

Outcomes of the HIV in Europe Initiative Annual report 2014

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1. Background

HIV in Europe is a pan-European initiative which started in Brussels in 2007. The initiative provides a European platform for exchange and activities to improve early diagnosis and care of HIV patients across Europe. Directed by an extensive and independent group of experts with representation from civil society, policy makers, health professionals and European public health institutions, the initiative is truly a multi-disciplinary and pan-European collaboration.

HIV in Europe is not an organisation, but an initiative formed to inform policy-making/implementation, knowledge sharing, and to improve the evidence base on important issues related to earlier HIV testing and care. It is unique in its collaboration between stakeholders from both clinical, advocacy and public health policy levels, who all share the common objective of ensuring that people living with HIV (PLHIV) enter care earlier in the course of their infection.

2. Status 2014 and Next Steps

After six years of research and advocacy activities, the HIV in Europe initiative is recognised as an important platform for moving the agenda on earlier diagnosis and care of HIV forward at a pan-European level. The biannual conferences (Brussels 2007, Stockholm 2009, Copenhagen 2012 and Barcelona 2014) are well attended and a forum for important research in optimising HIV testing. European Commission funding for the Copenhagen 2012 Conference and in 2014 a large consortium three year project, enlarge the remit and scope of the initiative, which has functioned on smaller project grants, a small coordination secretariat and the dedication of the steering committee members since the initiation.

By the end of 2013, the “**Optimising Testing for HIV in Europe – OptTEST for HiE**” project was awarded with a grant by the European Commission (<http://www.opttest.eu/>). The project officially started on 4 June 2014 and aims to help reduce the number of undiagnosed people with HIV infection in the European region and to promote timely treatment and care. The project focuses on innovative testing strategies inspired by the work done within the initiative during the past 5 years. The Commission is supporting the consortium with 60% of the total budget of 2.3 million Euros. The project means a completely new situation for the initiative, as many of the planned projects are to be a part of “OptTEST for HiE”, and the grant will triple the annual budget and output of the initiative. The project will also provide tools and assessment methods to analyse and effectively respond to late presentation for HIV care and treatment, with a particular emphasis on priority regions and groups throughout Europe and will run until June 2017.

As one strategy of the HIV in Europe initiative has been to maintain focus on Eastern Europe, an **OptTEST shell-project** is also currently being planned for 2015-17, whereby selected non-member states in Eastern Europe; Belarus, Georgia and Ukraine can also be involved in developing tools, guidelines and assessment methods needed to analyse and effectively respond to late presentation for HIV care and treatment in their regions. It is planned that the shell project should run in tandem with the EU co-funded OptTEST project and a separate source of funding will be needed.

The 4th HIV in Europe Conference: **HepHIV2014: HIV and Viral Hepatitis: Challenges of Timely Testing and Care**, was held in Barcelona 5-7 October 2014, as a collaboration between an number of well-established organizations within the field of Hepatitis as partners. It was attended by more than 200 people, with around 100 abstract submissions forming the basis of six parallel sessions. After the conference a Call to Action was released. This document, the conference proceedings and the evaluation report can be found on the [website](#). One important outcome from this was to formally expand the current remit of the HIV in Europe initiative to include viral hepatitis and expand the Steering Committee accordingly. With this initial step, several hepatitis projects are currently being developed, including formalising a consensus definition on late presentation with viral hepatitis in collaboration with EASL (European Association for the Study of the Liver).

During the HepHIV2014 conference, results were outlined from the second phase of the HIV Indicator Diseases Across Europe Study (HIDES), which collected data for conditions that expert opinion believed likely to be associated with HIV prevalence above 0.1%, indicating cost-effectiveness as HIV indicator conditions. HIDES II looked at 10 000 patients across Europe and found evidence to back up expert opinion for 9 conditions (in decreasing order of prevalence): simultaneous hepatitis B & C infection, ongoing mononucleosis-like illness, lymphadenopathy, leuko-/thrombocytopenia, pneumonia, HCV, seborrhoeic dermatitis/exanthema, HBV and cervical dysplasia/cancer. The results from the study will be published in a peer-reviewed journal.

In 2014 the second European HIV testing week was launched in the last week of November 2014. Building on the success of the first testing week in 2013, 709 participants across 49 countries represented a large diversity of participants.

On a strategic level, the HIV in Europe Steering Committee continuously prioritises involvement of Eastern European organisations in its projects and outreach undertaken. Further, a strategic discussion took place to include hepatitis testing within the agenda of the

initiative. A review of hepatitis testing is currently underway and discussions are still ongoing with regards to include viral hepatitis in next year's testing week.

Finally, a new Co-chair was elected by the HIV in Europe Steering Committee in December 2014 for the next 4 years. **Jürgen Rockstroh**, MD, Professor of Medicine and Head of the HIV Outpatient Clinic at the University of Bonn in Germany will take over as the clinical co-chair of the HIV in Europe initiative. He replaces Professor Jens Lundgren, who has acted as co-chair since the start of the initiative in 2007.

Fundraising remains key to the initiative and it has been made a priority to continue to seek funding from supporting companies to accompany the funding received from the European Commission. The work of the initiative is based on the voluntary engagement of the SC members and limited funding for the two secretariats (at CHIP in Copenhagen and EATG in Brussels). The SC decides how funding is allocated to the different projects and HiE remains committed to remain as an 'initiative' (not an organisation), which initiates new research and influences processes.

3. Achievements and Project Results 2014

3.1 The HepHIV2014 Conference

The HepHIV conference took place in Barcelona, Spain 5-7 October 2014 with the theme *HIV and Viral Hepatitis: Challenges of Timely Testing and Care*. The main objectives of the HepHIV conference were to:

1. Provide the fields of HIV and viral hepatitis with the opportunity to learn from each other and to reflect on their experiences.
2. Provide an overview of European innovative initiatives and best practices on optimal testing and earlier care for HIV and viral hepatitis from different settings across Europe.
3. Highlight and discuss achievements and obstacles experienced in both fields, whilst maintaining focus on the lefthand side of the "treatment cascade," with regards to undiagnosed cases, testing and initiation of care.
4. Sustain and fuel the political discussion of testing policies with the EU Commission and Parliament, the WHO Regional Office for Europe, ECDC and EMCDDA and the European Union HIV/AIDS Civil Society Forum and Think Tank and the implementation of testing policies at national levels.

5. Provide opportunities for multi-stakeholder dialogue to develop creative solutions to unresolved challenges in research and implementation of HIV and viral hepatitis policies and programmes to improve early diagnosis and care of HIV and hepatitis across Europe.
6. Inform leaders, including key policy makers and donors, as to increase their commitment to ensure that HIV and viral hepatitis infected patients enter care earlier in the course of their infection than is currently the case.
7. Increase public awareness of the public health problems associated with late presentation for HIV and viral hepatitis care.

The conference was the first European conference to bring together the fields of HIV and viral hepatitis and it was attended by 250 people. The overall evaluation of the three-day event was very positive, with 84% of the 86 participants evaluating the conference as excellent/good. This is supported by 88% of respondents scoring that the conference met or exceeded their expectations ([Evaluation Report](#)).

A [call for Action](#) has been developed by the HiE SC and the HepHIV Scientific Committee based on input at the conference.

3.2 OptTEST

The OptTEST project (Optimising testing and linkage to care for HIV across Europe) is a three year project funded by the EU Commission under the Second Health Programme 2013 call for proposals. The project officially started on 4th June 2014 and aims to help reduce the number of undiagnosed people with HIV infection in the European region and to promote timely treatment and care. The project will also provide tools and assessment methods to analyse and effectively respond to late presentation for HIV care and treatment, with a particular emphasis on priority regions and groups throughout Europe.

There are four core Working Packages in OptTEST (4-7). [Work Package 4](#) is working on linkage to and retention in HIV care after diagnosis. [Work Package 5](#) is working on developing and implementing tools and strategies for indicator condition guided HIV testing. [Work Package 6](#) is looking at cost effectiveness of HIV testing strategies in priority groups and regions and finally [Work Package 7](#) is looking at stigma and legal barriers to the provision and uptake of HIV testing services.

3.3 European HIV testing week

In response to the continued evidence of late presentation for HIV care across Europe, the HIV in Europe initiative coordinated the launch of the second European HIV testing week (21st - 28th November, 2014) and invited all interested organisations and networks in the WHO

European Region to participate, support dialogue, increase awareness and promote HIV testing. As the overarching aim was to increase HIV testing awareness, the central strategy was to create a public platform, which could act as an ‘information hub’ to inspire Testing Week activities throughout the European Region. The hub was in the form of a website (www.hivtestingweek.eu), developed specifically to act as a single locale for interested parties to readily obtain information and materials, to help kick-start and support ideas and activities for Testing Week.

Referring to existing European guidelines on HIV testing, the 2014 testing week was targeted at three key groups:

- Populations at risk (to encourage them to get tested regularly)
- Healthcare professionals (who should be offering HIV testing as part of routine care in specific settings and conditions)
- Policy makers (who should be aware of the benefits of HIV testing)

Further, a specific focus in 2014 was on the involvement of healthcare professionals and therefore a new toolkit was developed ([Toolkit 6](#)) with a summary of resources to support regular HIV testing in healthcare settings to assist the involvement of healthcare professionals.

709 organisations across Europe signed up to participate in the 2014 testing week. All activities during the testing week were formulated and driven by the implementers. An evaluation of the pilot testing week in 2013 is available on the website ([2013 Evaluation Report](#)) and an evaluation of the 2014 testing week is currently being written to direct future pan-European testing weeks.

3.4 HIDES 2 (HIV Indicator Diseases across Europe Study)

The objective of the HIV Indicator Diseases across Europe Study, part 2 (HIDES 2) was to develop focused HIV testing of patients presenting with certain indicator clinical conditions or diseases (ID). The project had two parts: i) Survey: Screening of 14000 persons not yet diagnosed with HIV presenting for care with 11 predefined indicator conditions: ii) Audit: a retrospective study, implementing and evaluating an audit system across Europe of the performance of HIV testing of persons presenting with already well-established HIV indicator diseases according to contemporary HIV testing guidelines.

In 2013, the audit part was finalized and results were presented at 14th European AIDS (EACS) Conference in October 2013.

A total of 48 audits were completed from 22 centres in 14 countries across Europe. The conclusion was that testing rates in well-established HIV IDs remained surprisingly low across Europe, despite high prevalence rates, reflecting missed opportunities for earlier HIV

diagnosis and care. Significant numbers (>100) of persons may have had an opportunity for HIV diagnosis if all persons included in ID audits had been tested.

At the HepHIV conference in Barcelona, Spain in October 2014 results were outlined from the second phase of the HIV Indicator Diseases Across Europe Study (HIDES), which collected data for conditions that expert opinion believed likely to be associated with HIV prevalence above 0.1%, indicating costeffectiveness as HIV indicator conditions. HIDES II looked at 10 000 patients across Europe and found evidence to back up expert opinion for 9 conditions (in decreasing order of prevalence): simultaneous hepatitis B & C infection, ongoing mononucleosis-like illness, lymphadenopathy, leuko-/thrombocytopenia, pneumonia, HCV, seborrhoeic dermatitis/exanthema, HBV and cervical dysplasia/cancer. With nearly the highest coinfection rate and symptomatic similarity to acute HIV infection, mononucleosis-like illness provides an especially good opportunity for early diagnosis.

Due to few patients enrolled with mononucleosis-like illness the enrolment of patients presenting with mononucleosis-like illness will continue until 1 July 2015.

3.5 Presentations, seminars, publications and press

- G Kutsyna on behalf of the HIDES Study Group: Which Conditions are Indicators for HIV Testing across Europe? Results from the HIDES 2 study. HepHIV conference 5-7 October 2014, Barcelona. [Presentation](#)
- S Bell: Health service-based HIV testing and counselling: a review of European guidelines. HepHIV conference 5-7 October 2014, Barcelona. [Presentation](#)
- B.C. West: The European HIV testing week pilot, 2013. 20th International AIDS Conference July 20-25, 2014, Melbourne. [Abstract](#)
- Conference proceedings. HepHIV2014 Conference. HIV and Viral Hepatitis: Challenges of Timely Testing and Care. 5-7 October 2014, Barcelona. [Proceedings](#)
- Press release, Renewed political leadership is key to halting the epidemics of HIV and viral hepatitis across Europe. HepHIV conference 5-7 October 2014, Barcelona. [Press release](#)

4. HIV in Europe Policy update

The Advocacy Secretariat of the HIV in Europe initiative is based with The European AIDS Treatment Group (EATG). EATG's mission is to achieve the fastest possible access to state of the art medical products, devices and diagnostic tests that prevent or treat HIV infection. EATG advocates for optimal testing and care for the HIV in Europe initiative and promotes HIV in Europe's specific projects and its achievements.

4.1 Objectives pursued, activities and outcomes in 2014

Promoting renewed political commitment to achieve universal access to prevention, testing, treatment and care for HIV/AIDS

Through its advocacy secretariat, HIV in Europe has maintained efforts to foster renewed political commitment at national and European level to achieve universal access to prevention, testing, treatment and care for HIV/AIDS at European level. Activities in the last two years have aimed the adoption of a pan-European ministerial declaration setting targets with clear indicators and an EU policy framework and action plan to improve the European response to HIV/AIDS and co-infections across the continent. Advocacy has also sought to ensure the inclusions of measures ensuring the human rights of key affected populations and to scale up of screening and timely access to treatment for key affected populations in policy documents and events.

The work undertaken in 2013, which have included a multi-stakeholders call to EU leaders and EU institutions on HIV, speeches at policy events, and policy letters to EU Presidencies, direct advocacy with Tonio Borg- European Commissioner for Health and contribution to the European Commission consultation for an updated action plan, came to fruition in 2014. Indeed, in March, the European Commission (the Commission) adopted an extended Action Plan in EU and neighbouring countries for 2014-2016 to prevent a policy void. The Action Plan emphasises measures to maintain HIV/AIDS high on the political agenda, to tackle HIV-related stigma and discrimination, to achieve better access to voluntary testing and counselling, as well as to early treatment and care, prevention. It underlines the need to focus on key affected groups, such as men who have sex with men, migrants, and injecting drug users. Moreover, the Commission organised the Conference "Health in Europe, making it fairer" in March, where the Commissioner for Health chaired a session focused HIV. HIV in Europe actively contributed to this session on measures to overcome stigma discrimination and to improve access to voluntary HIV testing and timely treatment for key affected communities. In addition, the Italian EU Presidency convened a high level conference "Fight against HIV/AIDS ten years after the Dublin Declaration: Leaving no One Behind – Ending AIDS in Europe" in November, whose aim was

the adoption of a ministerial declaration. HIV in Europe supported the process through contribution to the external advisory board for the event and declaration, the EU HIV Civil Society Forum, speakers and behind the scenes advocacy with the different stakeholders. The call for action from the HepHIV Conference was fed in the preparation of the meeting and the draft declaration. Unfortunately, the event did not conclude with a ministerial declaration but policy-makers agreed on the need for a new declaration and further discussion on the text. The Italian EU Presidency committed to bring it forward for further discussion among EU member states.

Before the event, EATG met with the then newly appointed Commissioner for Health, Vytenis Andriukaitis, to underline the importance of enhanced political leadership on HIV and co-infection and to discuss steps to be taken by the Commission during its five years mandate to support a more effective European response to HIV. The Commissioner expressed commitment to keep and HIV on the agenda and to address inequities in health in Europe.

Ensuring support and input from communities and policy makers to the European Testing Week

The advocacy secretariat sought to ensure support and input from a broad range of stakeholders for the European HIV Testing Week. It reached out to community organisations, agencies, government agencies for their involvement. In July, HIV in Europe presented the results of the evaluation of the first European HIV Testing week during the July session of the HIV Think Tank, a working group of national government representatives, the European Commission, EU and international agencies and as experts from civil society.

Ensuring support for targeted and more effective testing strategies for key populations

In March, the advocacy secretariat published two community country briefs on the impact of austerity measures on the HIV response in Portugal and Spain. The briefs examined the consequences of the budget cuts on prevention, testing, treatment and care, especially for key affected populations and put forward recommendations. The briefings, available in Spanish, Portuguese and English, were used for discussion with different stakeholders at national and European levels.

In July, EATG, NAM Aidsmap and HIV in Europe organised a satellite meeting on **“The Use of Antiretroviral Treatment for Prevention: the role of community, tensions and ways forward”** at the International AIDS Conference in Melbourne. Speakers and participants discussed

the need for the affected communities to get involved in guidelines developments, as well as preconditions for this tool to be able to contribute to curb the epidemic. These pre-conditions include effective testing strategies; access to treatment and use of a combination of prevention tools.

In November, EATG organised a policy seminar to promote innovative approaches to HIV screening in Belgium and in Europe with Belgian organisations within the framework of HIV Testing Week. The participants discussed best practices in screening in Europe; the legal and financial framework for testing; pilot outreach projects for key populations. The seminar concluded with a consensus-building debate on next steps towards decentralised and demedicalised screening in Belgium. Participants were policy-makers, doctors, testing centres, community organisations, and journalists. Prior to the seminar, the organisers held a press point to underline the urgency of a more proactive approach to testing allowing demedicalised and decentralised screening through rapid tests. Members of the parliament agreed to do a rapid test for HIV to show how these test works and raise awareness on the benefits for the individual and public health.

In the autumn, EATG collected data on legislative frameworks across Europe for community based testing and ways actors in countries have sought to bring testing closer to affected communities. The information, which is largely anecdotal, has been used in discussion with rapid test manufacturers around donations of testing kits for Testing Week activities at local level. It was also presented at the EU HIV Civil Society Forum for feedback on content and next steps. The information will be crossed checked and deepened in 2015 as part of the OptTEST project work-package dealing with legal and regulatory barriers to testing and linkage to care.

EATG has also included the issue of provider based and decentralised and demedicalised screening in its community capacity building activities. In the September module of the STEP-UP training programme, trainees discussed amongst others the role of community-based organisations in advocating HIV/HCV testing. In October, during the I-CAN conference led by EATG and which brought participants from over 25 countries together to learn, share, present and discuss best practices of community engagement and mobilization in HIV response.

5. Other on-going projects

5.1 An examination of the role of counseling

The HiE 2012 Conference spurred discussion on the role of counseling and a project initiated in 2013. The overall objective of the study is to support the development and implementation of best practice service models that contribute to increasing the uptake and frequency of HIV testing, as well as making optimal use of opportunities to promote reductions in the risk of HIV infections. The specific aims are to compare and integrate existing guidelines to promote HIV testing; review and synthesize the evidence regarding HIV testing service models; develop and consult on protocols of best practice HIV testing service models that appropriately address the needs of different individuals/communities in diverse service settings; conduct a demonstration project to gather evidence regarding the appropriateness, feasibility, efficacy and resource requirements of best practice HIV testing service protocols.

Among the deliverables produced during 2014, and currently under review is; a synthesis document of definitions, recommendations and related evidence, a technical report of a stakeholder survey on current HIV testing models performed in 2014 and presented at the HepHIV2014 Conference.

In 2015, a consultation document outlining panel recommendations and best practice protocols will be developed as well as activities to support dissemination.

6. Next Steps: on-going and approved projects for 2014-2017

Project	Description	Expected outcome	Period
Coordination, communication, fundraising and political advocacy	Secretariat (coordination and political), support for steering committee members, travel, website, fundraising, communication, advocacy, planning and development.	Efficient coordination of the initiative's projects and advocacy activities. HIV in Europe agenda widely known.	2014-2017

HIDES – phase 2, mono-like illness extention	Screening of persons with the predefined indicator condition mono-like illness.	Further development of the guidelines to recommend testing of HIV when patients present with mono-like illness.	Results by Q3 2015
Evidence and practice of HIV counselling	To support the development and implementation of best practice service models that contribute to increasing the uptake and frequency of HIV testing, as well as making optimal use of opportunities to promote reductions in the risk of HIV infections.	Workshops, research reports and papers/ empirical evidence regarding the comparison of guidelines and recommendations; an overview and analysis of current HIV testing models in different service settings across Europe; consolidated best practice HIV testing protocols for different service settings and client groups.	Q3 2013-Q2 2015
OptTEST by HIV in Europe Project			
The treatment cascade in Europe	To increase knowledge on linkage to and retention in HIV care after diagnosis across geographical and health care settings and target groups by 2016.	Applied model for Europe.	2014-2017
Introduce IC-guided testing in different regions	Create understanding and suggest evidence-based solutions to provider barriers to testing through pilot implementation of a novel HIV testing strategy (Indicator Condition-guided) in selected European healthcare settings and countries by 2016.	Indicator condition guided HIV testing tools and training materials.	2014-2017

Survival benefits, cost and cost-effectiveness of various HIV testing strategies	To assemble and evaluate various existing HIV testing strategies in Europe by 2016.	A paper on outcomes, costs, and cost-effectiveness of different HIV testing strategies in different European settings.	2014-2017
Addressing stigma/discrimination/ legal barriers is still essential to effectively respond to late presentation for HIV treatment.	To increase knowledge on the effect stigma and discrimination (as well as structural legal barriers to HIV testing) has on uptake of HIV testing and treatment particularly in most affected groups and regions by 2016.	Good practice manual on evidence based interventions to reduce HIV related stigma.	2014-2017



Financial statement

Financial support of the initiative provided by: EAHC, Gilead Sciences, Merck, Tibotec, Pfizer, Schering-Plough, Abbott, Boehringer Ingelheim, Bristol-Myers Squibb, GlaxoSmithKline, ViiV Healthcare, UNICEF and the Swedish Research Council.

The HIV in Europe Steering Committee and Study Groups

HIV in Europe Steering Committee:

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Panel on Guidance on Indicator Condition-Guided HIV testing in Adults: European Centre for Disease Prevention and Control, Sweden, represented by Marita van de Laar; WHO Europe, Denmark, represented by Lali Khotenashvili; Nathan Clumeck, CHU Saint-Pierre, Brussels, Belgium; Jose Gatell, Hospital Clínic –IDIBAPS, University of Barcelona, Spain; Brian Gazzard, Chelsea and Westminster Hospital, London, UK; Jens Lundgren, University of Copenhagen and Rigshospitalet, Copenhagen; Antonella d’Arminio Monforte, Infectious Diseases Unit, San Paolo University Hospital, Milan, Italy; Jürgen Rockstroh, Medizinischen Universitätsklinik, Bonn, Germany; Amanda Mcroft, University College London, UK; Ann Sullivan, Chelsea and Westminster Hospital, London, UK; Valerie Delpech, Health Protection Agency, UK; Martin Fisher, Royal Sussex County Hospital, Brighton, UK; Francesco Blasi, Alberto Mateelli, European Respiratory Society (ERS); Gabriele Arendt, Universitätsklinikum Neurologische Klinik Düsseldorf, Germany, European Neurological Society (ENS); Keith Radcliffe, European branch of the International Union against Sexually Transmitted Infections (IUSTI), Tallinn, Estonia; Deniz Gokengin, IUSTI Europe, Turkey; José Miro, Hospital Clinic IDIBAPS, University of Barcelona, Barcelona, Spain; Bruno Hoen, Centre Hospitalier Universitaire Hôpital Saint Jacques de Maladies Infectieuses et Tropicales, Besancon, France, on behalf of the European Society of Clinical Mikrobiology and Infectious Diseases (ESCMID); Erwin Tschachler, European Academy of Dermatology and Venereology (EADV); Anne-Françoise Gennotte, GP, Brussels VCT Center, Brussels; Mika Salminen, National Institute of Health and Welfare (THL), Helsinki, Finland (previously European Centre for Disease Prevention and Control).

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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)

Partners of OptTEST in HiE

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