EUROPEAN TESTING WEEK

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Toolkit 3

Dossier of evidence: a summary of the evidence to support free, confidential and voluntary HIV testing

Background information to the slide set

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Dossier of evidence: a summary of the evidence to support free, confidential and voluntary HIV testing

Thank you for downloading the background information to the HIV dossier of evidence slide set

The dossier of evidence has been developed to help support organisations, like yours, during European Testing Week. We see the HIV dossier of evidence being useful to you in two ways:

1. To improve and increase understanding within organisations around the necessity of increasing HIV testing activities
2. For advocacy purposes to support engagement with cooperating partners (such as government bodies, national and local HIV/AIDS programme planners and coordinators, healthcare providers and civil society organisations) with the aim of gaining their support for endorsing regular HIV testing

This background information has been drafted to provide additional information that is not included on the slides and to help support you if you are presenting the dossier of evidence to relevant governing bodies, partners and organisations. The information included in both documents provides support and evidence to back up the key messages for European Testing Week.

This document includes:

This document aims to provide support and guidance only. It is not mandatory that your organisation uses the information outlined in this document nor is it obligatory to use the dossier of evidence as part of your testing week activities. If you have any questions do get in touch: eurotest.rigshospitalet@regionh.dk

We are also active on Facebook and Twitter. Please tell us about your plans, share information and photos and tweet us to help build anticipation and excitement for the week.

Section 1 – List of abbreviations and definitions

Abbreviations used in this document

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral treatment
CD4	Cluster of differentiation (a measure of white blood cells used to measure HIV infection)
COHERE	Collaboration of observational HIV Epidemiological Research in Europe
ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EU	European Union
HIV	Human immunodeficiency virus
HTC	HIV testing and counselling
HTS	HIV testing services
MSM	Men who have sex with men
NGO	Non-governmental organisation
PLHIV	People living with HIV
PWID	People who inject drugs
RDT	Rapid Diagnostic Test
START	Strategic Timing of AntiRetroviral Treatment
STI	Sexually transmitted infection
SW	Sex worker
TB	Tuberculosis
UNAIDS	United Nations Joint Programme on HIV/AIDS
CDC	Centre for Disease Control
WHO	World Health Organization

Countries in the EU/EEA and non-EU/EEA countries

EU/EEA: Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Slovenia Spain, Sweden and the UK.

Non-EU/EEA: Albania, Andorra, Armenia, Azerbaijan, Belarus , Bosnia and Herzegovina, Georgia, Israel, Kazakhstan, Kosovo, Kyrgyzstan, Liechtenstein, Former Yugoslav Republic of Macedonia, Moldova, Monaco, Montenegro, Russia, San Marino, Serbia, Switzerland, Tajikistan, Turkey, Turkmenistan, Ukraine and Uzbekistan.

Section 2 – Key messages for European Testing Week

Overview of the key messages

Included in this section are the key messages for European Testing Week. In this HIV dossier of evidence, the messages for only HIV are included. For the messages developed for hepatitis, please refer to the key messages of the *hepatitis dossier of evidence* (Toolkit 3b).

The overarching goal of European Testing Week is to increase awareness of the benefits of HIV and hepatitis testing so that more people become aware of their HIV and/or hepatitis status. The information included in the dossiers of evidence provides the data to support the rationale and the key messages for European Testing Week.

Overarching message

EuroTEST is calling on the European community to unite for one week twice a year, during Spring (May) and Autumn (November), to increase awareness regarding the benefits of HIV and hepatitis testing; in order for more people to become knowledgeable about their risks, understand that there is effective treatment available and are aware of their HIV and/ or hepatitis status.

Core messages

European Testing Week expanded to include hepatitis testing back in 2015 because hepatitis B and C are common among people at risk of and among those living with HIV. This is because these viruses are transmitted in many of the same ways HIV is transmitted—through injection drug use and condomless sex.

It's better to know your status as soon as possible because today people living with HIV and/or hepatitis B can live well with a long life expectancy when treatment starts early; and those with hepatitis C can be cured.

Key messages – general audiences

Treatment

1. It's better to know your status as soon as possible because today people living with HIV can live well with a long life expectancy when treatment starts early.
2. HIV treatment advances mean that you can live a long healthy life if you are diagnosed early. Data from the START (Strategic Timing of AntiRetroviral Treatment) trial indicate that starting anti-HIV treatment soon after diagnosis of HIV infection, instead of waiting for the CD4 count to drop to 350, protects people's health and life longevity. Additionally, results from the PARTNER

study, in addition to evidence from other studies in serodifferent couples, indicate that the risk of transmission of HIV through condomless sex in the context of virally suppressive ART is effectively zero for both gay men and heterosexual couples. These results support the U=U (**U**ndetectable equals **U**ntransmittable) message, as well as promoting the benefits of early testing and treatment.

Prevalence

3. In 2017, an estimated 2.3 million people were living with HIV in the WHO European Region, where 1 in 5 were estimated to be unaware of their infection. Additionally, over 50% of those diagnosed were diagnosed at a late stage of infection. Although the pace of those newly diagnosed has slowed in comparison to previous years, the majority of people newly diagnosed (82%) were from the eastern part of the Region marking the highest number ever.

Key messages – healthcare workers

- Research shows that people in general will accept an HIV test when offered by their healthcare professional, so there's no need to be ambivalent about talking about HIV and offering an HIV test in the same way you would offer other routine tests.
- Help ensure you and your team can effectively assess individuals for HIV testing by offering training on the risk-factors. Such training should include preventive tools to enable staff to discuss sexual health with clients, e.g. risk-reduction with PEP, PrEP, and condom usage, provide information on relevant vaccinations and assess the need for STI-testing and/or offer testing for STIs.
- Help ensure that you and your team are familiar with HIV indicator conditions. Patients presenting with HIV indicator conditions, including hepatitis B and C, STIs and infectious mononucleosis-like illness, should be offered an HIV test.
- When people are diagnosed with HIV late, they are less likely to respond well to treatment and more likely to have health and treatment complications.
- A positive HIV test result requires that your patient is linked to appropriate care and treatment.
- HIV testing should be voluntary, confidential and offered in a wider range of settings than is presently available. Other settings may include healthcare and community-based settings and via outreach programmes by peers and/ or medical staff.
- Late diagnosis of HIV is more costly for the healthcare system.

Key messages – pharmaceutical industry

- European Testing Week presents a unique opportunity to promote your company and market its products, whilst simultaneously demonstrating a high level of corporate social responsibility through donating rapid testing kits to participating partners in 2019.

Key messages – Government Bodies

- Robust data collection and surveillance of HIV transmission on a country level is key to understanding how to develop cost-effective, targeted testing initiatives and strategies that help to reduce the number of new infections in your country.
- New testing technology offers a variety of cost-effective rapid testing kits that are now available across Europe and should be used to improve access to testing.
- HIV testing guidelines should state that HIV testing can take place in the community or in healthcare settings using blood testing kits or oral swabs.
- Legislation needs to allow integrated testing to take place. In many countries, HIV-testing is successfully carried out in community settings whereas testing for hepatitis or other STIs is not due to legislative barriers.
- Increasing access to, and acceptance of, **free**, **confidential** and **voluntary** HIV testing including linkage to treatment and care need to be a priority for governments across Europe.
- The 2015 WHO guidelines on HIV testing services state that lay providers who are trained and supervised can independently conduct safe and effective HIV testing using Rapid Diagnostic Tests (RDTs) to support task sharing in the health sector.
- To close the various gaps in coverage and quality, more proactive, rights-based HIV testing approaches are needed.
- It is recommended to offer re-testing at least once a year and up to every 3 months depending on ongoing risk to people from key populations and to HIV-negative partners in serodiscordant couples.

Key messages – supporting organisations

- We need your continued support for European Testing Week. Through united efforts, on a national and international level, we aim to ensure that more people become aware of their HIV and hepatitis status by providing access to free and safe HIV and/or hepatitis tests.

Section 3 – Know your HIV epidemic: the situation of HIV in Europe

This section includes an overview of the content contained on **slides 3 to 9**.

Situation of HIV in Europe

HIV remains a major public health problem in Europe and it is estimated that **approximately 2.3 million people** are living with HIV in the WHO European Region with over 650 000 people in the EU/EEA.

It is further reported that as many as one in five of those infected in the EU countries are unaware of their HIV status and that in some Eastern European countries this proportion is up to 50%.

The number of PLHIV and those who are unaware of their infection have been estimated by ECDC.

The estimates of the proportion of undiagnosed PLHIV in the EU/EEA and non-EU/EEA are shown here:

EU-EEA/Other	Country	% of all PLHIV living with undiagnosed HIV infection
Other	Albania	31%
Other	Armenia	33%
EU/EEA	Austria	8%
Other	Azerbaijan	29%
EU/EEA	Belgium	15%
EU/EEA	Bulgaria	16%
EU/EEA	Croatia	30%
EU/EEA	Denmark	8%
EU/EEA	Estonia	-
EU/EEA	France	15%
Other	Georgia	52%
EU/EEA	Germany	13%
EU/EEA	Greece	17%
EU/EEA	Hungary	-
EU/EEA	Ireland	13%
Other	Israel	7%
EU/EEA	Italy	12%
Other	Kazakhstan	20%
Other	Kyrgyzstan	32%
EU/EEA	Lithuania	6%
EU/EEA	Luxembourg	15%
EU/EEA	Malta	25%
Other	Moldova	21%
Other	Montenegro	54%
EU/EEA	Netherlands	12%
EU/EEA	Poland	-

EU/EEA	Portugal	8%
EU/EEA	Romania	12%
Other	Serbia	10%
EU/EEA	Slovakia	24%
EU/EEA	Spain	18%
EU/EEA	Sweden	10%
Other	Switzerland	10%
Other	Tajikistan	50%
Other	Ukraine	44%
EU/EEA	United Kingdom	9%
Other	Uzbekistan	-

(Undiagnosed fraction of HIV in European countries taken from Annex 1 of the ECDC Special Report on the Continuum of HIV care, 2019)

In 2006, 25 EU member states, plus five non-EU countries and WHO, UNAIDS, US CDC, ECDC and civil society organisations identified the high number of undiagnosed HIV infections as one of the key prevention priorities. In 2015, WHO published consolidated guidelines on HIV testing services. In these guidelines, it is underlined that to be effective, testing strategies should target populations at higher risk of HIV in a variety of healthcare and community based settings that are acceptable and convenient for people from key populations.

Addressing the European HIV epidemic, therefore, hinges on understanding predictors of late diagnosis, barriers to HIV testing among populations at high risk and involvement of healthcare providers not normally involved in HIV testing to propose HIV testing to both people from high risk populations and to people with conditions indicating HIV infection.

Scaling up HIV testing to increase the number of people who are aware of their status is a public health imperative in its broadest sense – it reduces the morbidity and mortality of individuals as people can be linked to the appropriate treatment and care, it reduces the HIV transmission rate and it has proven to be an economically sound approach. With the new UNAIDS treatment target 90-90-90, which aims for 90% diagnosed, 90% on treatment and 90% virally supressed by 2020, it is crucial to increase the number of people aware of their HIV status - the first step towards treatment.

The HIV epidemic varies in the European region. The HIV epidemic in Western and Central Europe has slowed while it is escalating in Eastern Europe and Central Asia. In Western Europe, HIV is mostly transmitted among MSM, whereas heterosexuals and PWID are most at risk in Eastern Europe.

Nearly 160 000 people were diagnosed with HIV in 2017, once again the highest rate ever reported for one year. An increasing majority, 82%, were diagnosed in the East of the Region and 16% in the EU/EEA. Newly diagnosed infections from two countries alone (the Russian Federation and Ukraine) contributed 75% of all cases in the WHO European Region and 92% of cases in the East. However, in data presented in the ECDC Surveillance Report 2018, countries in the EU/EEA reported a decline in rates of new diagnoses, mainly driven by a 20% decrease since 2015 among men who have sex with men.

International HIV testing guidelines recommend that voluntary, confidential and free HIV testing should be available in a variety of settings. Routine and universal testing should be offered to attendees of specified services such as STI clinics, antenatal care clinics and harm reduction services. Testing should also be available through community testing sites and outreach activities targeting key populations at high risk of HIV. Robust monitoring and evaluation are key when carrying out HIV testing activities. Increasing testing offer and uptake, particularly among those most at risk of infection, is an essential element of any strategy to curb HIV - as well as HBV and HCV - in Europe. It can be achieved by strengthening existing interventions while devising new strategies for testing including targeting more than one infection, as recommended by the 2018 ECDC public health guidance on HIV, hepatitis B and C testing in the EU/EEA.

HIV testing and HIV diagnosis are the crucial first steps to treatment and care of PLHIV. While ART coverage has expanded in most countries, the scale-up in Eastern Europe and Central Asia lags behind the increase in new infections, and limited access to ART in many countries contributes significantly to high levels of late diagnosis.

The results from the START Study provide scientific evidence to support that ART is recommended for all people with HIV regardless of pre-treatment CD4 count. This study does not only have important implications for how ART is used worldwide, but also further demonstrates the importance of improving access to HIV testing to get people earlier into care. Availability of earlier treatment can encourage more people to learn their HIV status and offer opportunities to provide expanded access to HIV testing services.

Although the overall situation is better in Western Europe, there are many settings where HIV test access, uptake and linkage to care need improvement. Data on linkage to care and treatment after a HIV diagnosis showed that among those reported linked to care, 86% had been linked within 3 months of diagnosis, however this percentage was the lowest in the eastern region (82%).

In a study from the UK, they conclude that ART has almost certainly exerted a limiting effect on HIV incidence and that higher rates of HIV testing combined with initiation of ART at diagnosis would be likely to lead to substantial reductions in HIV incidence. Therefore, testing is the entry point to treatment and effective treatment either eliminates or suppresses the virus leading to improved health of those tested and prevents further transmission.

Further reading

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Section 4 – Late diagnosis of HIV infection

This section includes an overview of the content contained on **slides 10 to 14**.

Late presentation for HIV care: definition

The expression 'late presentation' reflects people who are unaware of their HIV infection and do not test until the CD4 count has declined below a certain level.

The use of diverse definitions of late presentation of HIV infection has been a problem for years, but in October 2009, a consensus definition was reached. It was agreed that **late presentation** is when:

- Persons present for care with a CD4 count below 350 cells/mL
- Or present with an AIDS-defining event, regardless of the CD4 cell count

It was further agreed that presentation with **advanced HIV disease** is when:

- Persons present for care with a CD4 count below 200 cells/mL
- Or present with an AIDS-defining event, regardless of the CD4 cell count

Late diagnosis in Europe: EU/EEA countries

Data from the annual ECDC and WHO Regional Office for Europe on HIV/AIDS surveillance report shows that over half (53%) of those diagnosed with HIV in 2017 were diagnosed at a late stage of infection and the percentage was highest in the East (57%), lower in the Centre (53%) and lowest in the West (49%), while 49% were diagnosed late in the EU/EEA.

Of those diagnosed at a late stage of infection, the highest proportion was among women (52%), older adults (56% in people aged 40-49 years old, 63% in those over 50), men and women infected by heterosexual sex (63% and 53%, respectively), people who acquired HIV through injecting drug use (52%) and migrants from south and south-east Asia (53%) and sub-Saharan Africa (56%).

'… services should focus on reaching the most affected population groups in the local epidemic context, be tailored to the specific needs of these groups and support timely linkage to HIV prevention, treatment and care. This will ensure earlier diagnoses and treatment initiation and result in improved treatment outcomes, reduced morbidity, mortality and HIV incidence in support of the second and third 90-90-90 targets.'

The 25 EU/EEA countries that reported national percentages of late presenters in 2017 are:

EU countries Late Presentation for 2017			
Austria	**47.9%**	Latvia	**62%**
Belgium	**41.9%**	Lithuania	**66.3%**
Bulgaria	**47.8%**	Luxembourg	**50%**
Croatia	**57.8%**	Malta	**54.8%**
Cyprus	**41.3%**	Portugal	**51.5%**
Czech Republic	**32.6%**	Romania	**60%**
Denmark	**46.5%**	Slovakia	**46.6%**
Estonia	**53.8%**	Slovenia	**45.5%**
Finland	**48.4%**	Spain	**47.9%**
France	**48.2%**	Sweden	**46.9%**
Greece	**56.8%**	The Netherlands	**45.1%**
Ireland	**52.9%**	United Kingdom	**41.2%**
Italy	**55.9%**		

Data taken from table 14 in the European Centre for Disease Prevention and Control & WHO Regional Office for Europe HIV/AIDS surveillance in Europe 2018 – 2017 data report.

Late presenters in Europe: Non-EU/EEA countries

In the 17 non-EU/EEA European countries that submitted data, the situation is even worse than in the EU countries. In this region, over half (56.8%) of PLHIV were late presenters. The 17 countries with reported data on late presenters in non-EU/EEA countries in Europe are:

Non-EU countries Late Presentation for 2017			
Albania	**58.6%**	Moldova	**53.3%**
Andorra	**-**	Montenegro	**61.5%**
Armenia	**54.8%**	Serbia	**65.6%**
Azerbaijan	**52%**	Switzerland	**47.2%**
Bosnia and Herzegovina	**50%**	The Former Yugoslav Republic of Macedonia	**38.2%**
Georgia	**52.2%**	Tajikistan	**62.5%**

Israel	**46.6%**	Turkey	**-**
Kazakhstan	**45.6%**	Ukraine	**58.8%**
Kyrgyzstan	**67.5%**		

Data taken from table 14 in the European Centre for Disease Prevention and Control & WHO Regional Office for Europe HIV/AIDS surveillance in Europe 2018 – 2017 data report.

Section 5 – Characteristics of persons with late diagnosis

This section includes an overview of the content contained on **slides 15 to 17**.

Late diagnosis

Late diagnosis of HIV infection and entry into care remains a problem across Europe and despite continued efforts to optimise testing for HIV, data from an update of the COHERE study found that there has been no overall change in the proportion of late presenters across Europe since 2010.

The researchers analysed data from over 20 observational studies from across Europe that contribute data to the COHERE collaboration and found that nearly 54% of the participants diagnosed with HIV presented late to a clinic.

Researchers found that late presentation decreased from 57.3% in 2000 to 51.7% in 2010/11 across all populations. However, in some sub-populations, such as PWID in Southern Europe, late presentation increased over the same period. Furthermore, late presentation was found to be associated with an increased rate of AIDS related deaths, particularly in the first year after HIV diagnosis. They also found that less than 10% of individuals had delayed entry into care after diagnosis, although this information was only available for a minority of patients.

Characteristics of late presenters

Across Europe, the most common characteristics of individuals with late diagnosis include:

- Migrant status
- Being older
- Being heterosexual
- Living in low HIV prevalence areas
- Being male
- Having children

These characteristics are, however, overall findings. For example, most studies indicate that heterosexuals are at greater risk of late diagnosis than MSM – but in Eastern Europe it appears that MSM are more likely to present late.

Characteristics of late presenters thus vary from country to country and depend on local barriers to testing – on patient, healthcare provider and institutional levels.

Further reading

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Section 6 – Consequences of late diagnosis

This section includes an overview of the content contained on **slides 18 to 27**.

Consequences of late diagnosis

The consequences of late presentation are alarming, for the patient in terms of increased morbidity and mortality, and for society in terms of increased transmission of HIV to uninfected people. This in turn impacts upon the health system in terms of the resulting higher cost of care.

Consequences of late diagnosis: increased morbidity and mortality

Several studies have demonstrated severe health consequences of late HIV diagnosis with highly increased morbidity and mortality. Earlier HIV diagnosis is one of the most important factors associated with better life expectancy. Studies have shown that people who are diagnosed early and have access to a variety of current drugs can expect nearly the same life expectancy as that of HIV negative individuals. Further, the results from the START Study demonstrate that starting ART as soon as possible after diagnosis improves mortality and morbidity as opposed to starting ART after the CD4 count has dropped to 350 cells/mm^3.

For more specific information, see the further reading section.

Consequences of late diagnosis: increased transmission of HIV to uninfected people

When people are unaware of their positive HIV status, they have a higher risk of transmitting HIV to other (uninfected) people – studies have shown that a diagnosis of HIV motivates a proportion of infected individuals to adopt behaviour that reduce risk of infecting HIV-negative people.

Based on modelling data, half or more of new infections in the United States derive from PLHIV who are not yet diagnosed and therefore unaware of the possible risk of transmission. A study from the United Kingdom found that the source of most new infections is from undiagnosed men. An increase in HIV incidence in the last 10 years despite a gradually larger percentage of MSM on fully suppressive ART has been observed. This study demonstrates that increase of testing leads to a decrease in transmission.

However, if the person living with HIV is well treated on ART, they will reduce their viral load and dramatically decrease the possibility of transmission. The PARTNER Study has shown that among serodifferent heterosexual and MSM couples in which

the HIV-positive partner was using suppressive ART and who reported condomless sex, there were no documented cases of within-couple HIV transmission.

Consequences of late diagnosis: increased economic burden for health systems

People with HIV infection, who present late for care, incur higher cumulative direct HIV treatment expenditures than those who present earlier in the disease process.

A study from the United States has shown that:

- Mean medical care expenditures for late presenters were 1.5 to 3.7 times as high as expenditures for early presenters, similar to a Canadian study. Although expenditure differences between late and early presenters narrowed for those with more than 5 years in care, late entry was still associated with higher cumulative expenditures than early entry, even among those with 7 to 8 years of primary HIV care.

In another study from the United States, it was concluded that:

- Costs remain high or are increasing in patients with CD4 counts ≤75 cells/mL. Patients with very low CD4 cell counts are either long-term patients experiencing a serious decline in health following failure of ART or disconnection from healthcare, or are more recently diagnosed patients (i.e. late presenters) who were unaware of their HIV status until they were hospitalised with AIDS. Such patients with low CD4 levels usually require intense monitoring with frequent clinic visits, lab tests and complex ART regimens.

There are several benefits of early diagnosis and HIV testing has proven to be cost-effective. Studies suggest that HIV testing remains cost-effective as long as the undiagnosed HIV prevalence is above 0.1%.

Further reading

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Further reading

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Section 7 – Barriers to HIV testing

This section includes an overview of the content contained on **slides 28 to 34**.

Barriers to HIV testing

Despite the expectation that ART would lead individuals to seek earlier testing, this trend has not been observed in practice, with stable or even increasing rates of late diagnosis in Europe being witnessed. It is therefore important to examine barriers to HIV testing. Barriers to HIV testing vary from country to country but are usually present at three different levels:

- Patient level
- Healthcare provider level
- Institutional/policy level

Patient level

Barriers to testing at the patient level vary from country to country, between different groups (high risk vs. low risk groups) and depend on a variety of personal/individual perceptions of being infected with HIV.

The most often mentioned barriers at this level are:

- Low-risk perception
- Fear of HIV infection and its health consequences
- Fear of disclosure (worries about stigma, discrimination and rejection by significant others)
- Denial
- Difficulty accessing services, especially migrant populations

Additional barriers include:

- Poor accessibility of health services
- Lack of information on HIV testing
- Concerns about being associated with stereotyped groups (MSM, PWID, SWs)
- Fear of sexual exclusion by those who are HIV- negative or untested
- Fear of mistreatment by healthcare workers
- Concerns about losing their employment or schooling
- Fear of losing spouse/partner, friends or family and ability to marry
- Fear that their children would be stigmatised

Such patient-level barriers to HIV testing may remain despite shifts in both community and behavioural norms.

Healthcare provider level

The 2018 ECDC guidance on integrated testing of HBV, HCV and HIV supports countries in the global effort to combat viral hepatitis and eliminate HIV as a public health challenge by 2030. The guidance provides evidence-based recommendations on how to improve and implement testing policies. However, not all European countries have national guidelines on HIV testing and there is a great variety of testing strategies across Europe.

In many European countries, TB patients, STI patients and pregnant women are HIV tested on a routine basis. Routine HIV testing could – and should – be offered in all healthcare settings where most-at-risk populations are seen on a regular basis (e.g. PWID treatment centres, STI clinics, etc.).

The WHO/UNAIDS guidance on provider-initiated HIV testing and counselling in health facilities (2007) recommends that HIV testing should normally be performed at the initiative of healthcare providers, much like other routine investigations, unless the patient declines. Several studies have demonstrated that direct verbal offers of HIV testing improve uptake rates in different healthcare settings.

Barriers among healthcare providers may include:

- Healthcare providers are anxious (or even reluctant) to raise questions about HIV
- Lack of time for pre-test counselling or suitable location for counselling
- Concerns about distressing the patients and harming the doctor-patient relationship
- Lack of knowledge about HIV and HIV testing
- Lack of capacity for general practitioner/family doctor to offer testing and to communicate benefits of testing
- Anxiety on the part of the doctor about how to manage a positive result
- Feeling deskilled/need of training
- Patient not perceived to be at risk

Many of the barriers mentioned above depend on the attitude of the individual healthcare provider. Healthcare providers should be trained to be more proactive and confident in addressing HIV testing and should be trained to provide updated and relevant information on PrEP in addition to providing STI testing and/or give appropriate referral for testing for other STIs.

Institutional/policy level

Barriers to HIV testing at the institutional/policy level include: lack of training of health staff, inadequate financial resources and costs of tests and a lack of national guidelines for HIV testing.

The dossier of evidence focuses on provider-initiated, indicator condition-guided HIV testing and legal issues – including laws that jeopardise HIV prevention efforts.

HIV testing on basis of HIV indicator diseases – in healthcare settings where HIV testing may not be undertaken as part of the standard medical care for patients – has also proven both feasible and cost-effective. Indicator condition-guided HIV testing should be considered as an additional element of an overall comprehensive national HIV testing strategy.

Institutional/policy level: laws and justice system

Laws safeguarding dignity, health and justice are essential to effective HIV responses. The legal environment – laws, enforcement and justice systems – has immense potential to improve the quality of life of PLHIV and to curb the HIV epidemic.

'The Global Commission on HIV and the Law' concluded after 18 months of extensive research, consultation and analysis that punitive laws, discriminatory and brutal policing and denial of access to justice for people with and at risk of acquiring HIV are fuelling the epidemic.

These legal practices create and punish vulnerability. They promote risky behaviour, hinder people from accessing prevention tools and treatment, and exacerbate the stigma and social inequalities that make people more vulnerable to HIV. The Commission further concluded that many countries have laws that criminalise exposure to HIV or to transmit it, especially through sex. Such laws do not increase safer sex practices. Instead, they discourage people from getting tested or treated, in fear of being prosecuted for passing HIV to lovers/sexual partners or children.

The Commission also concluded that worldwide 123 countries have legislation to outlaw discrimination based on HIV; 112 legally protect at least some populations based on their vulnerability to HIV. But these laws are often ignored, laxly enforced or aggressively flouted. It is a common understanding that laws, based on evidence and grounded in human rights principles, are a relatively low-cost way of controlling HIV and reducing stigma.

Example: legislative and social environments affecting MSM

The legal situation facing MSM, and the social regulation of homosexuality, varies across the European region. There is a clear pattern of increased restrictiveness in the East compared to the West. In part, this is because membership of the EU requires the repeal of anti-homosexuality legislation, and the Treaty of Amsterdam requires its Member States to enact anti-discrimination legislation.

Slide 33 shows the legislative and social environments affecting MSM in the European region. Some countries display every feature of an enabling environment in terms of legislation, social inclusion and acceptance, including the recognition of civil partnership or marriage. In other countries, sex between two consenting male adults remains illegal and in a few countries, sex between men is punishable by imprisonment.

Institutional/policy level: regulatory barriers

Regulatory barriers to HIV testing vary across Europe and may hinder HIV testing uptake by limiting actions to appropriately target most at risk populations and providing appropriately located HIV testing sites. It is important to evaluate whether regulations act as obstacles to HIV testing. This, indeed also applies to integrated testing and STI testing across Europe as well as self-testing for HIV.

Further, rapid tests are advantageous in settings where venipuncture is not possible or where quick turnaround of test results is desirable, for example in busy clinical settings or community testing sites. However, rapid testing and community testing is limited in many countries.

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Section 8 – Overcoming barriers to HIV testing

This section includes an overview of the content contained on **slides 35 to 45**.

Implementation of national HIV testing guidelines

Countries of Europe vary widely in their political and social approaches to HIV. However, to ensure that a national HIV testing strategy takes an ethical approach based on human rights, countries need to adhere to core principles for HIV testing.

WHO published consolidated guidelines on HIV testing services in July 2015 and the 2018 ECDC public health guidance on HIV, hepatitis B and C testing in the EU/EEA provide the evidence-based framework to help develop, implement, monitor and evaluate testing guidelines and programmes on the national level. Some of the key recommendations are:

- The 2015 WHO HIV Testing Guidelines recommend that lay providers who are trained and supervised can independently conduct safe and effective HIV testing using RDTs to support task sharing in the health sector.
- Further, to close these various gaps in coverage and quality, more proactive, rights-based HIV testing approaches are needed, and integrated testing should be encouraged where appropriate.
- It is recommended to offer retesting at least annually – and up to every 3 months – depending on ongoing risk, sexual behaviour, history of transmitted infections, use of PrEP or PEP to people from key populations and to HIV-negative partners in serodiscordant couples. Depending on client risk behaviours, more frequent voluntary retesting should be offered, and available, and self-testing/self-sampling could be an option, where available with effective linkage to care.

Combination Prevention

The message of ‘combination prevention’ has evolved in recent years with its origins starting in the idea that HIV prevention programmes needed to be rooted in evidence-based behavioural, structural and clinical interventions. However, presently, ‘combination prevention’ addresses the diverse needs of HIV prevention programmes and how the many clinical options currently available, used in combination, can improve prevention outcomes. What were once single method strategies, pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP) and treatment as prevention (TasP), have now been combined with common HIV prevention messages, key population engagement, frequent HIV testing as well as for STIs, harm reduction, quick linkage to care and using condoms, to provide as many ways of prevention possible to an array of populations. Furthermore, when tied

to messaging that encourages and empowers the audience to decide which method would best suit their needs, the decision making is brought back into their own hands.

It is recommended that testing messaging should not only promote messages of regular testing and condom use, but also use of PrEP, PEP and TasP to inform audiences that by combining methods, HIV prevention can be the most effective and reach a more diverse range of people.

Options for more frequent testing can also include the offer of self-testing and/or self-sampling, where available and with established linkage to care.

Outreach for most-at-risk populations for HIV

Many people belonging to the populations most-at-risk (including PWID, MSM, SWs, migrants and mobile populations and national minorities) are in limited contact with the healthcare system.

WHO (2015) notes that:
'In almost all countries and settings, HTS for key populations are inadequate, and their access to HIV prevention, treatment and care services remains limited. Countries should prioritize, fund and support acceptable services for key populations and recognize and address health system, social and legal barriers that currently prevent equitable access to HTS by key populations.'

'Community-based HTS is a critical approach for reaching people from key populations who are unlikely to go to a facility for HIV testing, particularly those who are asymptomatic. To improve access to and uptake of HIV testing, community-based HTS should be made available in locations and settings acceptable and convenient to people from key populations.'

WHO (2015) recommends that:
'HIV testing services should be routinely offered to all key populations in the community, closed settings such as prisons, and clinical settings.'

'Community-based HIV testing services for key populations, with linkage to prevention, treatment and care services, is recommended in addition to provider-initiated testing and counselling'

'Couples and partners should be offered HIV testing services with support for mutual disclosure. This applies also to couples and partners from key populations'

ECDC (2018) recommends testing frequency for most at risk populations:
'It is recommended to offer retesting at least annually – and up to every 3 months – depending on ongoing risk, sexual behaviour, history of transmitted infections, use of PrEP or PEP to people from key populations and to HIV-negative partners in serodiscordant couples.'

In addition, a person can perform an HIV test on him or herself as a means of securing access and increase uptake of HIV testing. Self-testing can make it easier for at risk groups to test more frequently and may accommodate more as it provides the opportunity to test in your own home.

Normalisation of HIV testing

Several studies have demonstrated that HIV testing can be normalised in various settings and patient groups. One study has shown that offering an HIV test is acceptable to 83% of acute medical patients, but another study suggests that tests are often not offered, e.g. only 43% of cases of TB were tested for HIV. In a study in Lithuania that examined routine HIV screening during admissions to an infectious disease clinic found that that such programme was acceptable, feasible, sustainable and clinically effective. When compared to targeted testing, routine testing helped to identify patients in earlier stages of their infection. Another study from the United Kingdom found that the offer of an HIV test in non-traditional settings was acceptable to 92% of patients and 96% of staff supported expanding HIV testing. Another study suggested normalisation of testing leads to higher testing rates and more new HIV cases being found.

Overcoming barriers: HIV indicator conditions

In an indicator condition-guided HIV testing strategy, all patients presenting to any healthcare setting with specific indicator conditions, would be routinely recommended an HIV test. Routine testing for conditions with an HIV prevalence of >0.1% has been reported to be cost-effective and has the potential to increase earlier diagnosis of HIV, leading to earlier opportunities for care and treatment.

The guidelines recommend that any person (not known to be HIV positive) presenting with potentially AIDS defining conditions should be strongly recommended HIV testing.

AIDS defining conditions are:

Neoplasms

- Cervical cancer
- Non-Hodgkin lymphoma
- Kaposi's sarcoma

Bacterial infections

- Mycobacterium tuberculosis, pulmonary or extrapulmonary
- Mycobacterium avium complex (MAC) or Mycobacterium kansasii, disseminated or extrapulmonary
- Mycobacterium, other species or unidentified species, disseminated or extrapulmonary
- Pneumonia, recurrent (2 or more episodes in 12 months)
- Salmonella septicaemia, recurrent

Viral infections

- Cytomegalovirus retinitis
- Cytomegalovirus, other (except liver, spleen, glands)
- Herpes simplex, ulcer(s) >1 month/bronchitis/pneumonitis
- Progressive multifocal leukoencephalopathy

Parasitic infections

- Cerebral toxoplasmosis
- Cryptosporidiosis diarrhoea, >1 month
- Isosporiasis, >1 month
- Atypical disseminated leishmaniasis
- Reactivation of American trypanosomiasis (meningoencephalitis or myocarditis)

Fungal infections

- Pneumocystis carinii pneumonia
- Candidiasis, oesophageal
- Candidiasis, bronchial/tracheal/lungs
- Cryptococcosis, extra-pulmonary
- Histoplasmosis, disseminated/extra pulmonary
- Coccidiodomycosis, disseminated/extra pulmonary
- Penicilliosis, disseminated

The guidelines recommend that any person presenting with a condition with an undiagnosed HIV prevalence of >0.1% should be strongly recommended HIV testing.

Conditions associated with an undiagnosed HIV prevalence of >0.1 % are:

- Sexually transmitted infections
- Malignant lymphoma
- Anal cancer/dysplasia

- Cervical dysplasia
- Herpes zoster
- Hepatitis B or C (acute or chronic)
- Mononucleosis-like illness
- Unexplained leukocytopenia/thrombocytopenia lasting >4 weeks
- Seborrheic dermatitis/exanthema
- Invasive pneumococcal disease
- Unexplained fever
- Candidaemia
- Visceral leishmaniasis
- Pregnancy (implications for the unborn child)

For indicator conditions where expert opinion considers HIV prevalence likely to be >0.1%, but awaiting further evidence, it is recommended to offer testing.

The indicator conditions are:

- Primary lung cancer
- Lymphocytic meningitis
- Oral hairy leukoplakia
- Severe or atypical psoriasis
- Guillain–Barré syndrome
- Mononeuritis
- Subcortical dementia
- Multiple sclerosis-like disease
- Peripheral neuropathy
- Unexplained weight loss
- Unexplained lymphadenopathy
- Unexplained oral candidiasis
- Unexplained chronic diarrhoea
- Unexplained chronic renal impairment
- Hepatitis A
- Community-acquired pneumonia
- Candidiasis

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Section 9 – Monitoring and evaluation

This section includes an overview of the content contained on **slides 46 to 51**.

Monitoring and evaluation (M&E) is an essential component of an HIV testing programme and ensures that the programme provides high quality HIV testing. FACTS criteria can be used when designing M&E:

- **F**easibility
- **A**cceptability
- Effectiveness and **C**ost-effectiveness
- **T**arget populations are reached
- **S**ustainability

Several indicators can be applied in order to assess local HIV testing initiatives using FACTS criteria. Examples of indicators to measure **F**easibility can be: number and percentage of persons offered HIV testing or percentage of newly diagnosed individuals who are successfully transferred to care within three months (**see slides 47-48** for further examples of indicators).

Section 10 – Conclusions

This section includes an overview of the content contained on **slides 52 to 54**.

Conclusions

In 2017, a total of 159 420 people were diagnosed with HIV in Europe. Past efforts have not been able to prevent new HIV infections. Scaling up of HIV testing is therefore essential, and new and dedicated initiatives are needed to turn the epidemic around.

A successful scaling up of HIV testing and linkage to HIV treatment and care will decrease morbidity and mortality among patients, reduce the number of new HIV infections, decrease the ongoing transmission of HIV and consequently lessen the economic burden in health systems.

To be most effective, these efforts should be targeting barriers to HIV testing at three different levels: **patient level, healthcare provider** and **institutional/policy level**.

The specific kind of barriers varies from country to country and need to be targeted after careful analysis in individual countries.

- Populations most at-risk of HIV should be targeted with focused interventions and healthcare systems, and where HIV testing is not part of the standard medical care, indicator condition-guided HIV testing should be implemented
- National HIV testing guidelines, that are aligned with international recommendations, should be implemented
- Training and awareness raising is crucial in order to normalise HIV testing in the healthcare system, e.g. by implementing indicator condition-guided HIV testing strategies
- Laws that are jeopardising HIV prevention effort should be abolished and HIV testing strategies should take an ethical approach based on human rights
- Monitoring and evaluation systems should be implemented and help ensure that the programme provides high quality HIV testing

Section 11 – Template Slides

This section includes an overview of the template slides that are included in the slide deck. These can be edited by you with some or all of the information suggested on the slides.

Slide 9: Know your HIV epidemic

This is a template slide for you to insert data on national statistics such as HIV incidence and HIV prevalence.

Slide 14: Late diagnosis of HIV infection

This is a template slide for you to insert data on late diagnosis and advanced HIV infection.

Slide 34: Barriers to HIV testing

This is a template slide for you to insert information about local barriers to testing.

Slide 51: Monitoring and evaluation

This is a template slide for you to insert information about how monitoring and evaluation systems have been implemented locally.

Slide 55: Examples of efforts to scaling up HIV testing

This is a template slide for you to populate with examples of successful testing initiatives that you or other HIV organisations have been involved in. See also a collection of materials at the testing week website at www.testingweek.eu.