

# Report of the 20th HIV/AIDS Civil Society Forum

Rome, November 24 and 25, 2014

Meeting convened by the European Commission Health & Consumer Protection Directorate-General  
with co-chairing of AIDS Action Europe and the European AIDS Treatment Group



## The EU HIV/AIDS Civil Society Forum



European  
AIDS Treatment  
Group

# Introduction

*The HIV/AIDS Civil Society Forum (CSF) has been established by the European Commission as an informal working group to facilitate the participation of non-governmental organizations, including those representing people living with HIV/AIDS, in policy development and implementation and in information exchange activities. The Forum includes about 40 organizations from all over Europe representing different fields of activity. The Forum acts as an informal advisory body to the European Think Tank on HIV/AIDS. EATG and AIDS Action Europe co-chair the Forum. All annexes to this report are only available online at the CSF page on the [AIDS Action Europe website](#).*

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# November 24, 2014

## 1 Opening

### 1.1 Welcome and introduction

Lella Cosmaro and Tamás Bereczky open the 20<sup>th</sup> meeting of the EU HIV/AIDS Civil Society Forum. The meeting starts with the commemoration of Martine de Schutter who lost her life in the MH 17 plane crash in July after the last CSF meeting took place. Martine's merits as Executive Coordinator of AIDS Action Europe for the CSF are dignified. The incredible loss for her friends and family and for the community is expressed. The commemoration ceremony in Amsterdam in September honouring Martine was attended by several CSF members.

The opening continues with an introduction round of the attending CSF members.

### 1.2 Report and action list of last meeting

Michael Krone introduces himself as new Executive Coordinator of AIDS Action Europe and leads the CSF members through the action list of the last meeting. The results are listed in the following table:

What	Who	When	Status
Follow up on an initiative against the criminalization of sex work	CSF coordination team	Ongoing	Will remain on the action list
Follow up on the planning for the Conference in Rome	CSF coordination team/ Lella Cosmaro	ASAP	Done
Follow up with Cinthia Menel Lemos (Chafea) on information in regard of programmes on improving use/knowledge of structural funds.	CSF coordination team	ASAP	Done, email was sent out to CSF list
Distribute information, if available, on whether HIV falls within the funding line of chronic diseases for the new Call for Proposals of the Health Programme	CSF coordination team/ Silke Klumb	ASAP	Done by email
CSF members: engage with respective National CSF Ongoing Authorities to emphasize the importance of the Rome Conference	CSF coordination team		Done by mailings
CSF members: engage with respective National Authorities to keep HIV, HCV, TB and STIs on the agenda of the Health Ministers Council	CSF coordination team	before September 22 (next meeting of Health Ministers Council)	Done by mailings
Discuss with Aigars Cepitis (Latvia) how to support Latvian efforts in adopting international guidelines during the Latvian presidency	CSF coordination team	September	Done and on the agenda of this meeting
CSF members: Address national focal points to check if they are interested in participating in the Joint Action on harm reduction	CSF coordination team/ Silke Klumb	Deadline for feedback to EU is September 16	Done
Put together a Joint Advocacy Calendar for both CSFs	Ann Isabelle von Lingen (EATG)	During September	Pending
Share relevant information with Civil Society Forum on Drugs, i.e. regarding the planning of UNGASS meetings on drugs and on HIV in 2016	CSF coordination team	next CSF meeting	Done
Disseminate a presentation on new research on MSM and drug use by Aidshilfe North Rhine-Westphalia on the CSF mailing list	Silke Klumb (Deutsche AIDS-Hilfe)	As soon as results will be available	Only published these days and will be sent out immediately

Initiate letter to Health Ministries to be released on July 28 on universal access to Hepatitis C treatment and reach out to other organisation	CSF coordination team/ Luis Mendao	done	Done
Draft a call for a “Rome declaration” to create a strong commitment ensuring access to treatment in Europe	CSF Coordination team/ Lella Cosmaro	done	Done
Synthesize latest evidence/information on community based HIV testing outside medical settings	CSF Coordination team	November	Done and on the agenda of this meeting

### 1.3 CSF co-chairs update on advocacy and other actions

Lella Cosmaro and Tamás Bereczky update the CSF members on conducted actions and developments since the last meeting:

- In July, a call for action was sent to the EU Ministers of Health and the CEO's of pharmaceutical companies ensuring universal access to curative hepatitis C treatment in the EU and beyond. The call was delivered to the informal meeting of Ministers of Health in Milano (EPSCO) on September 22 and 23, 2014. Videos with interviews of Luís Mendao (EATG) and Achim Kautz (European Liver Patients Association) on occasion of the protests accompanying the EPSCO meeting are replayed and pictures of the protests with the delegation of the Italian civil society presented.
- A lot of time in preparation of the CSF meeting has been dedicated to the Rome conference and the development of the Rome declaration. The whole organisation of the conference has proven to be difficult due to the involvement of the Italian MoH and other MoHs in European efforts related to the Ebola outbreak. At this point, it seems unlikely that the Rome Declaration will be endorsed during the conference.
- For the second time, the European HIV Testing Week is conducted from November 21 to 28, 2014 with 709 organisations from 51 countries that signed up.
- The new European Commissioner for Health and Food Safety, Vytenis Andriukaitis will meet a delegation of six people representing the Civil Society Forum, on November 27, 2014 for 30 minutes before the start of the Rome conference.
- On 10-11 October 2014 the “Increasing Capacities, Achieving Novelties ( iCAN)” conference, organised by the EATG was conducted in Warsaw. It was an excellent opportunity for sharing good practices and experiences and it fuelled interesting discussions on PrEP, testing and other pressing and important issues.
- The Facebook page 'HIV policy in Europe' has proven to be an important communication means and has become very popular, well beyond the CSF.
- The Joint Action on HIV and co-infections and Harm Reduction was introduced with an information meeting in Luxembourg on November 6 and 7, 2014. The JA will be discussed more in-depth under topic “Any other business”.

### 1.4 The current state play of HIV Policy in Europe: Update from the Commission

Matthias Schuppe reports about recent developments from the Commission (see Annex 1). He notes that the Commission has been mobilised for the Ebola emergency and that this has significant implications for the work of the Health Threats unit:

- The key findings of the external evaluation of the Commission Communication and Action Plan on combating HIV/AIDS 2009-2013, which will inform considerations on a potential future EU policy framework on HIV/AIDS and co-infections
- Commission support of the European HIV Testing Week
- Preparation of a meeting of Commissioner Andriukaitis with the co-chairs and a delegation of the Civil Society Forum on the fringes of the Rome HIV Ministerial conference
- Chafea Dissemination event in Rome under the auspices of Italian EU Presidency in October 2014, that addressed health inequalities including HIV/AIDS
- Participation in the External Advisory Board for the Rome HIV Ministerial Conference, input to the conference programme and draft of the Rome declaration as well as the key note speech of Commissioner Andriukaitis for the upcoming conference, renewing the EC commitment to fight HIV/AIDS
- Meeting of Commissioner Andriukaitis with the new Latvian Minister of Health in November 2014, where the Commissioner expressed support to the Latvian MoH for the Latvian Presidency of the EU which will include a high level meeting on Tuberculosis in March 2015

- A Chafea dissemination session showcasing actions addressing HIV and co-infections particularly TB during the high-level meeting is planned.

**Discussion:**

Aigars Cepitis emphasises that the Latvian presidency is focused on healthy nutrition and healthy life styles and highlights the importance of keeping civil society concerns regarding HIV on the agenda for the Latvian presidency. It is agreed to move forward with a letter on low implementation of standards of care in Latvia. The lack of involvement of civil society in the Joint Action on harm reduction is briefly discussed and it is agreed to re-discuss the issue later during the meeting since the Joint Action will also be addressed during the Think Tank meeting.

**1.5 Update from the agencies - WHO Europe**

Martin Donoghoe, WHO Europe office, presents on the following points:<sup>1</sup>

- Support to the Latvian presidency MDR TB event. It should cover HIV
- Efforts to use the Latvian Presidency to draw attention to low implementation of standards of care in Latvia
- WHO will be working on a new health sector strategy for HIV/AIDS 2016-2020 and one on HCV
- The WHO Action Plan on HIV for Europe expires end of 2015. WHO Europe will organise consultations for the new plan
- Preparation work for next Global treatment guidelines will start (the last were released in June 2013)
- WHO also released its key population guidelines
- An HCV focal point position has been created in the HIV and HCV programme
- In December WHO released guidelines on Post-Exposure Prophylaxis and a Q&A sheet on Pre-exposure prophylaxis for MSM
- WHO Europe plans to scale up efforts with governments on community testing and harm reduction and is concerned about certain countries misinterpreting guidelines (WHO is looking at treatment cascades as indicators)
- There is a policy dialogue with Russia
- WHO Europe continues to work with Russia and also with Ukraine with the objective to avoid treatment interruptions.

**Discussion:** Regarding the involvement of CS, it is asked how exactly the plan to involve CS will look like: There will be a big meeting in the first quarter of 2015 and a strong message should be sent out regarding CS involvement. The framework for effective collaboration will be set.

**2 EC RTD: Open call on HIV vaccines and funding opportunities**

Alessandra Martini, EC Directorate General for Research and Innovation, presents on the EC research funding for HIV/AIDS under the Horizon 2020 programme. She highlights work on HIV vaccines. More detailed information can be found in her presentation (Annex 2). Furthermore, she underlines the importance of dialogue and the support of the community in the research agenda. Moreover, it is underlined that the European Commission is looking for external experts to support the research programme.

**Discussion:** The importance of including social sciences in HIV/AIDS research to boost the research and policy outcomes in the long run is underlined, together with the fact that scarce funds are available for civil society as a recipient to be engaged. Traceability of EU funding and transparency of EU funding: concerns are raised over transparency at national level of EU funding and the Innovative Medicines Initiative II. The Commission notes that there is no cash flow to the industry but rather to academics and SME and that new ideas for efficient mechanisms improving the research process are always needed.

**3 The Rome Conference – Latest updates and information**

Lella Cosmaro provides background information on the Rome conference program and on the objective to have a Rome Declaration. The Rome event was announced in March 2014 and CS contributed as much as possible to the preparation. Yet,

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<sup>1</sup> The presentation was moved due to his attendance the next day to the EACS meeting

it was challenging due to different reasons, specifically from the Italian side. An External Advisory Board was constituted very late, national ministries were not involved, invitations to speakers and ministers of health went out extremely late and this will result in lack of attendance on the part of the ministers. The draft document of the declaration has just been distributed. Nevertheless, the conference will take place and the latest draft of the agenda is presented to the CSF.

**Discussion:** While concerns are raised about the possibility to adopt the Declaration at this late stage, it is agreed that the review of the Dublin Declaration is needed and that the process of having a declaration in the near future needs to be followed up. It is deemed important to maintain strong attention on the declaration and to investigate procedures to involve the upcoming EU presidencies for the adoption of the document next year. Civil society contribution is needed to sustain the process. Moreover, even with no declaration being adopted, the need of having a statement out of the conference and a press release also considering future perspectives is expressed. The CSF coordination team is assigned to send out the latest version of the agenda, the declaration draft via the listserv and work on a press release.

#### 4 10 year Dublin overview

Teymur Noori, ECDC HIV programme, presents the Dublin 10 Years and the 2013 Surveillance reports, as well as the messages to be delivered in the next days (see Annex 3). The background of monitoring the Dublin Declaration, epidemiological overview, main achievements, remaining challenges and conclusions are outlined and the following issues are highlighted:

- Increase of newly diagnosed HIV cases in the Non-EU/EEA countries of 126%
- Increase of newly diagnosed HIV cases in EU/EEA countries among MSM of 33%
- Decrease of heterosexual cases from countries with generalised HIV epidemics in EU/EEA countries by 61 %; injecting drug use cases by 36% and mother-to-child transmission by 37%
- Decrease from 40% to 28% of the proportion of EU contributions since 2008 in financing the global AIDS response, but European countries remain the largest funders of the AIDS response when compared to GDP
- Latvia remains only European country with guidelines indicating HIV treatment initiation at 200 CD4 cells/mm<sup>3</sup>. The presented slide speaks for itself and needs no further comment
- 30% of PLHIV are unaware of their HIV status
- AIDS related deaths diminished from 2004 to 2013 by 75% in the EU/EEA countries
- High number of undetermined transmission cases among non-EU/EEA cases, with an increase of 160%
- OST remains a challenging factor in all six non-EU countries with coverage below 5%
- Late diagnosis critical issue in Europe and Central Asia with 49% diagnosed late.
- ART for undocumented migrants living in Europe available only in a minority of EECA countries.
- 5 key priority actions on prevention, testing, treatment, financing at scale (in particular where the GF is withdrawing from funding) and leadership are set.

**Discussion and remarks:** According to data from the UK, 50% of HIV infections among migrants occur after migrants have arrived in the UK. 98 % of funding goes into treatment while only 2 % are spent on prevention. It is noted that treatment also works as prevention. Nevertheless both are needed and should not be played off against one other.

Reported data are not always correct. It is noted that where governments and NGOs reported data are too similar, there may be arrangements. In other cases there is little reporting from NGOs and alternative ways to get data from CS are needed.

CSF is surprised at seeing that data say there are no legal and policy barriers to access, when there are. For instance, legislation and criminalisation hamper access to prevention, treatment and care in various countries for sex workers.

Presentation data need to be further detailed otherwise the report will be misinterpreted. For instance, it must be underlined that data about Russia were reported in 2008 and 2010. A request is made for regional differentiation. For instance, in low prevalence countries increase of new cases may be high but due to lower absolute figures it is not reflected in the overall European figures.

The representative from Romania asks why no data are given on OST coverage since there is OST and data are available. Concerns are also raised regarding the ECDC model to estimate treatment coverage rates. It is suggested to work further on the model since the only inclusion of those diagnosed does not reflect the actual treatment gap.

## 5 Keeping HIV, HCV, TB and STIs on the political agenda at European level

During this session, CSF discuss ways to keep the issues on the EU's political agenda

The CSF need to increase awareness among new MP's and to establish contacts with them to address relevant needs and issues. Channels can be for instance the European Parliament Intergroup on Public Health and the LGBT Intergroup. It is agreed that the CSF Coordination team sends a letter to the new Commissioner describing civil society concerns and highlighting thematic areas to be tackled. Another advocacy tool will be the outcome of the Rome conference. Against this background, the upcoming EU presidencies of Latvia, Luxembourg and the Netherlands will be of high relevance. Concerning the Latvian Presidency, Aigars Cepitis reports on the plans of the next EU presidency (Annex 4). The planning of activities, published on the Latvian MoH's website, indicate a focus on healthy nutrition and healthy lifestyle. There are no conferences on HIV or Hepatitis; whether the conference on Tuberculosis on March 31, 2014 will also highlight HIV remains unclear. A proposal made by civil society organisations to host a Baltic conference on HIV/Hep C was turned down by the Latvian MoH.

The Luxembourg presidency starts on July 1, 2015. Since there is no CSF representative from Luxembourg and the Commission has no information about related arrangements, the members do not have a contact person/group to address questions. It is noted that there is a Luxembourg government representative in the Joint Action who can be approached. Also, the Netherlands is in close contact with Luxembourg and could be contacted as well. The Luxembourgian MoH is very small and has limited staff.

The Netherlands Presidency: Anke Van Dam reports on preparations of the Dutch EU-presidency, for the first half of 2016, concerning the issue of HIV. There will be meetings held with CS representatives. UNGASS 2016 and the road to the New York summit with several preparation meetings are also accompanying thematically the Presidency preparations. Moreover, Amsterdam applied to host the International AIDS Conference in 2018. Rivalling city is San Francisco and the decision will be taken in December 2014. It would be of high impact for the whole region if the conference takes place in Amsterdam.

**Discussion:** The discussion aims at identifying how to keep the Rome Declaration on the agenda and how to have it adopted if not in Rome, then in one of the upcoming presidency semesters. It is agreed that the CSF and civil society in general have to keep the pressure and insist on the release of a new Declaration.

- The CSF coordination team is assigned to follow-up through letters and subsequent contacts with the respective addressees.

## November 25, 2014

### 6 The current state of HIV Policy in Europe: Updates from the agencies (ECDC, UNAIDS, WHO Europe)

Agenda changes are announced since ECDC and WHO already gave their presentations. Henning Mikkelsen of UNAIDS focuses on the importance of locations and populations at global level (see Annex 5), on the developments of the epidemic among PWID (with an extremely high prevalence in Romania and Estonia for Europe) and among MSM compared to the general burden of the epidemic. He presents the 90-90-90 strategy by 2020 and the Fast-Track-Targets by 2030.

**Discussion:** For Europe, the first 90 referring to PLHIV knowing their status seems to be the most important and critical issue. UNAIDS clarifies that developments are monitored based on progress reports from the assigned organisations of the member states. The persisting high incidence rates among MSM in Europe are discussed. A raising gap between AIDS organisations and the LGBTI community is mentioned as a critical point. LGBTI need to be better included into strategy and activity planning.

### 7 Share relevant information with Civil Society Forum on Drugs, i.e. regarding the planning of UNGASS meetings on drugs and on HIV in 2016

Maria Phelan, from Harm Reduction International was supposed to present but could not attend. She prepared a few points

presented by Ann Isabelle von Lingen. (see Annex 6)

In the CSF on Drugs, a discussion thread revolves around harm reduction as a specific topic and a specific working group has been established for it. Since there is little support for harm reduction funding in several countries, a call for the Harm Reduction Decade was initiated. The campaign goes with the slogan '10 by 20', to say that by 2020 for every dollar spent on law enforcement 10% of it should flow into harm reduction.

The challenge will be to join forces between the CSF on drugs, the CSF on HIV and harm reduction groups. Civil Society needs to influence the EU position, contribute to the UNGASS meeting, ensure that its voice is heard and facilitate the process. It will also be crucial to learn from the experiences that were made on HIV topics. Furthermore, advocacy activities at national level have to be implemented and decision makers have to be convinced that inclusion of civil society is critical.

It is also highlighted that structural prevention is crucial. There is high vulnerability due to circumstances as criminalisation, social barriers, discrimination etc. The issue of hepatitis C, its incredible burden impacting PWID and access to DAA for this key population need to be addressed as well.

Key points for follow up included:

- Urge EU governments and the EU to support civil society involvement and dialogue
- Re-affirm that new infections can be eliminated among PWID/PUD through a comprehensive harm reduction package (not only NSP and OST)
- Work with Drug Policy Commission
- Revisit the Statement issued in 2011 by CSF on HIV to include Hep C
- Ask for EASL, EACS, IAS support
- Challenge the regulation of not allowing CS in working groups

Develop CSF statement and advocacy strategy. Identified volunteers: Marianella, Elena

## **8 Rapid Tests – community based testing outside medical settings**

Ann Isabelle von Lingen, of the EATG reports on the preliminary findings of an informal survey carried out by EATG through its members and partners about the demedicalisation of testing in various European countries. She notes that additional and cross-checking information in some countries is needed to complete the results (Annex 7). The survey was done in the context of the European HIV Testing week, and rapid test manufacturers were asked to donate kits in the occasion of the I-Can conference which EATG organised in October. The situation varies between high barrier countries, where testing can only be performed by a doctor, to low barriers countries where demedicalised testing is allowed. Most countries are in the medium barrier categories. In the middle category, groups perform testing but are acting in a grey zone. Preliminary data can be shared with a disclaimer noting that it is only indicative data based on input of EATG members and partners and that it will be further cross-checked. It is noted that further work for community based testing will occur under the OptTest project - optimising testing and linkage to care for HIV across Europe - with one work package investigating the cost-effectiveness of different testing strategies and another one developing a toolkit for removing legal and regulatory barriers to testing and linkage to care.

**Discussion:** Several opinions are shared during the discussion.

- Action is particularly needed where NGOs act in a “grey zone” and testing sites act more or less by violating the existing law.
- Suggestions to investigate also administrative barriers, practical and financial burdens (for instance disposal of tests), how many tests are performed and who gets tested. Home testing should be included in the study
- An economic argument in favour of community based testing is that it is proven to be cost effective. Fewer tests with higher identification rates need to be conducted when they are performed in community based settings where key populations with higher prevalence are reached.
- Another barrier is the high price for testing kits.
- With the availability of home tests through the internet and the legalisation of home tests in some countries, legislation in other countries is bypassed by practical matters and the power of facts.
- Linkage to care is more likely to be ensured when a key population friendly care setting or network is in place. Community based testing is also important for STIs and hepatitis. The members agree that testing in community



based settings has to be kept on the agenda and advocated for by the CSF coordination team.

- EATG and AIDS Action Europe will discuss further collaboration on the issue of rapid testing.

## **9 PrEP - State of discussion in different countries**

Francesca Belli, AIDES presented on research and community work in relation to PrEP in France (see Annex 8).

After the Board of AIDES decided to participate in the Ipergay study, the trial was introduced in 2012 targeted to MSM, who are at high risk of HIV infection. Two trial arms were indicated, the first one with full prevention services and Truvada administered before and after risk exposition, the second one with full prevention services and a placebo dispensed before and after exposition, with 950 participants in each arm. The placebo arm was stopped in October 2014 out of ethical reasons as it would have been irresponsible to maintain the placebo arm. The final results will only be published next year. However, next steps including advocacy strategies at French and European level to establish guidelines and recommendations for usage as well as to ensure the marketing authorisation for Truvada are already in place. Moreover, with the Enquête Flash PrEP survey, introduced in April 2014, AIDES aims to characterise HIV negative people's willingness and intention to use PrEP and the informal use of PrEP. Preliminary results of the survey show that 33.6 % of 3024 respondents were aware of PrEP before answering the questionnaire. Moreover, 4.5 % indicated the informal use of PrEP. At the same time, the interim analysis of the open-label PROUD study published in October 2014 showed that PrEP reduces the risk of HIV infections among gay men. Published results are expected in early 2015.

### **Discussion:**

- There is consensus that PrEP offers a new option in prevention. If the medicines are taken, the risk of HIV infection decreases significantly.
- The price for Truvada and how PrEP should be financed remains an issue. It is noted that cost is not the issue, price is.
- It will be difficult to promote PrEP at political level as it is viewed as promotion of excessive sex and policy makers would like to avoid a moral controversy on this issue. Comparisons with the debate around the contraception pill in the 60ies are made.
- Further consideration should be given to the fact that for some communities, as for instance sex workers, the event driven use of PrEP with taking four pills of Truvada before and after exposition is not an option. We would also need to work on an ethical framework of PrEP that addresses also practice of law enforcement with PrEP confiscated by police, which can be viewed as an attack to the right of people to access prevention.
- Another issue to be considered is testing and to avoid the development of resistances.
- In any case, an informed decision needs to be offered to potential users, which implies sufficient information and trainings for public health professionals. Doctors need to be informed how to address adequately their patients on PrEP.
- While PrEP is under discussion in the Western countries, EECA are far away from setting up PrEP as an option in prevention.

The CSF coordination team is assigned to work on and advocacy statement directed to different stakeholders and authorities to promote a more progressive discussion aimed at keeping PrEP as another option on the agenda.

## **10 EU Communication for combating HIV/AIDS in the European Union and neighbouring countries - Action Plan after 2016 – State of affairs**

Although the Action Plan has been renewed until 2016, it is already crucial to advocate for a policy tool after 2016 to establish the commitment of the Commission and the EU to HIV and co-infections. Some aspects are important and need to be taken into consideration: the collaboration with the agencies and their strategies in order to use synergies, which key populations should be prioritized, which new developments should be considered, which kind of data are needed, prevention and/as treatment, access to treatment, health inequalities among many others. The external evaluation of the former EU Communication has been finalised and the results will soon be published. This will be the initial and necessary step for Civil Society to start the process of working on strategies for a new policy instrument. After that, about 12 months are needed for an impact assessment and another 6 months for the policy development itself. What kind of policy instrument CSF should advocate for has to be well thought about.

## **11 Preparation of the meeting of the CSF delegation with the new Commissioner**

On Thursday, November 27, 2014, a CSF delegation will meet with the new European Commissioner for Health and Food Safety, Vytenis Andriukaitis and a delegation of the Commission's department. The main points emerging from the preparatory discussion are the following:

- Harm reduction instruments have proven to be effective. The holistic prevention package including all methods that prevent people from HIV and co-infections needs to be implemented in the countries.
- Obstacles hampering effective prevention and decrease of HIV infections have to be removed, e.g. stigma and discrimination, law enforcement against sex work, drug use, the so called gay propaganda legislation or legislation against the trans-population, and the deprivation of human rights. Structural barriers have to be overcome to let people make conscious decisions about their lives and their health. The EU needs to take the lead to ensure access to prevention, treatment and care for everybody so that no one is left behind.
- It is unacceptable that a communicable disease as hepatitis C can be treated but people are still losing their lives although there is a life saving cure. Affordability of medicines has to remain on the agenda to make access possible and to tackle inequalities in health. It is not about costs, it is about prices. The commitment about the infectious disease act has to be strengthened.
- The term of human rights has to be filled with meaning again. Each human right has to be specified and its implication to be signified, e.g. the right to health or the right to autonomy to only name two of them.
- The EU has to take the leadership to make implementation of human rights based, effective and necessary Public Health policies at national level a reality. It also has to consider its role as funder where the Global Fund is increasingly withdrawing from the neighbouring countries. Uprising populism is an obstacle to evidence based prevention, treatment and care. The health of the European population is at stake.
- The recent increase of HIV infections among MSM has to be taken into focus. This is the key population that has been the first affected and 30 years after remains one of the most vulnerable groups.
- Civil society remains a reliable partner to achieve the 90-90-90 goals and to make AIDS history in Europe. We need the renewal of the Dublin Declaration and a new communication to fight HIV/AIDS.

## **12 Undocumented migrants: Access to treatment, prevention and care**

In the session on access to treatment, prevention and care for undocumented migrants the work of Medicos del Mundo and the aims of the upcoming European HIV Legal Forum of AIDS Action Europe are portrayed. Cristina Torró from Medicos del Mundo/Sevilla starts with a description on how migrants are affected by HIV, HBV and HCV and presents a mapping of legal barriers to access healthcare for undocumented migrants (see Annex 9). Main barriers according to a survey from 2013 are financial problems, administrative problems and lack of knowledge or understanding of the healthcare system and of their rights. Furthermore, hospital staff often does not know that urgent care is free. In regard of HIV, 68% of people who were offered a test accepted one. 93% of migrants in MDM's 2013 European data collection lived under the poverty line and 61% of individuals without permit to reside said they restricted their movement or occupation due to fear of being arrested. In essence, it is not easy to organise treatment when you don't have sufficient financial means, are alone, without proper housing, sometimes living in fear of expulsion, without guarantee of being protected against expulsion (If there is no access to ARV in country of origin). That health tourism is a myth has been often documented. It represented only 2.3% of the reasons for migration, far behind economic survival (47.2%), political, religious, ethnic or sexual orientation reasons (24.2%), to join or follow someone (14.6%), to escape from war (6.9%), etc. The impact of stigmatisation is immense, although European legislation protects HIV positive migrants from expulsion. Against this background, MDM demands universal public health systems built on solidarity and equity, open to everyone living in all EU Member States, with effective accessibility (risk strategies and adapted care), a coherent infectious disease policy meaning that nobody gets excluded from real access to testing, treatment and care and effective protection from expulsion of seriously ill migrants to countries where real access to adequate healthcare does not exist.

Ferenc Bagyinszky imparts insights of AAE's European HIV Legal Forum (EHLF) and its activities in 2014/15 (Annex 10). In 2011, the EHLF started with a pilot project aimed at improving access to prevention, treatment and care for migrants with irregular status. A survey, addressing the situation in five countries was rolled out to have a comparative analysis of the legal situation, identify good practice and innovative solutions and act as a catalyst for change. The AAE SC decided to search for

funding to make a broader approach real. Now there are with France, Spain, the UK, Italy, Poland, Hungary, Serbia, Greece, the Netherlands and Germany 10 countries involved to monitor HIV relevant legislation across the region, to create better and more strategic links between local, national and regional stakeholders and to produce locally relevant resources and good practice guidance. The kick-off meeting for the project will take place in Budapest on December 14 and 15, 2014. Outcomes of the project will be an overview of relevant EU laws, the monitoring and review of HIV-relevant legislation in key countries representing the epidemiological, political, geographical and economic diversity of Europe; a collection of case studies illustrative of the issues for each of these countries, the establishment of sustainable processes, capacity building and the production and dissemination of resources, best practice guidance and advocacy tools.

#### **Discussion:**

The plenary welcomes the activities in this field as they are very much needed. Synergies between projects and activities and collaboration between organisations should be used. The question occurs whether the Roma population will be explicitly a target group as there are some major problems for Roma to access health services. It is still under discussion whether the target group in the EHLF should be undocumented migrants or people with limited access to health services which would include people who are not entitled to health services, for instance due to health insurance issues. HIV should be a vehicle also in regard of other diseases since influence of civil society and advocacy impact is much higher. Results of the projects should be spread widely, also in EECA countries to provide good practice experience.

### **13 Debrief HepHIV conference Barcelona - outcomes and next steps**

The HepHIV conference in Barcelona, held on October 5-7, 2014 was a milestone in containing the HIV and viral hepatitis epidemic in Europe. A call for action addressing surveillance of viral hepatitis, defining late diagnosis of viral hepatitis for medical care, testing modalities and targeted testing and communication, indicator-condition-guided testing, health policy strategies, synergy of infectious disease efforts, continuum of care, affordability and political leadership was sent out (see press release as Annex 11). The CSF coordination team should follow up on the call for action and advocate for its endorsement. All presentations of the Barcelona conference are provided on its website (<http://newsite.hiveurope.eu/Conferences/HepHIV2014-Conference>).

### **14 Community advocacy at national level for ensuring access to affordable DAAs**

The session on affordable DAAs is set out to discuss experiences and strategies in different countries in order to coordinate CSF's efforts. France is considered to have successfully advocated for less costly treatment. Whether it was a good deal or not is for discussion. The real price for DAA treatment varies between countries and is often lower than officially announced depending on negotiation methods, strategies and basic principles in each country (costs between 25.000 and 49.000 Euros were mentioned).

- Prioritising patients to access treatment against the background of overpriced treatment was another point of discussion. While an expert commission in France recommended treatment in F1 grade, F2 is now the indicator for initiation of DAA treatment. In Greece only F3 and F4 grade patients can expect to be treated. In general, Europe has to pay attention that the gap between poorer and richer countries and hence the exclusion of patients' treatment is threatening the European unity.
- People who use drugs are in many countries not eligible for treatment which is specifically questionable since this key population experiences the highest burden of hepatitis C threat.
- Georgia is mentioned as good practice in advocating for lower prices in hepatitis C treatment involving a prisoners' group, which sued the state for not treating hep C patients. All over Europe, treatment of prisoners remains a problem irrespective of which kind of treatment.
- Young and adolescent people need to be addressed differently according to their vulnerability to infectious diseases in their respective countries. It is suggested that this should be a topic on the next CSF agenda.
- Compulsory use of licence is referred to as a vehicle to lower the prices and a strategy for advocacy.
- Another issue coming up in the discussion is the use of outdated medicines such as Stavudine (HIV) and Boceprivir and Telapivir (hep C). A European call to pharmaceutical companies should be sent to take those medicaments off the market.
- People are confused and frustrated because guidelines are contradictory or information about pricing is non-transparent. The involvement of peers in countries where treatment is available as credible sources was brought up

as good practice. So called community or treatment heroes who successfully have been treated could spread the word about their experiences to raise awareness among people living with hepatitis C in order to increase diagnosis and treatment rates.

## 15 Any other business

- The ECUO network developed a regional concept note together with the Eurasian Harm Reduction Network addressed to the GFATM. Wojciech Tomaszynski imparts objectives of the application aimed at increased treatment coverage in the EECA and increased domestic expenditure on continuum of care for PLHIV. In order to have a more comprehensive impression of the application and its progress, Wojciech is asked to give the presentation during the next CSF meeting.
- Michael Krone reports on recent developments in regard of the Joint Action on HIV and co-infections (aka as JA on Harm Reduction) and on the information event that took place in Luxembourg on November 6 and 7, 2014. Only five NGOs out of 29 organisations from 20 countries were nominated to participate in the JA. Since the recruiting process is finalised, the only possibility to get involved as a funded partner in the JA would be to get subcontracted by a recipient organisation in the country. Against the background that involvement of NGOs is crucial for successful harm reduction work, the CSF expressed its concerns. These concerns will be taken to the Think Tank.
- The CSF should take up again the update on stock-outs, which has been a meaningful tool in recent years.
- Following topics for the next CSF meeting are mentioned among the ones remaining on the agenda: Home tests, ECUO application, prevention among youths and adolescents
- Preliminary dates for CSF meetings in 2015 are June 29/30 and December 7/8 or alternatively December 14/15

## Action list

What	Who	When
Send out the latest version of the Rome conference agenda and the declaration draft, work on a press release	CSF Coordination Team	November 25, 2014
Send a letter to the new Commissioner describing Civil Society concerns and highlighting thematic areas to be worked on	CSF Coordination Team	ASAP
Contacting the Luxembourgian MoH on activities regarding their presidency in 2015	CSF Coordination Team	ASAP
Follow-up with upcoming EU presidencies to get the Rome declaration adopted	CSF Coordination Team	ongoing
Join forces between the CSF on drugs, the CSF on HIV and harm reduction groups to address interventions and demands in drug policies	CSF Coordination Team	ongoing
Keep testing in community based settings on the agenda by advocating in favour of it	CSF Coordination Team	ongoing
Work on argument strands and advocacy strategies directed to respective stakeholders to keep PrEP as prevention option on the agenda	CSF Coordination Team	ongoing
Follow-up on advocating for a policy tool after 2016	CSF Coordination Team	ongoing
Follow-up on the call for action out of the Barcelona conference to halt the epidemics of HIV and viral hepatitis across Europe and advocate for its endorsement	CSF Coordination Team	ongoing

## List of annexes

Annex 1: European Commission State of Play of HIV/AIDS dossier

Annex 2: EU-funded research in FP7 & H2020: funding opportunities in 2015

Annex 3: From Dublin to Rome: 10 years of the HIV epidemic and response in Europe

Annex 4: Latvia's EU Presidency in 2015

Annex 5: The GAP Report

Annex 6 Briefing from CSF on Drugs

Annex 7: Information on HIV Community Based Voluntary Testing Services in Europe and Central Asia

Annex 8: PrEP in France

Annex 9: Access to treatment, prevention and care for undocumented migrants in Europe

Annex 10: European HIV Legal Forum (EHLF)

Annex 11: Press Release: Renewed political leadership is key to halting the epidemics of HIV and viral hepatitis across Europe