define policies that support the long-term health of people living with HIV

In managing the long-term health of people living with HIV, guidelines such as those of the European AIDS Clinical Society (EACS) and the British HIV Association (BHIVA) Standards of Care for ageing and co-morbidity management are typically referred. Some country-specific guidelines - the GeSIDA guidelines in Spain, for example - are considered comprehensive. However, services that provide person-centred, long-term health for people living with HIV are insufficient at present, and HIV-specific policies do not adequately recognise the needs of the ageing population living with HIV or the importance of managing HIV as a long-term condition. The Steering Group of this report see an urgent need to define policy and focus appropriate resources in this direction.

**Recommendation 5**

Integrate HIV to long-term health policy

To manage the long-term health and wellbeing of people living with HIV successfully, it is critical to address HIV as a long-term condition, and integrate with policies that tackle the long-term care of the population in general. Lessons from HIV should be used to elevate the long-term health and well being of people living with HIV and the wider population as a whole.

**Recommendation 6**

Develop education and training for community care providers

A key element of providing person-centred long-term care is the ability to provide services in the community. Furthermore, the growing cohort of older people living with HIV - with new and additional requirements around co-morbidity management - requires new models of care delivery, frequently outside the hospital setting. A key step is to address limitations in HIV knowledge among community care providers through tailored education programmes.
4.4 Find, highlight, and spread examples of good practice

The response to HIV across Europe5 countries and beyond provides many examples of effective interventions and good practices. This report contains several such examples (see Figure 4), and other publications, such as the WHO Compendium of Good Practice in HIV [25] and the HIV Outcomes Compendium of Good Practice [18], contain many more. The Steering Group of this report stress the importance of not reinventing the wheel and urge policy makers to study such examples and integrate them into policy at scale.

Recommendation 7

Integrate effective local practices into policy

Many public sector, community, civil society and other institutions and bodies provide highly effective HIV services across the care continuum. They reflect local initiatives to solve specific issues and a number of these have proven to be highly effective. However, most are not carried out at scale due to funding or capacity limitations and are at times not sustainable. At a minimum, the successful initiatives and interventions should be identified and shared. Where possible, funding should be made available to implement at scale, and once proven, can be absorbed into policy and guidelines as good practice.
Figure 4. Good practice case examples (see country chapters for details)

**Awareness**

- **Your Health, Your Faith – HIV awareness among African migrant community**
  Involving African faith-based communities in HIV awareness and prevention

- **Peer education for sexual health – Youth Against AIDS**
  Peer-to-peer sex education in schools, run by young people for young people

- **Hurrah Love! For sexual health education in schools**
  A training course delivered in schools on sexuality and relationships, aimed at school teachers, teenagers aged 12-14 and families

**Prevention**

- **Barcelona Checkpoint**
  Supportive services for PrEP users (in addition to full sexual health testing and treatment services)

- **ECIMUD for drug users**
  Multidisciplinary medical teams that operate in hospitals, focusing on treatment for drug users

- **London HIV Prevention Programme**
  Joint commissioning of HIV awareness and prevention in London’s 33 Local Authorities

**Testing and Screening**

- **Testing in gay saunas**
  Free HIV test vending machines provided in gay saunas in Brighton

- **Bologna Checkpoint**
  Community run rapid HIV and STI testing centre – the first of its kind in Italy
Clinical Management

Dean Street Clinic
Immediate access to ART – aiming for access within 48 hours

Beyond Viral Suppression
Using the Positive Voices survey to develop a more complete view of wellbeing for the first time

Co-infection testing in public drug treatment centres
Guidelines on actively testing in drug centres, as well as pre and post-test counselling, specific prevention measures, and follow-up

Long-term Holistic Care

Clinica Metabolica di Modena
A multidisciplinary clinic for diagnosis and treatment of non-infectious comorbidities

Universités des personnes séropositives
A gathering of people living with HIV in order to work on individual and collective health aspects by sharing information and experiences

Hospital Clinic de Barcelona - telemedicine
An alternative model for long-term care, demonstrating the feasibility and convenience of telemedicine for some aspects of follow-up
05

Project rationale and methodology

Project rationale
This study was undertaken to assess current policies in place to tackle HIV / AIDS in selected countries in Europe and develop a set of recommendations on where improvements can be made. The report has been sponsored by Gilead Sciences Europe Ltd. However, it has been driven entirely by the Steering Group (see role of Steering Group) and is independent of the project sponsor.

Lessons have been taken from several reports which review the current legal and policy landscape in Europe and its effectiveness in tackling the epidemic, including: publications by the OpTEST project on legal and regulatory barriers to the HIV care continuum in Europe [26], reports by AIDS Action Europe on a comparative 16-country legal survey on migrant access to healthcare [27] and numerous evidence briefs and reports by the European Centre for Disease Prevention and Control (ECDC) monitoring implementation of the Dublin Declaration [28].

Country selection
Five Western European countries (England, France, Germany, Italy, and Spain) were included in the study. These countries have generally a low prevalence of HIV/AIDS (see Figure 1), which has been achieved through continued investment and effort in managing the epidemic. While they have achieved similar outcomes (see Figure 2), there are variations in their policy and legal frameworks, as well as in the provision of care to patients. Room for improvement exists in each of the Europe5 countries.

The role of the Steering Group
The report was compiled by KPMG but guided throughout by an independent Steering Group comprising of policy, clinical and patient experts in HIV (see Table 1). The Steering group had editorial control of the report and provided input at each stage of its production, including revision of discussion guides for primary research, guidance on sources of publically available information, revision of outputs (e.g., policy assessment by country, development of recommendations; The opinions expressed here are theirs alone, and may not necessarily reflect the opinions of the organisations to which they belong. The experts were compensated for their time and expertise in participation in line with the fair market values for each country.
Table 1. Project Steering Group

<table>
<thead>
<tr>
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<th>Name</th>
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Methodology
This report consists of a country by country assessment of HIV policy across England, France, Germany, Italy, and Spain. It identifies key gaps and proposes a set of recommendations on how these can be addressed. The report is structured to present findings at a European level, followed by a chapter for each country.

The report undertakes an assessment of existing policy related to HIV. While France, Germany, Spain and Italy currently have national-level policies on HIV (either as standalone or in combination with policy on sexual health or infectious diseases), England does not. Instead, a conglomeration of service specifications, recommendations by public bodies, and clinical guidelines by accredited medical societies form the national strategy for tackling HIV. For the purpose of this report, we have used such documentation to assess the current strategy where necessary (note: this is not isolated to England, as many countries refer to guidelines for details on implementing specific policy positions, particularly on clinical management).

For the purpose of this report, the HIV care continuum was broken up by stages of the patient journey to enable an assessment of policy related to each stage. However, it must be noted that these stages are interdependent and cannot be viewed in isolation.
Stages of the HIV care continuum used for assessing HIV policy

- **Awareness**
  - This includes interventions targeting high risk populations (see Figure 5) and the general public to increase awareness of testing and prevention, and to reduce HIV-related stigma.

- **Prevention**
  - This includes combined prevention interventions, including condoms, pre-Exposure Prophylaxis (PrEP), and Post-Exposure Prophylaxis (PEP) in occupational and non-occupational settings.

- **Testing and Screening**
  - This includes offer of testing through community (e.g., sexual health clinics), primary or secondary care settings (e.g., emergency rooms). It also takes into account self-administered options such as self-testing and self-sampling, and routine screening programmes (e.g., life time tests or ante-natal screening).

- **HIV Specific Clinical Treatment**
  - This includes interventions to ensure rapid treatment upon diagnosis and personalised, long-term management of the HIV condition for each individual. This equates to immediate initiation on ART, access to newly approved medications, and regular monitoring to ensure viral load suppression.

- **Long-term Holistic Care**
  - This includes interventions to provide age-appropriate care, taking into account co-infections or comorbidities, provision of mental health support and non-medical support such as peer mentoring or counselling programmes.

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**Figure 5: Definitions of high risk populations**

1. **Men who have sex with men (MSM)**
   - **Definition:** Most commonly means men who have sexual or romantic relationships with other men, regardless of self-determined sexual or gender identities.

2. **Sex workers**
   - **Definition:** Sex workers are considered to include female and male adults (18 or over) who engage in sexual services for goods or money. Sex work is consensual sex between adults and may be less formal or organised in nature depending on country or area.

3. **People who inject drugs (PWIDs)**
   - **Definition:** Refers to people who inject psychotropic or psychoactive substances for non-medical purposes. Injection may be through intravenous, intramuscular, subcutaneous or other injectable routes. This definition specifically excludes those who self-inject for medical purposes and those who self-inject non-psychotropic substances for sports enhancement.
The report also provides a high-level review of wider policies and legal positions that are known to have an impact on the management of HIV. This has not been reviewed at depth. Instead, an overview of current policy and evidence of impact (through limited review of publicly available data) is provided.

**Wider legal and policy barriers:**

- **Legal protection against stigma and discrimination:** Availability of laws that protect the rights of individuals with HIV, such as right to employment, right to services.
- **Free, non-discriminatory access to healthcare:** Availability of access to prevention, testing and treatment of HIV for all high risk population, irrespective of residence status (including undocumented migrants).
- **Decriminalisation of behaviours such as sex work / drug use:** Availability of laws that provide protection to high risk populations, promote access to state-run health services and provide support for managing risky behaviours.

To undertake our research, we reviewed publicly available sources of information: national plans, peer-reviewed journals, media, civil society publications, and reports on HIV/AIDS by national and international / multi-lateral organisations. Our findings were validated by interviews with experts from each country, comprising a combination of policy makers, patient and civil society representatives and healthcare professionals. The interviews were generally one hour in duration and were conducted over the phone. Opinions expressed by the individuals were their own and may not necessarily represent the opinions of the organisations to which they belong. Some experts wished to remain anonymous, although we have acknowledged some in this report (see Appendix 1 - Table 3: Contributors to the report). The experts were compensated for their time in participating in the research, in line with Fair Market Values for each country.

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1. Adapted from WHO guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations and The Migration Observatory [29][30]
18. “HIV Outcomes.”


Interviews from experts from the Europe5 countries were used to validate the findings of our report. The interviews were generally one hour in duration and were conducted over the phone. Opinions expressed by the individuals were their own, and may not necessarily represent the opinions of the organisations to which they belong. Some experts wished to remain anonymous. The experts were compensated for their time in participating in the research, in line with Fair Market Values for each country.

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<thead>
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