

## Outcomes of the HIV in Europe Initiative

### Annual Report 2010

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## Introduction

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 HIV testing in Europe and beyond (see Table 1). Building on achievements of the HIV in Europe initiative, including the adoption of the European Parliament joint resolution on early diagnosis and care, the initiative reinforces collaboration, advocacy and networking activities in the field throughout Europe at the national and European Union levels.

## 2010 in short

2010 has been an exciting year for the HIV in Europe initiative. Results of the projects initiated in 2009 have been published and the initiative has established itself as an important pan-European platform for sharing ideas and knowledge. The initiative is seen as an important stakeholder in the fight against HIV/AIDS, and has been invited to and had abstracts and articles accepted for a number of conferences and journals during 2010. One of the aims of the initiative is to stimulate organisations to put the issue on their agenda. As a result, the initiative has experienced a cascading of its messages during 2010 through the strong collaboration with HIV policy relevant organisations and other important stakeholders.



## 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"	Result 1. 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	Result 2. 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	Result 3. 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 7000 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	Result 4. Support for the People Living with HIV Stigma Index in 5 European countries.
5. Criminalisation of HIV	Result 5. A review of how criminalisation of HIV can deter people from seeking HIV testing and have other negative consequences for public health.

### HIV in Europe Call to Action

HIV in Europe is working according to the following call to action (adopted at the Stockholm Conference, November 2009).

- To promote early testing and treatment throughout the European and Central Asian region;
- To keep early testing and treatment on the political agenda in Europe and Central Asia;
- To identify and stimulate the implementation of best practices;
- To support the implementation of the consensus on late presentation;
- To develop one model to estimate the number of people infected and yet not diagnosed with HIV;
- To develop and implement indicator disease guided testing;
- To stimulate an evidence base on and reduce barriers to testing regarding human rights, stigma, discrimination and criminalisation;
- To stimulate health professionals, policy makers and civil society including people living with HIV to advocate and collaborate.

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 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.

### **Achievements 2010**

- Consensus definition of late presentation published in *HIV Medicine*, June 2010 and referenced in presentations and publications thereafter. ECDC special report 2010 use the definition and urge member states to report CD4 count when reporting surveillance data. HIV in Europe will continue advocating for its use through the communication and advocacy activities.
- Guidance on methods and surveillance data requirements to estimate the number of undiagnosed (currently being revised for publication as a special review in *AIDS*, co-authored by a working group). ECDC has launched a multi-year project contract “Improving Tools to Estimate HIV Prevalence in European Union and EEA/Efta Countries (Grant/2009/001)” to address the need of producing better tools for estimating HIV prevalence among EU/EEA Member States. HIV in Europe will continue advocating for the improvement of surveillance data on late presenters through the communication and advocacy activities.
- A new innovative statistical method to estimate the number of people in a country or region with HIV who are undiagnosed and in need of ART under development by Andrew Phillips and Rebecca Lodwick, UCL. The method requires CD4 count at diagnosis, with a specific application to estimating the number of undiagnosed people with low CD4 count.
- Indicator disease guided testing on the European (testing) agenda and development of European standard for how to do surveys of HIV prevalence in potential indicator diseases in specific settings.
  - The concept has proved effective through the pilot phase of the Indicator Diseases across Europe Study, the preliminary results of which were presented at Glasgow 10, November 2010.
  - Institutional support from centres across Europe and for the implementation of a 2<sup>nd</sup> phase of the project.
  - Indicator diseases as part of the ‘ECDC guidance HIV testing: increasing uptake and effectiveness in the European Union’, released in December 2010.

- Support for the People Living with HIV Stigma index in 5 countries (Poland, Ukraine, Estonia, Moldova and Turkey) focusing specifically on analysing stigmatisation as a potential barrier to access to testing and treatment.
- National rapporteur system in place – monitoring the development and implementation of national testing guidelines and national testing initiatives to the HIV in Europe website [www.hiveurope.eu](http://www.hiveurope.eu)
- HIV in Europe Communications policy and strategy 2010-2012 and monitoring system developed.
- HIV in Europe as part of the ECDC Technical Advisory Group on HIV testing and invited to present at the launch of the 'ECDC guidance – HIV testing: increasing uptake and effectiveness in the European Union' in the European Parliament on 1<sup>st</sup> December 2010, (with participation of the Belgian Minister of Social Affairs and Public Health for the Belgian EU Presidency, Commission for Health and Consumer Policy John Dalli, and ECDC Director Marc Sprenger among others.
- Engagement of the EU Civil Society Forum members on advocacy on HIV testing at national level.
- Engagement of the EU Think Tank members in focussed discussion on how to improve HIV testing across Europe.
- Project financed by EuroCoord with the objectives to study the epidemiology for those persons who are presenting late with HIV over time compared to those presenting early for care. The project has been funded through the EuroCoord Network of Excellence FP7 grant.
- In order to improve multi-profession, multi-country stakeholder dialogue to develop solutions in HIV research and policy to improve early diagnosis and care of HIV patients across Europe, the following concrete outputs can also be mentioned:
  - 500 brochures distributed at international conferences since July 2010
  - 4 newsletters produced
  - Hits on the website: 986 unique visits from 75 countries (from 22 September – 31 December)
  - 6 Steering Committee meetings and teleconferences
  - Update meetings with sponsors at Vienna 2010 and Glasgow 10

## **Publications**

*A timely reminder*, J Lundgren, T Coenen, D Raben, Public Service Review, Health and Social Care, issue 25, Nov 2010

*Overcoming obstacles to late presentation for HIV in Europe*, Jeffrey V. Lazarus, Ralf Jürgens, Matthew Weait, Andrew Phillips, Julian Hows, José Gatell, Ton Coenen, Anders Sönnernborg, Dorthe Raben, Jens D. Lundgren, HIV Medicine, Published Online: 29 Aug 2010

European late presenter working group: *Late presentation of HIV infection: A consensus definition*, HIV Medicine, Published Online: 17 Jun 2010

*Optimising testing and earlier care*, Ton Coenen and Jens Lundgren, European Parliament Magazine, Dec 2009

## **Presentations**

2010 National Summit on HIV Diagnosis, Prevention, and Access to Care, Washington, November 2010, Poster presentation by Nikos Dedes

10th International Congress on Drug Therapy in HIV Infection, Glasgow. November 2010, A pilot study to determine the prevalence of HIV in persons presenting for care with selected conditions: preliminary results from the HIV in Europe study, Anders Sönnernborg on behalf of the HIV Indicator Diseases Across Europe Study Group

EU HIV/AIDS Think Tank, Update on the HIV in Europe Initiative, Ton Coenen, October 2010  
EU HIV/AIDS Civil Society Forum, Update on the HIV in Europe Initiative, Ton Coenen, October 2010

International AIDS Conference, Vienna, July 2010, Ensuring optimal HIV treatment in Europe: Overcoming obstacles to late presentation, Dr Jeffrey V. Lazarus, on behalf of the HIV in Europe Initiative

Poster presentation: Overcoming obstacles to late presentation for HIV in Europe

Poster presentations: Poland and Turkey on the implementation of the stigma index supported by HIV in Europe.

12<sup>th</sup> European AIDS Conference, Cologne, November 2009, The "HIV in Europe" Initiative: Progress Towards Testing and Earlier Care, Lunch Session

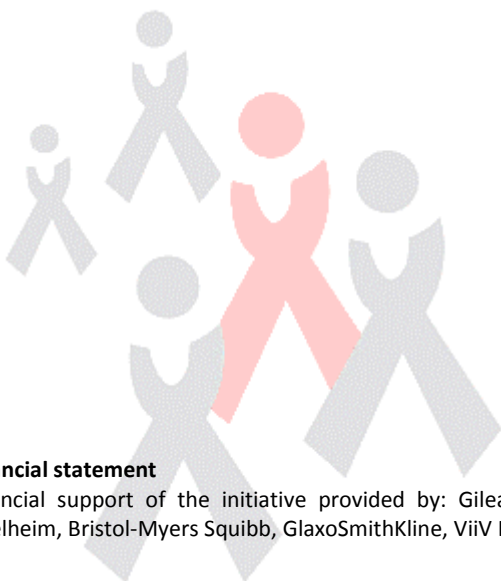
## **Next Steps – 2011**

- 1) Focus on communicating results and supporting the implementation of the consensus definition of late presentation, the "ECDC guidance HIV testing: Increasing uptake and

effectiveness in the European Union” document on methods and indicator disease guided testing

- 2) Implement 2<sup>nd</sup> phase of projects that have shown results and been able to create momentum on a large European scale.
- 3) 2011/2012 Conference on European testing initiatives.

The HIV in Europe Steering Committee will convene in February 2011 for a strategic meeting to discuss further priorities for the years to come. Being an initiative and not an organisation, HIV in Europe is dependent on the commitment of involved internal and external stakeholders to move the agenda forward.



**Financial statement**

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## The HIV in Europe Study Group

**HIV in Europe Steering Committee:** Co-Chairs: Ton Coenen, AIDS Action Europe, Executive Director Aids Fonds & Soa Aids Nederland, Netherlands and Jens Lundgren, Professor & Chief Physician, University of Copenhagen & Rigshospitalet, Director, Copenhagen HIV Programme, Denmark, Members: Henrique Barros, National Coordinator of HIV/AIDS Infections, Portugal, Nikos Dedes, Chair, Policy Working Group, European AIDS Treatment Group (EATG), Greece, José Gatell, Head, Infectious Diseases & AIDS Units, Clinical Institute of Medicine & Dermatology, Hospital Clinic, Professor of Medicine, University of Barcelona, Spain, Brian Gazzard, Professor of Medicine, Imperial College School of Medicine, HIV Research Director, Chelsea & Westminster Hospital, UK, Igor Karpov, Professor, Department of Infectious Diseases, Belarus State Medical University, Jürgen Rockstroh, Professor of Medicine University of Bonn and Head of an HIV outpatient clinic, Germany, Jean-Luc Romero, President Elus locaux Contre le Sida, France, Anders Sönnnerborg, MD, PhD, Professor, Department of Medicine Karolinska University Hospital, Sweden, John de Wit, Professor of Sociology, Utrecht University, The Netherlands, Observers: WHO Regional Office for Europe, STI/HIV/AIDS Programme, Represented by Smiljka de Lussigny, European Centre for Disease Prevention and Control (ECDC), Represented by Marita van de Laar, PhD, European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), Represented by Lucas Wiessing, epidemiologist, principal scientist, The Global Fund to Fight AIDS, Tuberculosis and Malaria, Represented by Jeffrey V. Lazarus, Centers for Disease Control and Prevention (CDC), Represented by Kevin Fenton.

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

**The HIV Indicator Diseases Across Europe Study Group.** Advisory Group: Nathan Clumeck, CHU Saint-Pierre, Brussels, Belgium, Jose Gatell, Hospital Clínic de Barcelona, Barcelona, Spain, Brian Gazzard, Chelsea and Westminster Hospital, London, England, Jens Lundgren, University of Copenhagen and Rigshospitalet, Copenhagen, Denmark, Antonella d’Arminio Monforte, Clinica delle Malattie Infettive, Milan, Italy, Jürgen Rockstroh, Department of Medicine, University of Bonn, Germany, Amanda Mocroft, University College London Medical School, UK. Centres: Austria: R Zangerle, University Hospital Innsbruck, Department of Dermatology and Venereology, Innsbruck. Belarus: A Vassilenko, Minsk Municipal Infectious Diseases Hospital, Minsk. Belgium: A Libois, S Clinic, J André, Department of Dermatology, P Kirkove, Saint-Pierre University Hospital, Brussels. Bosnia: V Hadziosmanovic, Clinical Center, University of Sarajevo, Infectious Diseases Clinic, Sarajevo. Croatia: J Begovac, University Hospital of Infectious Diseases, Zagreb. Denmark: H Sørensen, Bispebjerg Hospital, København. S Fangel, Infektionsmedicinsk Afdeling, CESOIRS/Skejby Sygehus; Århus. Germany: U Spengler, Outpatient Clinic for Hepatology, Department of Medicine, University of Bonn. I Schmidt-Wolf, Outpatient Clinic for Hepatology Department of Medicine, University of Bonn. S Esser, Uniklinikum Essen, Hautklinik, Essen. Italy: M Zuin, Liver Unit, Dept. of Medicine, San Paolo Hospital, Milan. G Podda, Hermathology Unit, Dept. of Medicine, San Paolo Hospital, Milan. M Cusini, STD Centre, Dermatology department, Milan. Netherlands: K Brinkman, Onze Lieve Vrouwe Gasthuis, Internal Medicine, Amsterdam. Poland: A Grzeszczuk, Medical University of Bialystok, Department of Infectious Diseases and Hepatology, Bialystok. Spain: F Garcia, A Leon, Hospital Clinic Barcelona, Infectious Diseases Unit, Barcelona. I Menacho, Primary Center of les Corts, M Muns, Primary Center of Raval Sur, Barcelona Spain. Sweden: A Sönnnerborg, Department of Infectious Diseases, Karolinska University Hospital, Stockholm. United Kingdom: A Sullivan, M Rayment, ChelseaWestminster Hospital, London. Ukraine: M Krasnov, Kharkov Regional Clinic of Infectious Diseases, Kharkov. Coordinating Centre Staff: D Raben, M Ellefson, RS Brandt

**The people living with HIV Stigma Index Advisory Group:** Wojciech Tomczynski on behalf of ECUO (the Eastern European Network for People living with HIV), Henrik Arildsen on behalf of HIV Europe (the European Network for People living with HIV), Jurek Domaradzki on behalf of the European Aids Treatment Group, Julian Hows on behalf of GNP+, Ton Coenen on behalf of the HIV in Europe Steering Committee.

**Working Group on the Criminalisation of HIV** (convener: Matthew Weait, University of London)