

Outcomes of the HIV in Europe Initiative

Annual Report 2015

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Background

HIV in Europe (HiE) 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 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.

Status and Achievements 2015

After eight 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 and care. European Commission funding for the Copenhagen 2012 Conference and the “Optimising Testing for HIV in Europe – OptTEST by HiE” 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.

1. OptTEST

In 2014 the large consortium three year project OptTEST was awarded with a grant by the European Commission (<http://www.opttest.eu> /). The project officially started on 1 July 2014 and will run until 30 June 2017. The project’s aim is 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 eight years. 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. The Commission is supporting the consortium with 60% of the total budget of 2.3 million Euros and the grant has tripled the annual HiE budget.

Half way through the three year project period, the project is progressing well. Baseline data collection has been completed and the first results have been produced. Five posters were presented at EACS 2015, one on late presentation, two on costs and cost-effectiveness and two on HIV indicator conditions (see details in section 10 of this report).

2. OptTEST Shell project

One strategy of the HIV in Europe initiative has been to maintain focus on Eastern Europe. In the current **OptTEST shell-project** (2015-17), selected non-EU Member States in Eastern Europe; Belarus, Georgia and Ukraine are 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. This shell project will run in tandem with the EU co-funded OptTEST.

3. Consensus definition for late presentation of viral hepatitis

As an outcome of the HiE conference: *HIV and Viral Hepatitis: Challenges of Timely Testing and Care* held in Barcelona, Spain 5-7 October 2014, a working group of viral hepatitis experts within the HIV Europe initiative was formed to develop a consensus definition for viral hepatitis.

After discussions, meetings and several reviews two definitions were agreed upon and approved by the European Association for the Study of the Liver (EASL) Governing Board in early October 2015. The consensus definitions of late presentation for viral hepatitis were announced by EASL and HIV in Europe on 22 October 2015 in Barcelona, coinciding with the EACS Conference.

The aim is to encourage policy makers, health professionals, public health institutions and civil society organisations to implement the definitions to improve the European surveillance of and response to the viral hepatitis epidemic. A manuscript on the consensus definitions is currently under submission.

Definition 1:

Advanced HBV, HCV or HDV associated liver disease is clinically defined by presence of hepatocellular carcinoma or decompensated cirrhosis (jaundice, hepatic encephalopathy, clinically detectable ascites, variceal bleeding).

Definition 2:

Late presentation of HBV or HCV associated liver disease is defined as a patient with chronic hepatitis B or C and significant fibrosis ($\geq F3$ assessed by APRI score >1.5 , FIB-4 >3.25 , Fibrotest >0.59 or alternatively a FibroScan >9.5 kPa) with no previous antiviral treatment.

4. HIDES 2 (HIV Indicator Diseases across Europe Study)

Audit results from the HIV indicator Diseases across Europe Study part 2 (HIDES 2) on HIV testing rates across Europe have been published by the HIDES Audit Study Group in [an article in PLoS One](#) in November 2015. Six HIV indicator conditions were selected for auditing of HIV testing: tuberculosis (TB), hepatitis B and C (HEP), non-Hodgkin lymphoma (NHL), anal and cervical cancer (ACCAN) and oesophageal candidiasis (ECAN). There were 49 audits from 23 centres representing 7037 persons and the median period of time for retrospective data collection was 1.5 years. The test rate was 72% overall (IQR 32–97), with the lowest rate in Northern Europe (median 44%, IQR 22–68%) and the highest in Eastern Europe (median 99%, IQR 86–100%). Testing rates in well-established HIV ICs remain surprisingly low in some regions of Europe despite high prevalence rates, reflecting missed opportunities for earlier HIV diagnosis, treatment and care. Offer rates were higher in Southern than in Northern Europe and in TB and oesophageal candidiasis than in those presenting with NHL, anal or cervical cancer.

As a continuation of HIDES 2 a 12 months Single Arm Extension has been conducted with the objective to assess whether there are European regional differences in the HIV prevalence in individuals presenting for care with infectious mononucleosis-like illness (MON). Results were presented at the 15th European AIDS Conference in Barcelona, October 2015 and are summarized below.

In September 2015, a total of 1569 persons presenting with MON were included from 16 clinics; 994 from East (63%, 6 clinics), 61 from West (4%, 3 clinics), 84 from South (5%, 5 clinics) and 430 from North (27%, 2 clinics). Of these, 85 tested HIV positive (5.4% [95% CI 4.3–6.5%]). The lower limit of the 99% confidence interval exceeds 0.1% for all regions combined, East, North, West/South combined and West/South/North combined. The prevalence of HIV varied from 2.3 in North to 6.7 in East ($p=0.0034$ comparing East versus North/West/South). Across all regions the positivity rate is considerably higher than the 0.1% cut-off for cost-effectiveness of routine offer of HIV testing and highlights very effective HIV case finding. The difference between regions might be explained by site of recruitment, whether in hospital departments or primary care.

The study concludes that mononucleosis-like presentation can mimic acute HIV sero-conversion and has the highest positivity rate observed in the HIDES study, this indicator condition (IC) in particular offers opportunities for earlier diagnosis. Interestingly when compared to other regions the sero-positivity rate was slightly less in the North which might in part be explained by site of recruitment and the patients being tested and their underlying prevalence of HIV. Little difference is however observed between regions and the routine offer of an HIV test for patients presenting

with MON should be urgently adopted into HIV testing and indicator condition specialty guidelines across Europe.

5. European HIV-Hepatitis Testing Week

The third European Testing Week (ETW) was launched and took place during the last week of November 2015 (20 - 27 November). In 2015, the ETW was expanded to include hepatitis and was re-named **European HIV-Hepatitis Testing Week**. The aim of ETW is to offer partners across Europe the opportunity to unite for one week to increase awareness regarding the benefits of HIV and hepatitis testing, so that more people become knowledgeable about their risks, understand that there is effective treatment available and are aware of their HIV and/ or hepatitis status.

To ensure support from a broad array of stakeholders, HIV in Europe presented the results of the evaluation of the 2014- European HIV Testing week during the July 2015 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.

In 2015, 417 participants across 46 countries signed up to participate representing a large diversity of participants. The ETW working group in collaboration with the two HiE secretariats ensured support and input from a broad range of stakeholders for the ETW 2015 by reaching out to community organisations, agencies, government agencies and international organisations for their support and involvement.

A variety of different activities took place during ETW which were formulated and driven by the participants. Of the 194 participants who submitted the evaluation survey (46.5%), the majority reported doing HIV activities (96.9%), and 44.8% and 27.8% reported doing hepatitis C and hepatitis B activities, respectively. An evaluation of the 2014 ETW is available on the website ([2014 Evaluation Report](#)) and an evaluation of the 2015 ETW is currently being finalised to direct future pan-European Testing Weeks.

The project website (www.testingweek.eu) is central in the communication with interested parties to help kick-start and support ideas and activities for the ETW. ETW also used [Twitter](#) and [Facebook](#) as platforms where participants could share a post, “like” ETW or tweet with the hashtag #EuroHIVHEPtestweek. Many stakeholders posted photos, described their testing activities or encouraged people to get tested.

In addition to the inclusion of viral hepatitis, a new initiative in 2015 ETW was the joint collaboration with smartphone dating apps to promote HIV testing in Europe. During the ETW three of the most popular dating apps for men who have sex with men in Europe (Grindr, Hornet and Planet Romeo) provided free advertising to promote the newly created and mobile-optimised [European HIV Test Finder](#) to millions of European users.

6. Policy/advocacy status and results in 2015

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.

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

Advocacy for increased political attention to HIV and co-infections in the last year aimed at securing 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, as well as viral hepatitis and tuberculosis co-infections across the continent. The Italian EU Presidency Ministerial event of November 2014 did not conclude with a ministerial declaration due to lack of adequate prior comprehensive consultations with the different governments, policy-makers agreed on the need for a new declaration. To follow up on this commitment and revitalise the discussion, the co-chairs of the EU HIV Civil Society Forum (EATG and AIDS Action Europe) sent a [letter to EU presidencies](#) in February 2015 about the next steps. Early summer, EATG initiated a collective letter of HIV, HCV and TB organisations addressed to the President of the European Commission on the urgent need of a European Policy Framework to address the epidemics. In the autumn, this collective of NGOs published a common position paper calling on the EU institutions (Council of EU and its member states, Commission and European Parliament) to enhance political leadership and action on these three epidemics. In November, the European health Commissioner responded that the Commission is exploring all possible options.

HIV in Europe, through EATG, participated in UNAIDS and WHO online and in-persons consultations for their 2016-2021 strategies making the case amongst others to scale up testing and counselling efforts focusing on groups at high risk and targeted approaches that have proved effective.

In spring 2015, HIV in Europe, through EATG and the EU Civil Society Forum, advocated the removal of a proposal to amend the law on public health to make HIV testing compulsory for high risk groups, particularly men who have sex with men (MSM) in the Czech Republic. Letters were sent to the Czech Minister of Health, Minister for Human Rights, Equal Opportunities and Legislation and member of the Parliament. A letter was also sent to the European Health Commissioner, Vytenis Andriukaitis, inviting him to raise concerns not only to the Czech Minister but also to other EU Ministers of Health, since there have been similar proposals in some other countries. The Commissioner replied that the Commission shared the concern and that will monitor the issue closely. The UNAIDS regional representative also raised the issue with the Czech government when visiting Prague. In the end, the Minister of Health withdrew the contested proposal.

Ensuring support for targeted and more effective testing strategies for key populations – decentralised and demedicalised testing

In 2015, HIV in Europe, through EATG, contributed to the review of the WHO consolidated HIV testing and counselling (HTC) guidelines. EATG reviewed the draft text of the guidelines and contributed with some best practices drawn from activities of its members. HiE welcomes the recommendation to enable trained lay providers to provide testing as one of the key approaches to ensure that testing reach those who need it.

In July and November 2015, the EU Civil Society Forums, co-chaired by EATG, organised sessions to exchange on self-testing and the UK and France experiences, as well as community based-testing and counselling projects in Finland, Portugal and Italy.

In October 2015, EATG published a [Prevention Position paper](#), including the need for adequate testing approaches as part of combined prevention strategies was published.

HIV in Europe, through EATG, has also included the issue of provider based and decentralised and demedicalised screening in its community capacity building activities. Testing for HIV and HCV were covered in the EATG [STEP UP trainings](#) and the AIM training to enhance treatment literacy on HIV, HCV and TB co-infections with a focus on people who inject drugs (PWID). Barriers to testing and ways to increase access for key affected groups were discussed with a focus on MSM and PWID and low threshold services. Trainees also shared experience and activities in the framework of European Testing Week.

7. An examination of the role of counselling

The HiE 2012 Conference spurred discussion on the role of counseling and a study was initiated in 2013. The overall objective of the study was to support the development and implementation of best practice service models that contribute to increasing the uptake and frequency of HIV testing.

Among the deliverables of the study produced during 2015 is a review article [HIV pre-test information, discussion or counselling? A review of guidance relevant to the WHO European Region](#) published in International Journal of STD & AIDS in May 2015.

8. Other on-going projects

Establishment of an HIV & HCV Testing Resource Centre

A new project launched by HIV in Europe is the establishment of an online resource centre of peer-reviewed scientific articles on HIV and HCV testing and national HIV and HCV testing guidelines in the WHO European Region as part of the HiE website.

Community testing – status document

In order to focus the potential work on community based HIV testing, the HIV in Europe Steering Committee has decided to commission a status document about community based testing outlining the existing evidence in this field (e.g. experiences with using mobile apps, lay provider testing) and unsolved issues (how to test, how to measure anonymous testing, etc.). This status document shall serve as fundament for further discussions and decisions in this field. Currently, the secretariat is writing up the Terms of Reference for this review task.

9. Expansion of the HIV in Europe Steering Committee

In 2015, the HIV in Europe Steering Committee included three new members: **Ludmila Maistat**, Alliance for Public Health, Ukraine, International Alliance Center for HIV, Hepatitis C and Drug Use. Ludmila Maistat has been working in HIV/AIDS field for more than 10 years, and since 2012 she has been leading the all-Ukrainian advocacy campaigns and projects aimed at expanding access to hepC diagnostics and treatment with particular focus on co-infection with HIV and key populations in Ukraine. **Tom Platteau**, HIV/STI clinic of the Institute of Tropical Medicine in Antwerp. Tom Platteau is mental health scientist and sexologist. He works at the HIV/STI clinic of the Institute of Tropical Medicine in Antwerp, Belgium. Since 2007, he coordinates projects on the development and implementation of novel HIV/STI testing using outreach and online strategies. **Mojca Maticic**, Head of the Viral Hepatitis Unit at the Clinic for Infectious Diseases and Febrile Illnesses, University Medical Centre Ljubljana, and Head of the Outpatient STI Service at the same University Medical Centre. Besides, she is Professor in the field of Infectious Diseases and Epidemiology at the Medical Faculty, University of Ljubljana, Slovenia.

10. List of HIV in Europe presentations, publications and press in 2015

- S A Bell et al. HIV pre-test information, discussion or counselling? A review of guidance relevant to the WHO European Region. International Journal of STD & AIDS, May 4, 2015. [Article](#)
- I Sperle on behalf of the Testing Week Working group. Expansion of HIV Testing. The 2014 European HIV testing week. At 2015 National Summit on HCV and HIV Diagnosis, Prevention and Access to Care, 4-6 June 2015, Virginia, US. [Presentation](#)
- Results of the evaluation of the 2014 European HIV Testing week, presentation at HIV/AIDS Think Tank, 7-8 July 2015, Luxembourg. [2014 Evaluation Report](#)
- D Raben on behalf of the HIDES Mono Extension Study Group: Ongoing Mononucleosis-like Illness –a clear indicator condition for HIV testing: Results from the HIDES 2 Study –Single Arm Extension. 15th EACS Conference, 22-25 October 2015, Barcelona. [Poster](#)
- E Lord et al: [Evaluation of HIV Testing Recommendations In Specialty Guidelines for the Management of HIV Indicator Conditions](#), 15th EACS Conference, 22-25 October 2015, Barcelona Poster
- S Croxford et al: [Linkage to Care Following HIV Diagnosis in Europe: A Review of the Literature](#), 15th EACS Conference, 22-25 October 2015, Barcelona, Poster
- C Rae et al: [Healthcare Related Costs of Missed Opportunities for HIV Diagnosis: A Potential Driver to Increase Indicator Condition Guided HIV Testing](#), 15th EACS Conference, 22-25 October 2015, Barcelona, Poster
- L Lemsalu et al: [Direct Costs of HIV/AIDS Care in Estonia](#), 15th EACS Conference, 22-25 October 2015, Barcelona, Poster

- Y Rivero-Montesdeoca et al: [Impact of Decentralized Drug Purchase on Antiretroviral Treatment Costs in Spain](#), 15th EACS Conference, 22-25 October 2015, Barcelona, Poster
- Press release: New consensus definition of late presentation for viral hepatitis, Thursday 22 October 2015, Barcelona. [Press release](#)
- D Raben on behalf of the HIDES Audit Study Group: Auditing HIV Testing Rates across Europe: Results from the HIDES 2 Study. [PLOS One](#). 2015 Nov 11;10(11). [Article](#)

Next steps

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 Steering Committee Members and limited funding for the two secretariats (at CHIP in Copenhagen and EATG in Brussels). The Steering Committee 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.

HIV in Europe, in collaboration with European stakeholders, has announced the 2nd HepHIV conference **HepHIV 2017 Malta Conference, 31 January - 2 February 2017**. More details will be available soon at the [HiE webpage](#) and news and updates can be followed on Twitter (conference hashtag #HepHIV2017).

Table 1. On-going and approved projects for 2016-2020

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.	2016-2018
Status document on community testing	Commissioned review tasks, producing a status document on existing	The status document shall serve as fundament for further discussions	ToR by Q1 2016 Document by

	evidence (e.g. experiences with using mobile apps, lay provider testing) and unsolved issues (how to test, how to measure anonymous testing, etc).	and decisions in this field	Q3 2016
Online resource centre with scientific articles and national HIV/HCV testing guidelines in the WHO European Region	A resource center as part of the HiE website - latest evidence and national guidelines on HIV and HCV testing.	A strong database would be very useful, it will need continuous updating	Q1 2016-Q4 2016
HIVHep Testing Week 2016	Testing Week offers partners across Europe the opportunity to unite for one week to focus on testing	Increased awareness regarding the benefits of HIV and hepatitis testing,	Q1 2016-Q4 2016
HepHIV 2017 Malta Conference, 31 January - 2 February 2017	The 2nd HepHIV conference by HIV in Europe in collaboration with European stakeholders. News and updates on Twitter by following the conference hashtag #HepHIV2017		Q1 2016-Q1 2017
OptTEST by HIV in Europe Project (2014-2017)			
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	Indicator condition guided HIV testing tools and training materials.	2014-2017

	novel HIV testing strategy (Indicator Condition-guided) in selected European healthcare settings and countries by 2016.		
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	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

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HIV in Europe Steering Committee

Co-Chairs: Brian West, Chair, Board of Directors, European AIDS Treatment Group, (EATG), Scotland and Jürgen Rockstroh, Professor of Medicine University of Bonn and Head of an HIV outpatient clinic, Germany.

Members: Jens Lundgren, Professor & Chief Physician, University of Copenhagen & Rigshospitalet, Director, Copenhagen HIV Programme, Denmark, Ton Coenen, AIDS Action Europe, Executive Director Aids Fonds & Soa Aids Nederland, Netherlands, Jordi Casabona, Scientific Director, Center for HIV/STI Epidemiological Studies of Catalonia, (CEEISCAT), Nikos Dedes, European AIDS Treatment Group (EATG), Greece, Valerie Delpech, Health Protection Agency, London, United Kingdom, 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, Stefan Mauss, Center for HIV and Hepatogastroenterology, Germany, Jeff Lazarus, Professor of International Health Systems, University of Copenhagen, Denmark, Anders Sönnernborg, MD, PhD, Professor, Department of Medicine Karolinska University Hospital, Sweden, Stanislas Pol, Professor of Hepatology and Gastroenterology, Université Paris Descartes, Paris, France, Nino Tsereteli, Executive Director of “Center for Information and Counseling on Reproductive Health – Tanadgoma”, Georgia, John de Wit, Professor and Director, Centre for Social Research in Health, The University of New South Wales, and Visiting Professor of Social Psychology of Health and Sexuality, Utrecht University. Ludmila Maistat, Senior Programme Manager in Alliance for Public Health, Ukraine, International Alliance Center for HIV, Hepatitis C and Drug Use, Tom Platteau, mental health scientist and sexologist at the HIV/STI clinic of the Institute of Tropical Medicine in Antwerp. Mojca Maticic, Professor in Infectious Diseases and Epidemiology at the Medical Faculty, University of Ljubljana, Slovenia and head of the Viral Hepatitis Unit at the Clinic for Infectious Diseases and Febrile Illnesses, University Medical Centre Ljubljana, and Head of the Outpatient STI Service at the same University Medical Centre.

Observers: Public Health England (PHE), Represented by Kevin Fenton, WHO Regional Office for Europe, Communicable Disease Unit, Represented by Lali Kotenashvili, European Centre for Disease Prevention and Control (ECDC), represented by Andrew Amato, European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), Represented by Lucas Wiessing, epidemiologist, principal scientist, , UNAIDS Regional Support Team ECA, Represented by Jean-Elie Malkin.

Partners of OptTEST by HiE

CHIP, Rigshospitalet, University of Copenhagen, Denmark; AIDS Fonds, Netherlands; European AIDS Treatment Group (EATG), Belgium; Institut national de la santé et de la recherche médicale (Inserm), France; Instituto de Salud Carlos III, Spain; Medical Foundation for HIV & Sexual Health (MEDFASH), UK; Public Health England (PHE), UK; Saint Stephen's AIDS Trust (SSAT), UK; Tervise Arengu Instituut (National Institute for Health Development), Estonia; The Global Network of PLHIV (GNP+), Netherlands.

