THE HIV IN EUROPE INITIATIVE – THE FIRST 10 YEARS

Connecting stakeholders to promote early testing and care, 2007–2017

HIV in Europe

Working Together for Optimal Testing and Earlier Care

CONTENTS

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PREFACE

Over the past 10 years, the HIV in Europe initiative has played a critical role in the HIV response by uniting policymakers, community activists, clinicians, researchers and many other stakeholders who work in the HIV arena. Together we have increased HIV awareness, rolled out HIV testing, fought HIV-related stigma and criminalization and reduced late presentation. The initiative's signal achievements include the initiation of European Testing Week at hundreds of sites across Europe; the studies identifying the indicator diseases that should trigger an HIV test (HIDES I and II); and the development of consensus definitions for late presentation of HIV and, more recently, viral hepatitis. Along with the other projects described on the following pages, these undertakings have been instrumental in improving HIV and hepatitis awareness, testing and linkage to care throughout the European region. New guidelines introduced in the last few years on starting treatment as soon as possible make this important collegiate upstream work more vital than ever.

We owe a special debt of gratitude to Jens Lundgren and Ton Coenen for their many years of leadership as co-chairs. Without them, the initiative would never have become reality and accomplished all it has. We'd also like to express appreciation for the hard work of Dorthe Raben, who has invested endless amounts of time and energy to keep HIV in Europe moving forward.

It has been an honour to be part of this great initiative and the collaborative efforts of so many people over the past decade. For it is only by working together that we can hope to keep expanding early testing and care and finally curb the HIV epidemic in Europe.

Brian West
Co-chair

Jürgen Rockstroh
Co-chair

CONFERENCE IN BRUSSELS 2007

HISTORY

STARTING WITH A BANG: BRUSSELS, 2007

Even though combination therapy had been making an enormous difference for patients for more than a decade, HIV research in 2007 was still focused on what to do with people once they entered the clinic – not on getting them there. Scientific conferences on HIV, for instance, typically didn't include any sessions on testing.

The HIV in Europe initiative was established against that background in June 2007, when clinician Jens Lundgren and community activist Ton Coenen invited three other HIV experts to meet in Paris. They weren't planning to found anything long-term; the idea was just to organize other HIV experts to Paris to conference on overcoming the obstacles to early testing and care, modelled on a smaller HIV summit that took place in the US the previous year. The other experts included another clinician, Brian Gazzard, another activist, Nikos Dedes, and an advisor from WHO Europe, Jeffrey Lazarus.

Together, the five committed to holding a conference later that year, in a location that would maximize their chances of getting early testing and care on the political agenda: Brussels. They would continue the multi-stakeholder approach, in both the conference programme and the conference steering committee, led by one co-chair who was a clinician and one who was a community representative. That model continues to be used today.

As the steering committee expanded in the following months, it also added two observers, from the US Centers for Disease Prevention and Control (CDC) and the newly established European Centre for Disease Prevention and Control (ECDC). Gilead Sciences provided the bulk of the financing from the very start, but the committee also obtained support from other industry sponsors to help not only underwrite the conference itself, but also to fund travel for Eastern European participants so that all parts of the European region would be represented.

The Brussels conference was a challenge to arrange, not only because of the short lead-up, but also because there was little precedent for such a meeting. It couldn't

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JEFFREY LAZARUS

In 2007, when I was working at the HIV/STI programme at WHO Europe, the organization's global HIV department issued global guidelines on provider-initiated testing. We were quite concerned that they could have negative consequences in Eastern Europe. With the region's history of using mandatory testing to persecute MSM and people who inject drugs, we feared that the guidelines would undermine our efforts to promote voluntary testing. We were looking for a forum where we could discuss these issues, when we were approached about helping found the HIV in Europe initiative. My supervisor, Srđan Matić, asked me to represent WHO Europe at the founding meeting in Paris, and later on the steering committee. Our programme was already collaborating closely with the EATG, and Nikos Dedes, who chaired the EATG board, urged us to get involved.

We still face some of those same concerns today, a decade later. Yet the age of AIDS exceptionalism is ending, and HIV needs to be treated like other health conditions. That means that provider-initiated testing is essential – but so is community-based testing, and the latter is often more effective, even though it is still prohibited in parts of Eastern Europe.

Going forward, I think HIV in Europe needs to focus more on tandem testing for HIV and hepatitis C. We have to encourage countries to scale up HCV testing to match their HIV testing – or, in countries like Georgia and Iceland that already have hepatitis C elimination strategies, the reverse!

TON COENEN

Its three constituencies – clinicians, civil society and health policymakers – make HIV in Europe a unique partnership. Yet it was not a given that such a partnership would be successful. In the early years, I think that civil society played an especially critical role in bringing the three groups together due to the linkage we have with the other two. The clinicians weren't really linked to the policymakers, so those of us who represented civil society on the steering committee served as a bridge.

Then after the Brussels conference, HIV in Europe had to reinvent itself. We pushed to define it as an initiative, which meant going beyond conferences to starting projects. The civil society members were also very active in diversifying our funding base so that HIV in Europe had ownership and wasn't so dependent on Gilead anymore. We helped provide some balance as well in the choice of projects, so that they addressed criminalization and stigma in addition to medical and epidemiological issues.

Finally, those of us involved in the EU's HIV/AIDS Civil Society Forum and HIV/AIDS Think Tank used them as platforms to help get testing and early treatment on the EU agenda. The resulting EU policies then made EU funding feasible. So in a sense, our early lobbying work paved the way for OptTEST and the new joint action Link2Care.

be structured like a conventional scientific meeting; it was important to address not only evidence – and the lack of it – but also policy issues and the experience of PLHIV and key populations.

Markos Kyprianou, the European Commissioner for Health and Consumer Protection, opened the conference on November 26th, 2007. Later that first day, community advocates, clinicians and policymakers broke into three separate groups to define the problems specific to each group. After reporting back to plenary, they had lively breakout sessions the next day in mixed stakeholder groups, charged with suggesting particular actions for delegates to bring back to their home countries and organizations.

This first HIV in Europe conference ended up being a resounding success, with more than 300 participants from 44 countries, and it imparted a great deal of momentum for further activity. In addition

> "The great success story in HIV screening is that of antenatal testing. Once it was made a routine, universal, opt-out process, it worked very well indeed. Patients don't like to feel that they're being singled out – and physicians don't like to single people out."
>
> –Keith Radcliffe, IUSTI (Copenhagen, 2012)

to the concrete commitments that the European Parliament made in adopting the conference's call to action, additional individual commitments were made by the ECDC and UNICEF; national bodies in Germany, the Netherlands, Portugal and Turkey; various NGOs; and the HIV in Europe steering committee.

BRUSSELS CALL TO ACTION

When the first HIV in Europe conference ended on November 27th, 2007, the European Parliament adopted the *Resolution on HIV/AIDS – early diagnosis and early care*, based on the conference call to action, which consisted of the following commitments:

- Acknowledge that earlier diagnosis and care is urgently needed to improve the lives of people living with HIV and reduce transmission.
- Develop more precise estimates – size, characteristics, etc. – of the undiagnosed population.
- Communicate the benefits of earlier care and reduce barriers to testing.
- Implement evidence-based testing and treatment guidelines in every country.
- Commit the necessary political, financial and human resources for their timely implementation.

GETTING ORGANIZED: 2008–2009

Before the Brussels conference even began, it had become evident to the steering committee that a more sustained effort was called for, and the committee began to lay plans for future projects and conferences. The first project – on a consensus definition for late presentation – had already got underway during the Brussels conference, but it became clear that additional activities would require some support teams. The committee began to describe HIV in Europe as an initiative – to indicate that it would initiate projects rather than carry them out itself – and now it needed to delegate practical tasks in three areas: project coordination, financial management and political advocacy.

Accordingly, the steering committee tapped three of its organizational partners to take on responsibility for these three areas. First, it established a coordination secretariat in what was then known as the Copenhagen HIV Programme (CHIP) to oversee the day-to-day running of HIV in Europe and its various projects. Dorthe Raben was recruited as project coordinator soon afterward, and she still heads the coordination secretariat.

Second, the committee chose the Dutch NGO Aids Fonds (now Aidsfonds) to administer the initiative's financial matters.

Finally, the European AIDS Treatment Group (EATG) assumed the role of advocacy secretariat. Its own secretariat had moved to

BRIAN GAZZARD

Why would a clinician get involved in a testing initiative? Well, clinicians clearly have an interest in reducing the scale of the HIV epidemic, and we should be aware that one of the major reasons for the epidemic persisting, especially in some parts of the world, is that many people who are seropositive do not know their status.

There is a belief – one that isn't supported by data – that non-medical testing sites can increase testing uptake better than those in conventional medical settings. But the truth of that is likely to depend greatly on geographic location.

I think the chief value of HIV in Europe has been its ability to keep HIV infection at the very top of the political agenda. I have always been impressed by people who are able to influence European policy.

Looking forward, the biggest challenge facing the HIV in Europe initiative is simply to keep HIV testing near the top of the political agenda – and to continue the process of increasing HIV testing and reducing stigma across Europe.

Brussels in 2004 in order to lobby EU bodies more effectively, and it had been instrumental in planning the first HIV in Europe conference. In addition, the EATG and Aids Action Europe served together as co-chairs of the HIV/AIDS Civil Society Forum and as observers for the HIV/AIDS Think Tank. These two EU mechanisms were perfect entry points for influencing EU policy.

One of the EATG's first major projects for HIV in Europe was to organize a roundtable in September 2008 with members of the European Parliament and other policymakers, calling for an EU strategy to promote early diagnosis, reduce barriers to testing and ensure earlier treatment and care. The roundtable led to the parliament passing a joint resolution two months later, echoing that call, and to the European Commission emphasizing expanded testing in the HIV strategy it adopted a year later.

In January 2009, the steering committee committed to several projects in preparation for a follow-up HIV in Europe conference that November, in Stockholm. The projects included HIV Indicator Diseases Across Europe Study (HIDES); several European country studies for the People Living with HIV Stigma Index; a project to estimate the population of undiagnosed PLHIV in Europe; and the development of a definition of late presentation for HIV care.

The coordination secretariat also stepped up its communication efforts, launching the HIV in Europe website, hiveurope.eu, in April and issuing the first HIV in Europe newsletter, which has since appeared several times a year.

STOCKHOLM TO COPENHAGEN, 2009–2012

Meanwhile, the coordination secretariat was also preparing for the follow-up to the Brussels conference. Thanks to the efforts of steering committee member Anders Sönnerborg, it became possible to hold it at the Nobel Forum in Stockholm in November 2009, to coincide with the Swedish presidency of the EU – a strategy that has been repeated with most of the initiative's subsequent conferences. By doing so, HIV in Europe has been able to challenge the conference host country to act not only nationally, but in some cases to initiate broader EU action in promoting early diagnosis and care.

After the pioneering success of Brussels, the intention was for Stockholm to be a workshop conference, dedicated to discussing the progress of the recently initiated

DORTHE RABEN

When CHIP took on the role of coordination secretariat after the Brussels meeting, I was hired as programme coordinator – to essentially *be* the secretariat. Much of what we heard in the beginning was scepticism about whether HIV in Europe was just another AIDS organization, trying to move in on other organizations' turf.

When we began working with viral hepatitis, there was also some hesitation from hepatitis organizations, because their focus tended to be less on getting people into treatment and more on treatment itself. But the overlap in key populations makes it natural for people in the two fields to collaborate, and some of the strategies developed for HIV could prove useful for hepatitis too. The steering committee has actually been talking over the last couple of years about whether our remit should be even broader, so it would also cover STIs and TB. What's the benefit of keeping everything in disease silos?

It's important for us to frame our projects as pilots. We start things that we want other people to build upon, rather than things we'll keep doing for 10 years. That pushes us to be innovative.

HIV in Europe is a lovely, lovely initiative, and I feel a lot of passion for the work, and a great deal of affection for the people in the initiative. We wouldn't have got where we are if not for all *their* passion, all these very busy people dedicating their time because they believe in it.

NIKOS DEDES

HIV in Europe was established to address one goal: to get PLHIV tested and into care earlier. And we've achieved what we called for in our first three calls to action, except the one thing that has proven most elusive: reducing stigma and discrimination, which act as barriers to both testing and treatment.

Yet you could argue that, given the steady number of new diagnoses and the failure to diagnose PLHIV earlier, HIV in Europe still hasn't achieved its main goal – or at least you could until the end of 2015. Then it appears that something changed, with a drop in new diagnoses and perhaps new infections. We still have to ascertain if that's the case, determine the contributing factors and then work to augment them.

Of course, our vision has expanded in one significant way since the early years. Recognizing that the viral hepatitis field faced similar challenges, we invited more hepatitis experts onto the steering committee and started to address those problems.

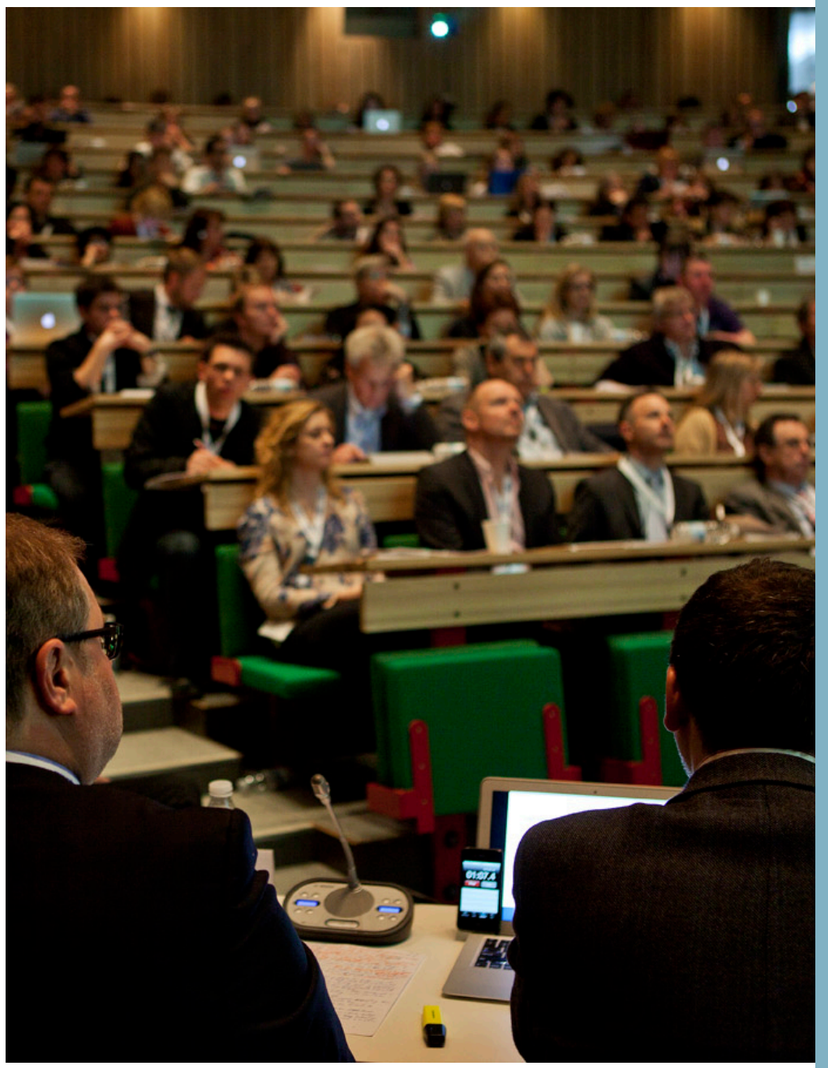
The committee has been contemplating whether we ought to broaden our scope again and address other communicable diseases, and how we could best do so. Yet even if HIV in Europe stays the same, it has secured a place in the history of the European response to the HIV epidemic!

projects, with just over 100 participants. This time the proceedings were also webcast, and the presentations were accessed online more than 1000 times during and just after the conference. The gathering also served as a technical support meeting for all the collaborating European clinics involved in the pilot phase of HIDES, which had begun earlier that year. Programme highlights included José Gatell discussing the work on developing consensus definitions for late presentation and advanced HIV disease, and Andrew Phillips presenting new estimates for HIV prevalence in Europe, drawing on some innovative models that provided more robust estimates of undiagnosed populations.

In 2010, HIV in Europe was represented on the ECDC's Technical Advisory Group on Testing, helping to develop the national testing guidance that the centre launched on World AIDS Day. The year also saw the initiative's various working groups begin to produce a steady stream of major publications and presentations that established the initiative as an important actor in HIV research in the European Region.

In addition, two of the working groups commenced on phase 2 of their respective projects. HIDES II started assessing HIV prevalence in 11 potential indicator diseases in specific populations, in addition to the 8 assessed through HIDES I. Meanwhile, the Stigma Index group, following up on the stigma studies it had facilitated in Estonia, Moldova, Poland, Turkey and Ukraine, started to develop advocacy and action plans to address stigma in the five countries.

The next HIV in Europe conference took place in Copenhagen in March 2012, attracting more than 300 participants from 46 countries. The European Commission was the conference's main sponsor, and the deputy director-general of DG Sanco delivered a keynote speech. The programme emphasized best practices in community testing, evidence for additions to the list of indicator conditions, and characteristics of late presenters. To accommodate participants from Eastern Europe, the organizers provided simultaneous Russian translation of the plenaries and published the conference proceedings in both English and Russian. For the first time, the conference also had a call for abstracts, and more than 100 abstracts were submitted, underscoring the great unmet need for a forum dedicated to research on HIV testing. The initiative arranged for the publication of a special supplement of *HIV Medicine* featuring highlights from the research presented at the conference.



JENS LUNDGREN

One of the HIV in Europe's biggest accomplishments was already there at the first conference: getting the different stakeholders to talk to each other. But that was organizational, and I prefer to measure success by tangible results.

The first tangible result was getting everyone to agree on a definition for late presentation – a basic but crucial step. It's satisfying to see how the ECDC has the entire region using the definition now, and everyone refers back to the paper we published on it in 2011. Second was indicator-guided testing and the evidence base for it, HIDES I and II. And now with OptTEST we've moved into how to implement it.

The third major achievement has been the science around modelling, which used to be quite deficient. Not that we can claim sole responsibility for it, but we did convene people to meet and discuss the issue, resulting in the seminal paper led by Andrew Phillips on different models for estimating undiagnosed populations. Look at surveillance today and 10 years ago and they're two different worlds.

Finally, HIV in Europe has been instrumental in promoting the normalization of testing and the diversification of testing approaches – the emphasis on different modes of community testing, self-testing, and getting all the various medical specialties involved. Everything isn't rosy yet, but at least it's headed in the right direction.

CONFERENCE IN BARCELONA 2014

HEPHIV2014 CONFERENCE PARTNERS

- Correlation Hepatitis C Initiative
- European Association for the Study of the Liver (EASL)
- European Liver Patients Association (ELPA)
- Hepatitis B & C Public Policy Association (HEPBCPPA)
- HEPScreen Project
- HIV in Europe
- International HIV/AIDS Alliance in Ukraine
- WHO Regional Office for Europe
- World Hepatitis Alliance

HEPHIV2014 CALL TO ACTION

The Call for Action was developed by the HIV in Europe steering committee and the HepHIV2014 Scientific Committee based on input at the conference.

1. SURVEILLANCE OF VIRAL HEPATITIS

Assess, nationally and regionally, how many people are infected with viral hepatitis (B and C, acute and chronic), their fibrosis stage, how many present late, and how many remain undiagnosed, over time and by key population, in order to monitor trends and to better target interventions.

2. DEFINING LATE DIAGNOSIS OF VIRAL HEPATITIS FOR MEDICAL CARE

Support further consultation to establish a simple and lasting consensus definition for late presentation of viral hepatitis to improve surveillance and enable monitoring of health systems and testing strategies.

3. TESTING MODALITIES AND TARGETED TESTING AND COMMUNICATION

Promote multiple testing platforms in community settings, health care facilities and in the home (self-testing), with special attention to cost and cost-effectiveness and the possibility of testing all three blood-borne diseases – HIV, HBV and HCV – at the same time. Involve key communities in the tailoring of testing and health promotion messages to their audiences.

4. INDICATOR-CONDITION-GUIDED TESTING

Broadly implement indicator-condition-guided HIV testing in health care settings, especially general practices. Develop the evidence to support the concept of indicator-condition-guided testing for viral hepatitis.

5. HEALTH POLICY STRATEGIES

Correlate national health policy strategies with public health outcomes for viral hepatitis, HIV and TB, comparing eastern and western European regions, as well as the European Union and the rest of the WHO European Region. Advocate for expansion and support the funding of successful harm-reduction models, such as those developed by Ukraine, and adoption of international standards in national strategies.

6. SYNERGY OF INFECTIOUS DISEASE EFFORTS

Facilitate collaboration between HIV, HBV, HCV, STI and TB activities in research, policy, health promotion, surveillance, testing and education – and at regional, European Union and national levels and in civil society, including organizations representing key populations.

7. CONTINUUM OF CARE

Develop robust data to inform each component of the continuum of care for viral hepatitis and for HIV, including linkages to affordable state-of-the-art treatment and interventions for prevention and testing.

8. AFFORDABILITY

Make HIV and viral hepatitis (HBV and HCV) treatment affordable by working to lower drug prices and ensuring that both domestic and international funders contribute to financing the treatment of both conditions.

9. POLITICAL LEADERSHIP

Renewed political leadership of governments, the European Union and international agencies in the European Region is crucial to address the important challenges in viral hepatitis and HIV. Policies and public health interventions need to be based on existing scientific evidence and validated guidelines are needed to inform viral hepatitis and HIV policies and programmes.

STEFAN MAUSS

As someone who's worked with both viral hepatitis and HIV, I can say that people in both fields can definitely learn a lot from each other. And the HepHIV conferences provide them with that opportunity. In particular, people who work with viral hepatitis can benefit from the experience of HIV experts in scaling up therapy in resource-limited settings, involving non-specialists in providing care and improving logistics. Testing is area where HIV efforts have led the way.

Those treating viral hepatitis, on the other hand, have much to remind those working with HIV/HCV coinfection about the advantages of delivering structured care based on the health status of a single organ – in this case the liver – rather than basing care on viral infection alone.

However, it has proven to be more difficult than anticipated for HIV in Europe to engage viral hepatitis experts – in part due to the fact that the major international organizations devoted to hepatitis and the liver are well established, with their own approaches to policy issues.

Looking to the future, HIV in Europe should help identify the best targeted approaches for testing HBV and HCV in low-prevalence countries, where general testing is not very effective. In high-prevalence countries, given the prohibitive cost of HBV and HCV drugs, it's important not to cater too much to industry. Governments like Spain and Italy that negotiate are generally able to get better prices, although negotiating may cause delays in access.

TACKLING VIRAL HEPATITIS: BARCELONA, 2013–2014

HIV and viral hepatitis are both blood-borne diseases that are typically asymptomatic for years, and the response to both diseases involves many of the same stakeholders – and many of the same challenges, including stigma, large undiagnosed populations and late presentation. Moreover, HIV and HCV have similar prevalences in the European Region, with two thirds of the people infected found in Eastern Europe, and HIV/HCV coinfection rates are high. Yet while HIV has been high on the European public health agenda for decades, viral hepatitis has been relatively overlooked.

> "We can provide Russian policymakers with all the cost-effectiveness data anyone could want, but I will tell you frankly: they don't care about drug addicts! They just don't care!"
>
> –Jean-Elie Malkin, UNAIDS Europe and Central Asia (Copenhagen, 2012)

The same could be said of hepatitis in the HIV in Europe initiative during the early years as well, and none of the plenary presentations at the 2012 conference addressed viral hepatitis except in passing. However, the Copenhagen call to action did include the item "Investigate linkages and collaboration between HIV testing and hepatitis testing and access to care." And the following year, 2013, found the steering committee making a concerted effort to prioritize viral hepatitis. In addition to new projects concerning the HIV treatment cascade in Europe, the role of HIV counselling, and European Testing Week, the committee added a hepatitis project to collaborate with hepatitis organizations on testing, conduct multidisciplinary research on viral hepatitis testing in Europe and carry out studies and advocacy relating to HIV/hepatitis coinfection.

Initial plans to include viral hepatitis as a special focus of the 2014 HIV in Europe conference in Barcelona gave way to granting hepatitis equal billing with HIV. HepHIV2014 was the first European conference to address the two diseases in tandem, and no less than six international hepatitis organizations agreed to be

conference partners. Experts in both diseases were also well represented at the conference.

As the conference demonstrated, there is a great deal that the two fields can learn from each other's experiences, and a great deal of synergy to be had in working together to address the challenges of getting more people living with either disease into care earlier. One concrete example connected with the conference was the formation of a working group to develop consensus definitions of late presentation and advanced disease for viral hepatitis, inspired by the development of corresponding definitions for HIV disease.

The conference also marked changes in the leadership of the steering committee. Brian West had been the community co-chair since the previous November, after Ton Coenen had stepped down. At the end of the conference, Jens Lundgren also resigned as co-chair, and the committee replaced him with Jürgen Rockstroh. In conjunction with these changes, the committee decided to limit co-chairs to four-year terms.

"The 'hard-to-reach community' is a myth. My community's not hard to reach … for me. The people who are hard to reach are the people with the money."

–Julian Hows, GNP+ (Copenhagen, 2012)

EXPANDING THE REMIT: 2014–2017

For the first five years of its existence, the HIV in Europe initiative functioned successfully on sponsor generosity, a series of individual project grants, a small coordination secretariat and the dedicated efforts of otherwise very busy steering committee members. While that began to change with the European Commission funding of the 2012 conference in Copenhagen, a much larger Commission grant commencing in 2014 has changed the scope of the initiative radically.

Optimising Testing and Linkage to Care for HIV Across Europe (OptTEST) is a project that seeks to reduce the number of undiagnosed PLHIV in the European region and promote timely HIV treatment and care. The project officially started in July 2014 and will run through the end of September 2017, utilizing strategies inspired by the earlier work of the initiative. With a budget of € 2.3 million, of which the European Commission is contributing 60%, the project has tripled the annual budget and output of HIV in Europe.

Besides supporting previously planned projects, OptTEST inspired a separately funded project aimed at Eastern Europe, a part of the region that the initiative has long wanted to devote more energy to because of the extra challenges that it faces in early testing and care. Focusing on Belarus, Georgia and Ukraine, the activities of this "shell project" have been integrated into OptTEST's project work. The shell project commenced in 2015 and will run for two years.

In 2016, HIV in Europe was commissioned by the ECDC to evaluate the impact of its 2010 guide to increasing HIV testing uptake and effectiveness. The initiative will be helping develop new guidelines in 2017. Independently, it also prepared a status report on HIV testing in the European region, to inform future projects.

The European Commission has recently approved funding for a joint action to be carried out by 33 partners from Europe, particularly Eastern Europe, that focuses on reducing new infections and expanding access to treatment and care for HIV, viral hepatitis, TB and STIs. Led by HIV in Europe, the joint action will build upon the experience of projects that have proven successful in the past, notably those from the European response to HIV, including European Testing Week, OptTEST and Euro HIV EDAT.

A second HepHIV conference is taking place from January 31st through February 2nd, 2017, in Malta, to coincide with the country's EU presidency. Among other things, the conference provides an important venue for presenting and disseminating the preliminary results of OptTEST. Later, in September, a joint conference will be held in connection with the end of the project period for OptTEST and Euro HIV EDAT. Euro HIV EDAT is an EU-sponsored HIV testing project that parallels OptTEST in many ways, but it concentrates on community-based testing rather than testing in healthcare settings.

The close collaboration with European projects focused on HIV such as HIV-COBATEST and Euro HIV EDAT both co-funded by Chafea will continue.

"The core principle behind self-tests is to 'democratize' testing – to get testing technologies out into the communities and mobilize them to take up the offer. It's better for people to know, and better to let them know when they're ready. Which means multiple venues using as many different modalities as possible."

–Kevin Fenton, Public Health England (Barcelona, 2014)

Finally, it should be noted that while the projects that the coordination secretariat oversees lend themselves readily to thumbnail descriptions, the ongoing work of the advocacy secretariat is harder to assess and summarize. In that role, the EATG has arranged several noteworthy meetings in recent years, including a satellite meeting at the International AIDS Conference in Melbourne on the community and treatment as prevention (July 2014); a policy seminar to promote innovative approaches to HIV testing within the framework of European Testing Week (November 2014); and one session with the Civil Society Forum on self-testing and another on community-based testing and counselling projects (July and November 2015, respectively). Yet much of its advocacy work is carried out through individual communications and face-to-face meetings, with the purpose of influencing specific national and European policies relevant to early testing and treatment.

LUÍS MENDÃO

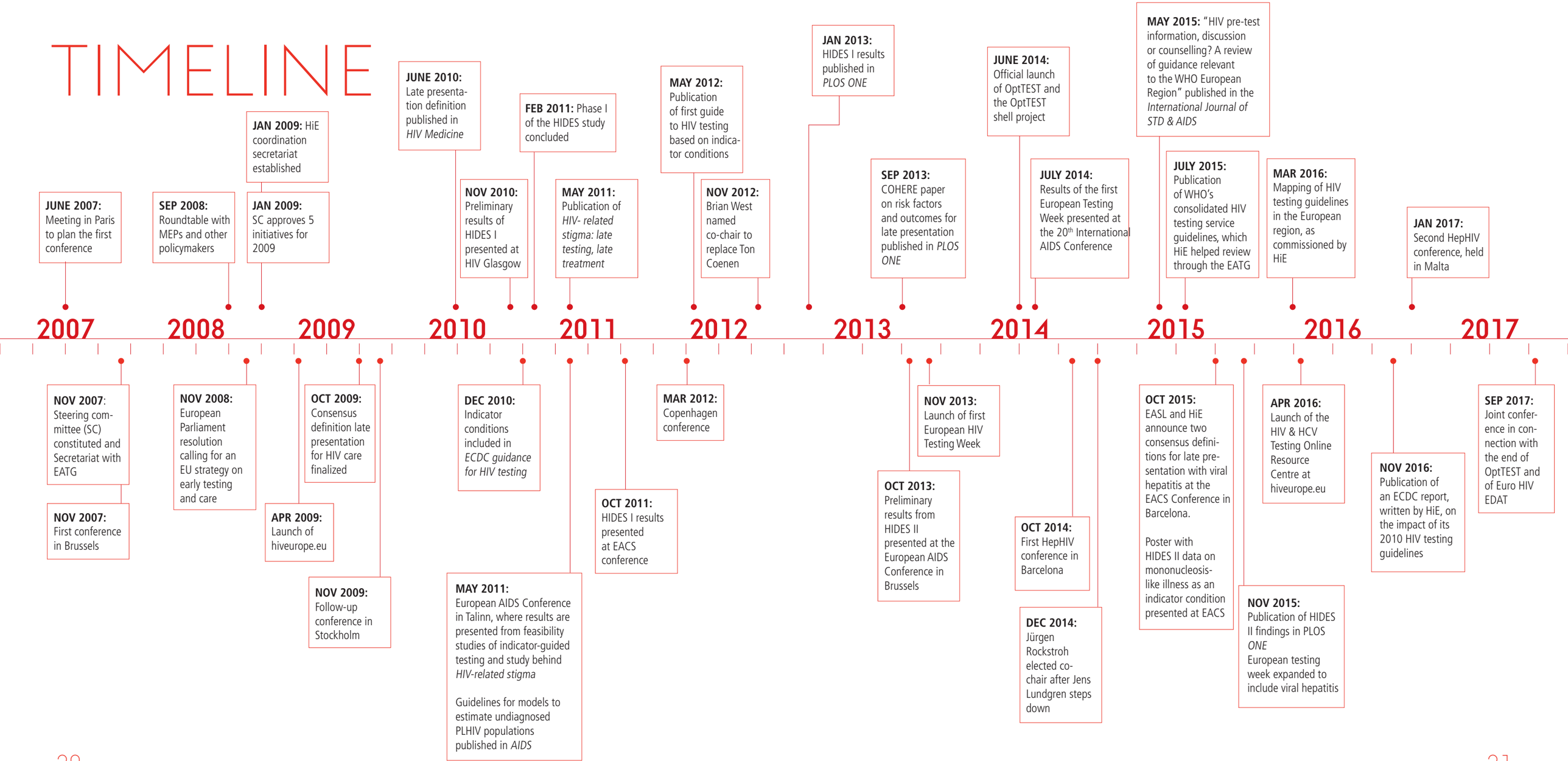
In 2007, many of the HIV NGOs in Portugal were focused on the care of sick people and traditional prevention. They didn't know how important early diagnosis and care was – and neither did any policymakers. Then HIV in Europe gave 25 of our community representatives scholarships to the first conference in Brussels.

It was critical in changing the agenda of our national HIV response. And it inspired the 2009 formation of HIV in Portugal, which similarly brings different stakeholders together, focuses on pilot projects, develops evidence and measures the impact on PLHIV's daily lives. We've also held four conferences and helped set up a network of community-based testing centres. Portugal still has the largest epidemic in Western Europe, but HIV in Europe has made a real difference.

As a steering committee member and chair of the EATG board, I believe that HIV in Europe needs to develop a vision that embraces HIV, TB, viral hepatitis and perhaps STIs. My proposal is that the initiative become HepHIVTB in Europe.

We also need a vision for the entire WHO European Region, which means a greater effort in Central and Eastern Europe. While Eastern Europe has by far the largest undiagnosed and untreated PLHIV populations, I think Central Europe has the biggest potential for serious outbreaks.

TIMELINE


2007
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JUNE 2007: Meeting in Paris to plan the first conference
NOV 2007: Steering committee (SC) constituted and Secretariat with EATG
NOV 2007: First conference in Brussels
SEP 2008: Roundtable with MEPs and other policymakers
NOV 2008: European Parliament resolution calling for an EU strategy on early testing and care
JAN 2009: HiE coordination secretariat established
JAN 2009: SC approves 5 initiatives for 2009
APR 2009: Launch of hiveurope.eu
OCT 2009: Consensus definition late presentation for HIV care finalized
NOV 2009: Follow-up conference in Stockholm
JUNE 2010: Late presentation definition published in HIV Medicine
NOV 2010: Preliminary results of HIDES I presented at HIV Glasgow
DEC 2010: Indicator conditions included in ECDC guidance for HIV testing
MAY 2011: European AIDS Conference in Talinn, where results are presented from feasibility studies of indicator-guided testing and study behind HIV-related stigma
Guidelines for models to estimate undiagnosed PLHIV populations published in AIDS
FEB 2011: Phase I of the HIDES study concluded
MAY 2011: Publication of HIV- related stigma: late testing, late treatment
OCT 2011: HIDES I results presented at EACS conference
MAY 2012: Publication of first guide to HIV testing based on indicator conditions
NOV 2012: Brian West named co-chair to replace Ton Coenen
MAR 2012: Copenhagen conference
JAN 2013: HIDES I results published in PLOS ONE
SEP 2013: COHERE paper on risk factors and outcomes for late presentation published in PLOS ONE
NOV 2013: Launch of first European HIV Testing Week
OCT 2013: Preliminary results from HIDES II presented at the European AIDS Conference in Brussels
JUNE 2014: Official launch of OptTEST and the OptTEST shell project
JULY 2014: Results of the first European Testing Week presented at the 20th International AIDS Conference
OCT 2014: First HepHIV conference in Barcelona
DEC 2014: Jürgen Rockstroh elected co-chair after Jens Lundgren steps down
MAY 2015: "HIV pre-test information, discussion or counselling? A review of guidance relevant to the WHO European Region" published in the International Journal of STD & AIDS
JULY 2015: Publication of WHO's consolidated HIV testing service guidelines, which HiE helped review through the EATG
OCT 2015: EASL and HiE announce two consensus definitions for late presentation with viral hepatitis at the EACS Conference in Barcelona.
Poster with HIDES II data on mononucleosis-like illness as an indicator condition presented at EACS
NOV 2015: Publication of HIDES II findings in PLOS ONE
European testing week expanded to include viral hepatitis
MAR 2016: Mapping of HIV testing guidelines in the European region, as commissioned by HiE
APR 2016: Launch of the HIV & HCV Testing Online Resource Centre at hiveurope.eu
NOV 2016: Publication of an ECDC report, written by HiE, on the impact of its 2010 HIV testing guidelines
JAN 2017: Second HepHIV conference, held in Malta
SEP 2017: Joint conference in connection with the end of OptTEST and of Euro HIV EDAT

PROJECTS

LATE PRESENTATION DEFINITIONS: HIV

Late presentation for treatment and care compromises the health of PLHIV and is costly for society. Efforts to estimate the extent of the problem at the Brussels conference in 2007 were stymied by a lack of a shared definition for late presentation. In fact, there proved to be more than 20 different definitions in use. An HIV in Europe working group began to explore definitions, joining forces in March 2009 with Late Presentation for HIV Treatment in Europe to develop a common definition.

Together, the two groups developed consensus definitions of late presentation and presentation with advanced HIV disease, both based on current recommendations for when to begin combination therapy. The definitions were finalized in October 2009, and José Gatell presented the definitions the following month at the HIV in Europe conference in Stockholm. The definitions are now used in ECDC surveillance, and outside Europe as well.

Late presentation: persons presenting for care with a CD4 count below 350 cells/μL or presenting with an AIDS-defining event, regardless of the CD4 cell count.

Presentation with advanced HIV disease: persons presenting for care with a CD4 count below 200 cells/μL or presenting with an AIDS-defining event, regardless of the CD4 cell count.

Late presentation of HIV infection: a consensus definition

- Published 2011 in *HIV Medicine*
- 179 citations
- Second most citied article from HIV Medicine

European Late Presenter Consensus Working Group: A Antinori, **E Girardi**, National Institute for Infectious Diseases "Lazzaro Spallanzani" IRCCS; **T Coenen**, Aids Fonds & Soa Aids Nederland; **D Costagiola**, INSERM; **N Dedes**, EATG; **J Gatell**, Clinical Institute of Medicine & Dermatology, Hospital Clinic, University of Barcelona; **M Johnson**, Royal Free Hampstead NHS Trust; **M Ellefson, O Kirk, J Lundgren, D Raben**, CHIP, Rigshospitalet, University of Copenhagen; **A d'Arminio Monforte**, Department of Medicine, San Paolo Hospital; **A Mocroft, A Phillips, C Sabin**, University College London Medical School, Royal Free Campus; **JK Rockstroh**, Medizinischen Universitätsklinik, Innere-Rheuma-Tropen Ambulanz; **A Sönnerborg**, Department of Infectious Diseases, Karolinska Institutet; **F de Wolf**, HIV Monitoring Foundation.

LATE PRESENTATION DEFINITIONS: VIRAL HEPATITIS

At the 2014 HepHIV conference in Barcelona, Maria Buti of the Hepatitis B & C Public Policy Association made the case for developing consensus definitions for late presentation for viral hepatitis. The grounds for creating it were similar to those made for the corresponding definitions for HIV, including better surveillance and testing strategies.

The definitions were being developed by a working group of hepatitis experts from the HIV in Europe initiative and elsewhere. After much discussion and review, the members agreed to two definitions, which the governing board of the European Association for the Study of the Liver (EASL) approved in October 2015. HIV in Europe and EASL made a joint announcement of the consensus definitions at a European AIDS Clinical Society conference shortly thereafter.

Late presentation of HBV- or HCV-associated liver disease is defined as a patient with chronic hepatitis B or C and significant fibrosis (≥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.

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).

Consensus Working Group on Late Presentation for Viral Hepatitis Care: Stefan Mauss, Center for HIV and Hepatogastroenterology; **Maria Buti**, HEPBCPPA; **Erika Duffell**, ECDC; **Charles Gore**, World Hepatitis Alliance; **Jeffrey V Lazarus, Dorthe Raben, Jens Lundgren**, CHIP, Rigshospitalet, University of Copenhagen; **Hilje Logtenberg-van der Grient**, ELPA; **Antons Mozalevskis**, WHO Europe; **Stanislas Pol**, Liver Department, Cochin Hospital; **Eberhard Schatz**, Foundation De Regenboog Groep (FRG) representing Correlation Network, Hepatitis C Initiative; **Stefan Wiktor**, WHO; **Jürgen K Rockstroh**, University of Bonn.

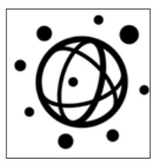
"Good epidemiology drives and monitors good policy, prevention and interventions at all levels."
–Valerie Delpech, Public Health England (Barcelona, 2014)

THE HIV INDICATOR DISEASES ACROSS EUROPE STUDY (HIDES)

At the first HIV in Europe conference in 2007, a team led by Brian Gazzard and Nathan Clumeck presented a list of diseases that might indicate the presence of comorbid HIV infection, and the conference supported their plans to develop a pilot study. Within a year, the steering committee had launched HIDES to survey undiagnosed cohorts. An HIV prevalence rate of 0.1% was chosen as the threshold for cost-effectiveness among patients presenting with a given condition.

The first phase, HIDES I, surveyed patients presenting with 8 conditions associated with HIV risk behaviour or immune deficiency. The study was conducted among 3588 patients in 14 European countries in 2009–2011 and found that all 8 conditions exceeded the threshold.

Feasibility and effectiveness of indicator condition-guided testing for HIV: results from HIDES I (HIV Indicator Diseases Across Europe Study)



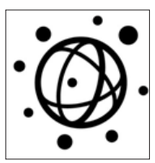
- Published 2013 in *PLOS ONE*
- 5,052 total article views
- 861 PDF downloads
- 30 XML downloads
- 44 citations

There were two elements in HIDES II, which commenced in 2012. The first was a survey of another 10,000 patients across Europe for HIV prevalence in an additional 11 conditions; it found that 9 of these conditions met the standard for cost-effectiveness. The second element was a series of audits, examining whether people who had presented with selected indicator diseases had been tested for HIV. The study found that, even for well-known indicator conditions, testing rates were surprisingly low. In addition, while the patient uptake of offered tests exceeded 95%, the offer rate was as low as 31%, showing that the primary barrier to testing lay with providers.

Since infectious mononucleosis-like symptoms were found to have the highest rate of HIV seropositivity (5.3%), as well as mimicking the symptoms of HIV seroconversion, it is the indicator condition that offers the best opportunity for early diagnosis. The study strongly recommended that this condition be included in testing guidelines throughout the European region as soon as possible.

In 2012, HIV in Europe published guidelines for implementing indicator condition-guided testing in health care settings. Besides the conditions being studied by HIDES, the guidance addressed two other categories of indicator conditions: AIDS-defining conditions and conditions where a failure to identify HIV infection would greatly compromise clinical care. The initiative later prepared a condensed version of the guide and had it translated into 30 languages. The short version has since been updated with the final results of HIDES II, and the full-length version is being updated now.

Auditing HIV testing rates across Europe: results from the HIDES 2 Study



- Published 2015 in *PLOS ONE*
- 2,296 total article views
- 293 PDF downloads

hides
HIV indicator diseases across Europe study

The HIDES (HIV Indicator Diseases Across Europe) Study Group. Advisory Group: N Clumeck, Saint-Pierre University Hospital, **J Gatell**, Hospital Clínic de Barcelona, **B Gazzard**, Chelsea and Westminster Hospital, **J Lundgren**, CHIP, Rigshospitalet, University of Copenhagen**, A d'Arminio Monforte**, Unit of Infectious Diseases, San Paolo Hospital, University of Milan, **J Rockstroh**, Department of Medicine, University of Bonn, **A Mocroft**, University College London Medical School, **Y Yazdanpanah**, Hopital Bichat Claude Bernard. Centres: **R Zangerle**, M Kitchen, University Hospital Innsbruck, Department of Dermatology and Venereology. **A Vassilenko**, Minsk Municipal Infectious Diseases Hospital, Minsk. **VM Mitsura**, Gomel State Medical University, Gomel. **C Necsoi, P Kirkove**, Saint-Pierre University Hospital. **V Hadziosmanovic**, Clinical Center, University of Sarajevo, Infectious Diseases Clinic. **J Begovac**, University Hospital of Infectious Diseases. **C Pedersen, H Frederiksen, I Hegelund**, Odense Universitetshospital, **UB Dragsted**, Roskilde Sygehus. **Y Yazdanpanah**, Hopital Bichat Claude Bernard. **N Chkhartishvili**, Infectious Diseases, AIDS and Clinical Immunology Centre. **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. **H Sambatakou**, Ippokration General Hospital. **Z M Sthoeger**, Ben Ari Institute of Clinical Immunology, Rehovot. **A d'Arminio Monforte**, T Bini, Unit of Infectious Diseases, San Paolo Hospital, **M Celesia**, U.O. Mallattie Infettive Università di Catania, Catania, Sicily, **G Orofino**, Amedeo di Savoia Hospital. **P Aldins**, Infectology Center of Latvia. **K Brinkman**, Onze Lieve Vrouwe Gasthuis, Internal Medicine. **A Grzeszczuk**, Medical University of Bialystok, Department of Infectious Diseases and Hepatology. **A Horban**, Wojewodzki Szpital Zakazny, Warszawa. **F Maltez**, Hospital Curry Cabral, Lisbon. **M A Goenaga Sánchez**, Hospital Donostia, San Sebastian, A Castro, Hospital Juan Canalejo, Coruña, **V P Estrada**, Hospital Universitario San Carlos, Madrid, **E Ortega Gonzalez**, Consorcio Hospital General Univ de Valencia, Valencia, **A Ocampo**, Complexo Xeral Cies de Vigo, Vigo, **M Masiá**, Hospital Universitario de Elche, Elche, 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, **C Agustí**, CEEISCAT, Barcelona. **A Sönnerborg**, Department of Infectious Diseases, Karolinska University Hospital. **P Vernazza**, Kantonsspital, St Gallen. **A Sullivan, M Rayment**, Chelsea and Westminster Hospital, **S Morris**, Western General Hospital, Edinburgh, **M Fisher**, Royal Sussex Country Hospital, Brighton, **A Winston**, St. Mary's Hospital, London, M Tenant-Flowers, London, **J Anderson**, Homerton University Hospital, London, **A Palfreeman**, Leicester, **J Minton**, St James's University Hospital, Leeds, **M Farazmand**, Huddersfield Royal Infirmary, West Yorkshire, ELC Ong, The Newcastle upon Tyne Hospital, Newcastle. **G Kutsyna**, Luhansk AIDS Center, Luhansk, **A Kuznetsova**, Kharkov Regional Clinic of Infectious Diseases, Kharkov. Coordinating Centre Staff: **D Raben, ML Jakobsen, G Nanfuka, F Marcher, RS Brandt**. Statistical Analysis: **A Mocroft**, University College London.

OPTIMISING TESTING AND LINKAGE TO CARE FOR HIV ACROSS EUROPE (OPTTEST)

In 2013, the European Commission's 2nd Health Programme approved the HIV in Europe application to fund OptTEST, a project to be carried out by 10 partners from across the EU. The project commenced on July 1st, 2014 and will run through September 2017.

The purpose of OptTEST mirrors HIV in Europe's own: to reduce the number of undiagnosed and late-presenting PLHIV in the EU, and to promote timely treatment and care. It features four core work packages, as follows:

Linkage to HIV treatment and care. To obtain better data on linkage to care and observe any regional differences, OptTEST is monitoring and assessing the HIV treatment cascade in seven EU countries that represent different epidemics and health care structures. Then it will develop geographically specific guidelines and tools for improving linkage to care after HIV diagnosis. In september 2015 an ECDC expert meeting on the HIV continuum of care agreed upon a working definition of linkage to care which includes the time between HIV diagnosis and the first contact with whoever is responsible for initial care (e.g., the date of first CD4 test, viral load tests or, ART initiation).

Indicator condition-guided HIV testing. Since the first conference in Brussels, HIV in Europe has promoted this evidence-based strategy as a critical supplement to testing that targets key populations. Other than HIV clinics, however, few healthcare providers have adopted indicator condition-guided testing. In this work package, OptTEST has been developing tools and training materials to help health systems implement the strategy.

Cost-effectiveness of HIV testing strategies. In this work package, OptTEST has been assessing survival rates, costs and cost-effectiveness for a variety of testing strategies in three countries. It will then develop geographically specific guidance tools for use elsewhere in Europe.

Stigma and legal and regulatory barriers to HIV testing. By drawing on the Stigma Index studies and other data, OptTEST has been helping PLHIV and key populations to partner with health care providers and advocate for better, more equitable access to services. It is developing a best-practice toolkit as well.

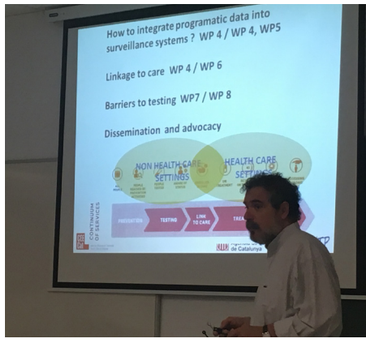
The HIV in Europe initiative has also created an OptTEST shell project focusing on three Eastern European countries, Belarus, Georgia and Ukraine. Functioning as an extension of the main OptTEST project, the shell project is utilizing its outputs to develop tools, guidelines and assessment methods for analysing and responding to late presentation for care in Eastern Europe.

Through OptTEST, HIV in Europe has enjoyed close collaboration with European projects focused on HIV, including HIV-COBATEST and Euro HIV EDAT, both co-funded by Chafea (the European Commission's Consumers, Health, Agriculture and Food Executive Agency). The initiative will also participate in the development of a joint policy brief with OptTEST and Euro HIV EDAT to be launched at the joint final conference of both the latter two in September 2017.

OptTEST
OPTIMISING TESTING AND LINKAGE TO CARE FOR HIV ACROSS EUROPE

The OptTEST Steering Committee: Jens Lundgren and **Dorthe Raben**, CHIP, Rigshospitalet, University of Copenhagen, **Jorrit Kabel**, AIDS Fonds, **Koen Block**, EATG, **Yazdan Yazdanpanah**, INSERM, **Julia del Amo**, Instituto de Salud Carlos III, **Ruth Lowbury**, MEDFASH, **Valerie Delpech**, PHE, **Ann Sullivan**, SSAT, **Kristi Rüütel**, Tervise Arengu Instituut and **Julian Hows**, GNP+.









EUROPEAN TESTING WEEK

In 2013, HIV in Europe launched European HIV Testing Week to prompt more testing. The week was also designed to give test-providing organizations an opportunity to promote their services and garner some media attention.

Two years later, the initiative broadened the focus of testing week to include viral hepatitis testing and changed its name to European HIV-Hepatitis Testing Week. The week takes place each year during the last week of November.

Testing week has its own dedicated website, testingweek.eu, with a simple lookup tool that lets people find their nearest testing sites.

Testing providers can access testing guidelines, a testing week toolkit, web banners and flyers online.

So far, some 500 partners from almost every country in the European region have participated in the testing week each year.

18–25 NOVEMBER
EUROPEAN HIV TESTING WEEK
2016
TEST.TREAT.PREVENT.
www.testingweek.eu

European Testing Week Working Group: Co-chairs: **Valerie Delpech**, PHE, **Cary James**, Terrence Higgins Trust. Members: **Anna Zakowicz**, The AIDS Healthcare Foundation, Europe Bureau, **Ann-Isabelle Von Lingen**, EATG, **Ben Collins**, EATG, **Brian West**, AIDS Action Europe, **Caroline Daamen**, ECDC, **Jason Farrell**, Correlation Network, **Josip Begovac**, EACS, **Lisa Power**, Individual consultant, **Nikos Dedes**, EATG, **Ricardo Fernandes**, GAT, **Teymur Noori**, ECDC, **Tonni van Moonfort**, EuroINPUD, **Tudor Kovacs**, IGLYO, **Zoran Dominkovic**, Iskorak. Former members: **Margaret Walker**, ELPA.

OTHER PROJECTS IN BRIEF

Estimating undiagnosed PLHIV populations
Countries vary considerably in the kinds of HIV surveillance data they collect and how they collect them. Andrew Phillips led an early HIV in Europe working group in developing a guide that summarized the various models for estimating the size of an undiagnosed PLHIV population, including the data needed by each one and their strengths and weaknesses. He first presented the group's work at the Stockholm conference in 2009, and the group published an invaluable guidance paper in *AIDS* in 2011. Phillips and Rebecca Lodwick also pioneered an innovative method utilizing CD4 counts to estimate the undiagnosed population in need of antiretroviral therapy.

HIV in hiding: methods and data requirements for the estimation of the number of people living with undiagnosed HIV

- Published 2011 in *AIDS*
- 22 citations

Working Group on Estimation of HIV Prevalence in Europe: Andrew Phillips, **Rebecca Lodwick**, **Caroline Sabin**, University College London Medical School, Royal Free Campus; **Ahmadou Alioum**, **Cecile Sommen**, **Daniel Commenges**, INSERM U897; **Chris Archibald**, **Ping Yan**, Center for Communicable Diseases and Infection Control, Public Health Agency of Canada; **Paul Birrell**, **Michael Sweeting**, **Anne Presanis**, **Daniela De Angelis**, MRC, Biostatistics Unit, Cambridge; **Dominique Costagliola**, **Virginie Supervie**, **Jacques Ndawinz**, INSERM U943; **Martin Donoghoe**, WHO Regional Office for Europe; **Geoff Garnett**, **Ard van Sighem**, Imperial College London; **Peter Ghys**, **Karen Stanecki**, UNAIDS; **Matthew Law**, **Handan Wand**, **David Wilson**, National Centre in HIV Epidemiology and Clinical Research; **Jens Lundgren**, CHIP, Rigshospitalet, University of Copenhagen; **Phil Rhodes**, Centers for Disease Prevention and Control; **Mika Salminen**, **Marita van de Laar**, ECDC; **John Stover**, Futures Institute.

"In EU countries, HIV infections have not gone away. In the last 10 years, if you want to be cynical, you could say nothing happened. There has been no change."
–Andrew Amato-Gauci, ECDC (Barcelona, 2014)

CONFERENCE IN BRUSSELS 2007

HIV-RELATED STIGMA

In 2009, HIV in Europe began contributing to the People Living With HIV Stigma Index, which assesses the stigma and discrimination experienced by PLHIV by training PLHIV to conduct their own national assessments. The initiative supported the implementation of the Stigma Index in Estonia, Moldova, Poland, Turkey and Ukraine, focusing especially on the role of stigma and discrimination as potential barriers to accessing testing and care. The results were presented at the 2009 Stockholm conference and published in the report HIV-related stigma: late testing, late treatment. A cross-analysis of findings from the Stigma Index for these five countries is available at hiveurope.eu.

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 EATG, **Julian Hows** on behalf of GNP+, **Ton Coenen** on behalf of the HIV in Europe Steering Committee.

EVIDENCE AND PRACTICE OF HIV COUNSELLING

This project, originally inspired by a public debate at the Copenhagen conference 2012, explores the role of HIV counselling in the European region, both pre- and post-test, in reducing sexual risk-taking and scaling up testing. Activities to date have included working out definitions, surveying European national guidelines, and developing and implementing best-practice models. The project publications can be accessed at the initiative website, hiveurope.eu, under Ongoing Projects.

Delivery of HIV Test Results, Post-Test Discussion and Referral in Health Care Settings Project Group: John de Wit, Centre for Social Research in Health, University of New South Wales, **Stephen Bell**, Centre for Social Research in Health, University of New South Wales, **Valerie Delpech**, Public Health England, **Jordi Casabona**, Center for STI/HIV Epidemiological Studies of Catalonia (CEEISCAT/ASPCAT) and CIBERESP; **Nino Tsereteli**, Center for Information and Counseling on Reproductive Health - Tanadgoma; **Dorthe Raben**, CHIP, Rigshospitalet, University of Copenhagen.

CONFERENCE IN STOCKHOLM 2009

ANNEXES

KEY PUBLICATIONS

JOURNAL ARTICLES

Mauss S, et al. Late presentation of chronic viral hepatitis for medical care: a consensus definition. BMC Medicine (under review).

Lazarus JV et al. Are the testing needs of key European populations affected by hepatitis B and hepatitis C being addressed? A scoping review of testing studies in Europe. Croatian Medical Journal 2016 Oct 31;57(5):442-456.

Bell S, et al. (2016) HIV pre-test information, discussion or counselling? A review of guidance relevant to the WHO European Region. International Journal of STD & AIDS 27(2): 97-104.

Raben D, et al. on behalf of the Study Group. (2015) Auditing: Auditing HIV Testing Rates across Europe: Results from the HIDES 2 Study. PLOS ONE 10(11).

Lazarus JV, et al. on behalf of the HIV in Europe Initiative Steering Committee. (2013) The case for indicator condition-guided HIV screening. HIV Medicine 14(7): 445-8.

Mocroft A, et al. for the Collaboration of Observational HIV Epidemiological Research Groups (COHERE) study in EuroCoord. (2013) Risk Factors and Outcomes for Late Presentation for HIV- positive Persons in Europe: Results from the Collaboration of Observational HIV Epidemiological Research Europe Study (COHERE). PLOS Medicine 10(9).

Sullivan A, et al. (2013) Feasibility and Effectiveness of Indicator Condition Guided Testing for HIV: Results from HIDES I (HIV Indicator Diseases across Europe Study). PLOS ONE 8(1).

Lazarus JV, et al. (2011) Overcoming obstacles to late presentation for HIV infection in Europe. HIV Medicine 12(4): 246-9.

Phillips A, et al. for the Working Group on Estimation of HIV Prevalence in Europe. (2011) HIV in hiding: methods and data requirements for the estimation of the number of people living with undiagnosed HIV. AIDS 25:1017-1023.

Antinori A, et al. for the European Late Presenter Consensus working group. (2010) Late presentation of HIV infection: a consensus definition. HIV Medicine 12(1): 61-4.

PRESENTATIONS AND POSTERS

Sullivan A, et al (2016): HIV testing in Europe: Evaluating impact, added value, relevance and usability of ECDC's 2010 HIV testing guidance [Presentation]

Sperle I, on behalf of the Testing Week Working group. (2016) Increase in HIV testing during European testing week and type of tests used [Poster presentation].

Sperle I, on behalf of the Testing Week Working group. (2015) Expansion of HIV Testing. The 2014 European HIV testing week [Poster Presentation].

Raben D, on behalf of the HIDES Mono Extension Study Group. (2015) Ongoing Mononucleosis-like Illness –a clear indicator condition for HIV testing: Results from the HIDES 2 Study –Single Arm Extension [Poster Presentation].

Lord E, et al. (2015) Evaluation of HIV Testing Recommendations In Specialty Guidelines for the Management of HIV Indicator Conditions [Poster Presentation].

Croxford S, et al. (2015) Linkage to Care Following HIV Diagnosis in Europe: A Review of the Literature [Poster Presentation].

Rae C, et al. (2015) Healthcare Related Costs of Missed Opportunities for HIV Diagnosis: A Potential Driver to Increase Indicator Condition Guided HIV Testing [Poster Presentation].

Lemsalu L, et al. (2015) Direct Costs of HIV/AIDS Care in Estonia [Poster Presentation].

Rivero-Montesdeoca Y, et al. (2015) Impact of Decentralized Drug Purchase on Antiretroviral Treatment Costs in Spain [Poster Presentation].

Kutsyna G, on behalf of the HIDES Study Group. (2014) Which Conditions are Indicators for HIV Testing across Europe? Results from the HIDES 2 study [Presentation].

Bell S. (2014) Health service-based HIV testing and counselling: a review of European guidelines [Presentation].

West BC. (2014) The European HIV testing week pilot, 2013 [Abstract presentation].

Mitsura V, on behalf of the HIDES 2 audit study group (2013) Auditing HIV Testing across Europe: results from HIDES 2 [Presentation].

Coenen T. (2012) HIV in Europe: working together for optimal testing and earlier care [Presentation].

Raben D. (2012) Reducing barriers to HIV testing – what influences testing offer and uptake? Lessons learned from the HIV in Europe Initiative [Presentation].

Sullivan A, on behalf of the HIV Indicator Diseases across Europe study group and the HIV in Europe initiative. (2011) A pilot feasibility study of HIV testing in selected indicator conditions [Presentation].

Dedes N. (2010) Overcoming Obstacles to Late Presentation for HIV in Europe [Poster Presentation].

Sönnerborg A, on behalf of the HIV Indicator Diseases Across Europe Study Group. (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 [Presentation].

Coenen T. (2010) Update on the HIV in Europe Initiative [Presentation].

Lazarus JV, on behalf of the HIV in Europe. (2010) Ensuring optimal HIV treatment in Europe: Overcoming obstacles to late presentation [Presentation].

HIV in Europe. (2009) The "HIV in Europe" Initiative: Progress Towards Testing and Earlier Care [Presentation].

OTHER PUBLICATIONS

Centre for Social Research in Health, UNSW Australia with funding from the HIV in Europe initiative and supported by the HIV in Europe Steering Committee. (2016) HIV Testing Services: Analysis of guidelines and perceptions of practice across the WHO European Region Summary Report.

Centre for Social Research in Health, UNSW Australia with funding from the HIV in Europe initiative and supported by the HIV in Europe Steering Committee. (2016) HIV pre-test practices: An online survey examining perceptions of informed consent and pre-test information delivery in health care settings across the WHO European Region.

Centre for Social Research in Health, UNSW Australia with funding from the HIV in Europe initiative and supported by the HIV in Europe Steering Committee. (2016) HIV post-test practices: An online survey examining perceived delivery of HIV test results, post-test discussion and referral in healthcare settings across the WHO European Region.

Centre for Social Research in Health, UNSW Australia with funding from the HIV in Europe initiative and supported by the HIV in Europe Steering Committee. (2016) Delivery of HIV test results, post-test discussion and referral in health care settings: A review of guidance for European countries.

Centre for Social Research in Health, UNSW Australia with funding from the HIV in Europe initiative and supported by the HIV in Europe Steering Committee. (2016) Delivery of HIV pre-test information: A review of guidance relevant to the WHO European Region

HIV in Europe. (2014) HIV and Viral Hepatitis: Challenges of Timely Testing and Care [HepHIV2014 Conference Report]

HIV in Europe. (2012) Concept note seminar on the criminalisation of HIV non-disclosure, potential exposure and non-intentional transmission [Concept note]

HIV in Europe. (2012) HIV Indicator Conditions: Guidance for Implementing HIV Testing in Adults in Health. Care Settings.

HIV in Europe. (2012) HIV in Europe Copenhagen 2012 [HIV in Europe Conference Report]

HIV in Europe. (2009) HIV in Europe Follow-up Meeting [HIV in Europe Conference Report].

HIV in Europe. (2007) Working together for optimal testing and earlier care [HIV in Europe Conference Report].

PRESS RELEASES AND POPULAR MEDIA

New consensus definition of late presentation for viral hepatitis, October 2015, Barcelona [Press release]

Renewed political leadership is key to halting the epidemics of HIV and viral hepatitis across Europe. HepHIV conference October 2014, Barcelona [Press release].

Why do HIV cases keep rising in Russia? Inside story on Aljazeera, January 2013 [Press release].

The HIV epidemic in Eastern Europe is out of control and entering into care late is fuelling and HIV/TB epidemic, March 2012 [Press release].

New Indicator Disease reveal hidden HIV. HIV in Europe Copenhagen 2012 Conference, March 2012 [Press release].

Lundgren J, Coenen T and Raben D. (2010) A timely reminder, Public Service Review, Health and Social Care, issue 25 [Review]

Coenen T and Lundgren J. (2009) Optimising testing and earlier care, European Parliament Magazine [Article].

FUNDING

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"It isn't about groups being hard to reach, but services being hard to access."

–Charles Gore, World Hepatitis Alliance (Barcelona, 2014)

CO-CHAIRS AND STEERING COMMITTEE MEMBERS, 2007-2017

CO-CHAIRS: **Ton Coenen**, AIDS Action Europe, Executive Director Aids Fonds & Soa Aids Nederland, Netherlands, (2007-2012); **Jens Lundgren**, Professor & Chief Physician, University of Copenhagen & Rigshospitalet, Director of CHIP, Denmark, (2007-2014); **Brian West**, Board of Directors, European AIDS Treatment Group, (EATG), Scotland, (2013-); **Jürgen Rockstroh**, Professor of Medicine University of Bonn and Head of an HIV outpatient clinic, Germany, (2014-).

STEERING COMMITTEE MEMBERS: **Henrique Barros**, National Coordinator of HIV/AIDS Infections, Portugal (2007-2010); **Nikos Dedes**, Chair, Policy Working Group, European AIDS Treatment Group (EATG), Greece (2007-); **José Gatell**, Head, Infectious Diseases & AIDS Units, Clinical Institute of Medicine & Dermatology, Hospital Clinic, Professor of Medicine, University of Barcelona, Spain (2007-); **Brian Gazzard**, Professor of Medicine, Imperial College School of Medicine, HIV Research Director, Chelsea & Westminster Hospital, UK (2007-); **Igor Karpov**, Professor, Department of Infectious Diseases, Belarus State Medical University, Belarus (2007-); **Jürgen Rockstroh**, Professor of Medicine University of Bonn and Head of an HIV outpatient clinic, Germany (2007-2013); **Jean-Luc Romero**, "President Elus locaux Contre le Sida, France" (2007-2010); **Gregory Vergus**, Regional Coordinator, International Treatment Preparedness Coalition, Russia (2007-2009); **Anders Sönnerborg**, MD, Professor, Department of Medicine Karolinska University Hospital, Sweden (2008-); **John de Wit**, Professor and Director, National Centre in HIV Social Research, The University of New South Wales, and Visiting Professor of Social Psychology of Health and Sexuality, Utrecht University (2007-); **Jordi Casabona**, Scientific Director, Center for HIV/STI Epidemiological Studies of Catalonia (2011-); **Valerie Delpech**, Public Health England, London, United Kingdom (2012-); **Nino Tsereteli**, Executive Director of "Center for Information and Counseling on Reproductive Health – Tanadgoma," Georgia (2012-); **Ton Coenen**, AIDS Action Europe, Executive Director Aids Fonds & Soa Aids Nederland, Netherlands (2013-2015); **Jeffrey V. Lazarus**, Professor of International Health Systems, University of Copenhagen, Denmark (2013-); **Jens Lundgren**, Professor & Chief Physician, University of Copenhagen & Rigshospitalet, Director of CHIP, Denmark (2014-); **Stefan Mauss**, Center for HIV and Hepatogastroenterology, Germany (2014-); **Stanislas Pol**, Professor of Hepatology and Gastroenterology, Université Paris Descartes, France, Member (2014-); **Ludmila Maistat**, Senior Programme Manager in Alliance for Public Health, Ukraine, International Alliance Center for HIV, Hepatitis C and Drug Use (2015-) ; **Tom Platteau**, Mental health scientist and sexologist at the HIV/STI clinic of the Institute of Tropical Medicine in Antwerp, Belgium (2015-); **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 (2015-); **Wim Zuilhof**, Manager of the National HIV and STI prevention programs for MSM and ethnic minorities, STI Aids, Netherlands (2016-).

OBSERVERS: WHO Regional Office for Europe, represented by **Jeffrey V. Lazarus**, (2007-2008), represented by **Srdan Matic** (2009-2010); WHO Regional Office for Europe, STI/HIV/AIDS Programme, represented by **Smiljka de Lussigny** (2009-2010), represented by **Lali Kotenashvili** (2011-2015), represented by **Martin Donoghoe** (2016-); European Centre for Disease Prevention and Control (ECDC), represented by **Marita van de Laar** (2009-2012), represented by **Andrew Amato-Gauci** (2013-); European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), represented by **Lucas Wiessing**, epidemiologist, principal scientist (2009-); The Global Fund to Fight AIDS, Tuberculosis and Malaria, represented by **Jeffrey V. Lazarus**, (2009-2010); Centre for Disease Control and Prevention (CDC), represented by **Kevin Fenton** (2010-2012); The Global Fund to Fight AIDS, Tuberculosis and Malaria Represented by **Vitaly Zhumagliev** (2011-2012); UNAIDS Regional Support Team ECA, represented by **Jean-Elie Malkinr** (2011-); Public Health England, represented by **Kevin Fenton** (2013-); Hepatitis B & C Public Policy Association, represented by **Angelos Hatzakis** (2016-).

HIV IN EUROPE IN NUMBERS

- Number of European countries collecting data on late presentation for HIV in 2007: 0. In 2015: 41
- Number of media representatives at the press conference for the first conference in Brussels: 35
- Number of media/press clips it generated: 160 Total number of HIV indicator conditions before HIDES I, excluding AIDS-defining conditions: 0. After HIDES II: 16
- Round-trip kilometres flown by participants to attend the 2014 HepHIV conference in Barcelona: 952,600
- Percentage of Barcelona participants who were community representatives: 34%. Who were clinicians: 25%. Who were policymakers: 10%.
- Number of organizations participating in the 2016 European HIV-Hepatitis Testing Week: 519
- Cups of coffee drunk in steering committee meetings, 2007-2017: 164,250

ACRONYMS

CDC	United States Centers for Disease Prevention and Control
EASL	European Association for the Study of the Liver
EATG	European AIDS Treatment Group
ECDC	European Centre for Disease Prevention and Control
HiE	HIV in Europe
HIDES	HIV Indicator Diseases Across Europe Study
OptTEST	Optimising Testing and Linkage to Care for HIV Across Europe

Dedicated to improving early HIV diagnosis and care throughout the European Region, HIV in Europe provides a European platform for the exchange of research findings and the promotion of related activities. The initiative is directed by an independent group of experts who represent civil society, research institutions, policy bodies, health systems and public health institutions.

HIV in Europe

Working Together for Optimal Testing and Earlier Care