



# Overcoming Obstacles to Late Presentation for HIV in Europe

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## OBJECTIVE

The overall objectives of the HIV in Europe Initiative are to:

- 1) Determine and work towards reducing the number of people living with HIV in Europe who are unaware of their serostatus;
- 2) Identify political, structural, clinical and social barriers to achieving optimal counseling and testing and earlier access to care;
- 3) Promote evidence based practices and guidance on HIV counseling and testing in Europe;
- 4) Study the proportion of people living with HIV presenting late for care.

## METHODS

HIV in Europe is a pan-European initiative launched in 2007. The initiative has developed concrete projects in order to provide evidence and recommendations on the key barriers to testing in Europe and beyond (see **Table 1**).

Building on past achievements of the HIV in Europe initiative, including the adoption of the European Parliament joint resolution on early diagnosis and early care, the initiative reinforces collaboration, advocacy and networking activities in the field throughout Europe on national and EU levels.

## RESULTS

- Consensus definition of late presentation published and commenced implemented (**Results 1**)
- Improved methods to estimate the number of undiagnosed (**Results 2**)
- Indicator disease guided testing on the European (testing) agenda (**Results 3**)
- Initiatives started to develop and implement evidence-based strategies to reduce the barriers to testing due to stigmatisation, discrimination and criminalisation; (**Results 4 & 5**)

Tables	
Overcoming obstacles to late presentation for HIV in Europe	
Key barriers	Results
1. A lack of understanding of what is meant by "a person presenting late for care"	<b>Result 1:</b> A consensus definition of late presentation has been developed.
2. Great uncertainty with regard to the number of people living with HIV in the European Region	<b>Result 2:</b> Preparation of a document to provide guidance to countries on methods available and data needed to estimate numbers of people infected but not yet diagnosed.
3. No list of HIV indicator diseases across Europe	<b>Result 3:</b> A pilot study initiated will assess HIV prevalence in eight indicator diseases in specific populations. The project includes 17 centres in 14 countries and the plan is to screen 7,000 persons with an indicator disease for HIV.
4. Stigma is one of the major barriers for both early HIV testing and earlier initiation of HIV Treatment	<b>Result 4:</b> Support for the People Living with HIV Stigma Index in 5 European countries.
5. Criminalisation of HIV	<b>Result 5:</b> A review of how criminalisation of HIV can deter people from seeking HIV testing and have other negative consequences for public health.

### Results 1: When is a patient presenting late for care?

<b>Late presentation:</b> Persons presenting for care with a CD4 count below 350 cells/μL or presenting with an AIDS-defining event, regardless of the CD4 cell count.
<b>Presentation with advanced HIV disease:</b> Persons presenting for care with a CD4 count below 200 cells/μL or presenting with an AIDS-defining event, regardless of the CD4 cell count.

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The European Late Presenter Consensus working group recommends that all national health agencies, institutions, and researchers implement this definition when reporting surveillance or research data related to late presentation of HIV.

### Results 2: The number of undiagnosed PLHIV

- The surveillance to identify the exact extent of the number of undiagnosed PLHIV remains insufficient across Europe. Different estimation approaches exist, using different sources of data, and many countries do not appear to produce any estimates.
- The HIV in Europe initiative has initiated a Working Group on Estimation of HIV Prevalence in Europe who will present a document outlining all available approaches and providing the necessary guidance for using them.
- The guidance document can help countries decide which data to collect in order to improve approaches of estimating the number of undiagnosed people living with HIV.

Guidance for countries on requirements and available methods for estimation of the number of people with HIV, to be published as a review in *AIDS* 2010

## CONCLUSION

HIV in Europe recommends:

- The initiation of audits to evaluate whether testing is being conducted in situations where there is an obvious indication;
- Increased interaction and awareness raising among clinicians within different specialities and implementation of indicator disease guided testing;
- Collection of key additional surveillance data for more reliable estimations of the size of the infected but not yet diagnosed population;
- Collaboration and coordination across borders and cross-sectoral collaboration between clinicians, affected communities, program implementers and policy makers;
- Monitoring the implementation of testing and treatment guidelines across Europe.

### The HIV in Europe Study Group

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**Working Group on Estimation of HIV Prevalence in Europe** (conveners: Andrew Phillips and Rebecca Lodwick, University College London Medical School, Royal Free Campus, London, **UK**)

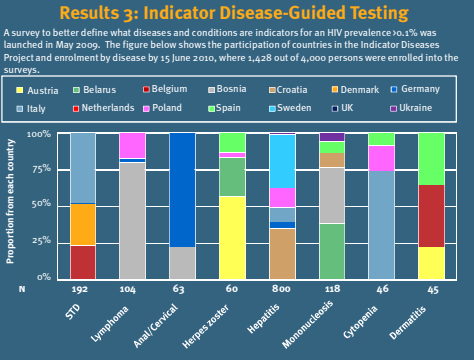
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### Results 4: The influence of stigmatisation on access to testing and treatment

- In 2008 the Global Network for People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS presented 'The People living with HIV Stigma Index'. The index aims to build the evidence base for understanding stigma and discrimination experienced by people living with HIV.
- HIV in Europe supports the implementation and roll-out of the stigma index in Poland, Ukraine, Estonia, Moldova, and Turkey. The issue of access to treatment and barriers to testing has been embraced by the country teams wishing to implement the index.

Country reports and a report examining the effects of stigma and discrimination on access to testing and treatment available by 4<sup>th</sup> quarter 2010

### Results 5: Criminalisation of HIV and the impact on testing and treatment

- The aim of the "Criminalisation of HIV in the European Region" study is to review legislation across the European Region that singles out the criminalization of HIV, and describe such laws, the reasoning for them and investigate whether this has had any effect on the spread of the disease in the country including its potential impact on testing.
- The pilot study consists of an analysis and evaluation of the HIV transmission and exposure laws in 5 countries (Hungary, The Netherlands, Sweden, Switzerland and the UK (England and Wales)).

Discussion and Issues Paper on Criminal Liability for Exposure to and Transmission of HIV, to be published in 2010