

Outcomes of the HIV in Europe Initiative

Status Report, July 2011

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Status and Next Steps

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. 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. The HIV in Europe initiative continues to have an added-value in setting the policy agenda by both the projects initiated and the advocacy work and by implementing projects that would not otherwise have been implemented.

2010 was an exciting year for the HIV in Europe initiative. Results of the projects initiated in 2009 were published and the initiative 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 the last 3 years. 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 2010-2011 through the strong collaboration with HIV policy relevant organisations and other important stakeholders.

Strategy Meeting - February 2011

In February 2011, the Steering Committee of HIV in Europe met in Copenhagen to discuss possible research themes, events and projects for 2011-2012 and decide on the future structure and fundraising strategy of the initiative. The outcomes of the meeting were the approval of a number of projects presented below as well as the holding of the 3rd HIV in Europe Conference to be held in Copenhagen 12-13 March 2012 as Denmark holds the EU Presidency first half of 2012. Further, a strategic priority of the initiative in the future will be to reinforce the collaboration with Eastern European countries as well as with WHO Europe and ECDC.

Approved projects (2011-2012)

Project	Description	Project lead	Period
Coordination, Communication, Fundraising and Political Advocacy	Secretariat function, website, fundraising, political profiling, travel, SC meetings, communication etc	Coordination Secretariat: CHIP, Copenhagen and Advocacy Secretariat: EATG, Brussels	2011-2012
Copenhagen 2012 Conference	3 rd HIV in Europe Conference under the auspices of the Danish EU Presidency	CHIP	2012
HIDES II – The HIV Indicator Diseases across Europe Study – phase II	Phase 2: Surveys (n=15000), audits (n=5000), testing guidelines recommendations	CHIP	2011-2012
The people living with	Development of advocacy and	GNP+	2011-2012

HIV stigma index – phase II From evidence to action	actions in the 5 phase I countries		
The HIV-COBATEST Project	Acceptability, feasibility and impact of community-based testing practices	ICO/Universitat Autònoma de Barcelona	2011-2012

In addition to these approved projects, the SC discussed possible projects related to the cost-effectiveness of testing and the organisation of a testing conference with Eastern European focus to take place in late 2012.

HIV in Europe at the HIV in European Region, Unity and Diversity, Tallinn Conference May 2011

HIV in Europe was highly profiled at the recent conference in Tallinn, and had representatives in both the scientific and the organising committee. One session, in particular focused on HIV testing and had presentations on the HIV Indicator Diseases across Europe Study and the Stigma Index Project.

PARALLEL SESSIONS

SESSION III

Overcoming obstacles to late presentation for HIV in Europe - the role of HIV testing

Chairs

Jose Gatell, University of Barcelona, Spain

Ton Coenen, Executive Director, Aids Fonds & Soa Aids, Netherlands

Speakers

Patient and staff attitudes towards routine HIV testing programmes in general healthcare settings in London, UK: the HINTS (HIV in non-traditional settings) study
Alicia Thornton, Chelsea and Westminster Hospital, United Kingdom

HIV in Europe Study; a pilot feasibility and acceptability study of HIV testing in selected Indicator Conditions
Ann Sullivan, Chelsea and Westminster Hospital, United Kingdom

HIV testing: increasing uptake and effectiveness in the EU
Mika Salminen, ECDC

Late Testing, Late Treatment in Eastern Europe and Central Asia: Findings from the PLHIV Stigma Index in Estonia, Moldova, Poland, Turkey and Ukraine
Magdalena Ankiersztejn-Bartczak, SIEĆ PLUS Polish Network of People Living with HIV/AIDS Association, Poland

Rights of pregnant IDUs in Ukraine: HIV testing and antenatal care
Halyna Skipalska, Ukrainian Foundation for Public Health, HealthRight International, Ukraine

Furthermore, the conference programme included a session on HIV testing policies and technologies. Jens Lundgren, Co-chair of the initiative, spoke at the closing session on “Main challenges in the field of HIV in the European region”, and HIV in Europe sponsored a workshop on the stigma index arranged by GNP+

with the aim of discussing the result of the report “HIV-related Stigma: Late Testing, Late Treatment”, released in conjunction with the conference.

Copenhagen Conference, 12-13 March 2012

Venue: Copenhagen University

Time: 12-13 March 2012

The 2-day programme will consist of:

1. A high level meeting with a political agenda in relation to the Danish EU Presidency;
2. A smaller workshop involving groups from Europe working with innovative testing programmes.

A broad European Organising Committee has been formed to assist the secretariat in the planning of the conferences. Call for abstracts will be send out in Autumn 2011.

Objectives

- To provide an overview of European initiatives and best practices on optimal testing and earlier care.
- To present and discuss the outcomes of the pilot projects of HIV in Europe and discuss progress in the projects initiated in 2011.
- To discuss and develop a strategy for implementation of changes based on the concrete outcomes of the projects and initiative.
- To inform leaders, including key policy makers and donors, as to increase their commitment to ensure that HIV infected patients enter care earlier in the course of their infection than is currently the case.
- To provide opportunities for multi-stakeholder dialogue to develop creative solutions to unresolved challenges in research and implementation of HIV policies and programmes to improve early diagnosis and care of HIV across Europe.
- To increase public awareness of the public health problems associated with late presentation for HIV care
- To present data available on the cost-effectiveness of HIV testing demonstrating how scaling up HIV testing can contribute to more sustainable health systems
- To sustain the political discussion of the WHO EURO testing guidelines (2010) and ECDC testing guidelines (2010) and their implementation at national level
- To accompany the debate at EU HIV/AIDS Civil Society Forum and Think Tank level on Council Conclusions on HIV testing towards possible Council Conclusions under the Danish Presidency

HIV in Europe moving East

The projects of HIV in Europe are to a great extent implemented in Eastern European countries. The stigma index project builds on data from Estonia, Moldova, Poland, Turkey and Ukraine and approximately 40% of persons enrolled into the pilot phase of the HIV Indicator Diseases across Europe study are from Eastern European countries. Further, the newly approved HIV-COBATEST project will be implemented in Eastern Europe.

The Steering Committee in collaboration with WHO Europe is currently discussing the possibility of arranging a conference in Eastern Europe in 2012 on testing to discuss barriers to testing etc from an Eastern European perspective.

Background and Publications

HIV in Europe Call to Action 2009-2012

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 2010-2011

- Newly released report: [HIV-related Stigma: Late Testing, Late Treatment](#), May 2011
[Late Testing, Late Treatment, Russian version](#)
- Press release - HIV in Europe, European AIDS Conference, Tallinn 25-27 May, [Press release](#)
- HIV in hiding AIDS 2011 Publication. [Methods and data requirements for the estimation of the number of people living with undiagnosed HIV. Working Group on Estimation of HIV Prevalence in Europe](#)

- 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 2nd phase of the project.
 - Indicator diseases as part of the ‘ECDC guidance on 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
- 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 1st 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

Recent Publications

HIV-related Stigma: Late Testing, Late Treatment, May 2011

HIV in hiding AIDS 2011 Publication. Methods and data requirements for the estimation of the number of people living with undiagnosed HIV. Working Group on Estimation of HIV Prevalence in Europe

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 Sönnnerborg, 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

Presentations

2011 HIV in European Region, Unity and Diversity, Tallinn Conference May 2011, HIV in Europe Study; a pilot feasibility and acceptability study of HIV testing in selected Indicator Conditions
Ann Sullivan, Chelsea and Westminster Hospital, United Kingdom

2011 HIV in European Region, Unity and Diversity, Tallinn Conference May 2011, Various presentations on the stigma index from Estonia, Moldova, Poland, Turkey and Ukraine

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

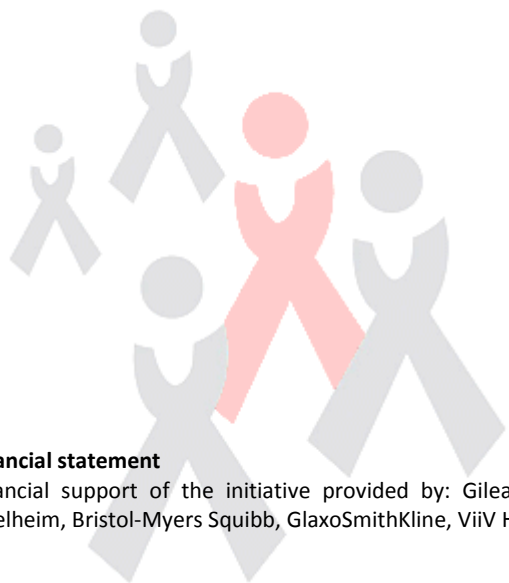
10th International Congress on Drug Therapy in HIV Infection, Glasgow. November 2010, A pilot study to determine the prevalence of HIV in persons presenting for care with selected conditions: preliminary

results from the HIV in Europe study, Anders Sönnnerborg 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.

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



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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: Jordi Casabona, Scientific Director, Center for HIV/STI Epidemiological Studies of Catalonia 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 Sönnernborg, 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 Lali Kotenashvili, 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, UNAIDS Regional Support Team ECA, Represented by Michelle Williams-Sherlock.

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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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