

Report of the 22nd HIV/AIDS Civil Society Forum

Luxembourg, November 23 and 24, 2015

Meeting convened by the European Commission Directorate-General Health & Food Safety
with co-chairing of AIDS Action Europe and the 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](#).

Inhalt

| | | |
|-----|---|----|
| 1 | Opening | 2 |
| 1.1 | Opening and welcome | 2 |
| 1.2 | Report and Follow-up on the Action List of the last meeting | 2 |
| 1.3 | CSF co-Chairs update on advocacy and other actions | 3 |
| 2 | The current state of HIV Policy in Europe: Update from the Commission | 4 |
| 3 | The current state of HIV Policy in Europe: Updates from the agencies | 5 |
| 3.1 | European Centre for Disease Prevention and Control (ECDC) | 5 |
| 3.2 | UNAIDS | 6 |
| 3.3 | WHO and EMCDDA | 6 |
| 4 | Road map to a new policy framework and action plan | 6 |
| 5 | Policy implications of new treatment guidelines and scientific findings | 7 |
| 6 | Eastern Europe and Central Asia – Needs, challenges and strategies to support CSO in EECA countries | 7 |
| 7 | Migrants with irregular status | 8 |
| 8 | Keep HIV, HCV, TB and STIs on the agenda: EU Presidencies | 9 |
| 9 | Update on Harm Reduction Policies: UNGASS meeting on Drugs and relevant information from the Civil Society Forum on Drugs | 9 |
| 10 | Excursus: Policy Framework | 9 |
| 11 | Community based voluntary counselling testing (CBVCT) – Reports from Italy, Portugal and Finland | 9 |
| 12 | The current state of HIV Policy in Europe: Update from EMCDDA and Access to Direct Acting Antivirals (DAA) 10 | |
| 13 | Any other Business | 11 |
| | Action list | 11 |
| | List of annexes | 12 |

November 23, 2015

1 Opening

1.1 Opening and welcome

Lella Cosmaro and Tamás Bereczky open the 22nd CSF meeting and welcome the participants. The meeting starts with some housekeeping rules and a round of introductions.

1.2 Report and Follow-up on the Action List of the last meeting

Michael Krone reports on behalf of the CSF Coordination Team about the work performed since the last meeting and follows up on the Action List with following results:

| What | Who | When | Status |
|---|-----------------------|-----------------------------|---|
| Write a letter to Juncker together with viral Hepatitis and Tuberculosis networks and groups | CSF Coordination Team | September 2015 | Sent out on September 14, 2015 |
| Share links in regard of sexual education | CSF Coordination Team | Asap | Was sent out immediately during the last CSF meeting |
| Send the list of national focal points | CSF Coordination Team | Asap | Was sent out immediately during the last CSF meeting |
| Members suggest that the CSF issues a position paper on pricing and also that we address a formal complaint to the European Court for breaking the rules of transparency on drugs pricing | CSF Coordination Team | Within the next CSF meeting | Is on the agenda of this meeting |
| UNGASS: Write a letter to the new Commissioner of DG Migration and Home Affairs, to the Horizontal Working Party on Drugs (HDG), to the Dutch Government in view of the upcoming EU-presidency semester and to EU President Juncker | CSF Coordination Team | September 2015 | The letter was sent out to the Commissioner of DG Home, to the Dutch Government and the Dutch AIDS Ambassador on November 18. It will be sent to the Horizontal Working Party on Drugs (HDG) within the next week |
| Ask ECDC for a Technical Report on Women and HIV | CSF Coordination Team | Autumn 2015 | See remark below this table |

Remarks:

- Velina Pendolovska asks about the letter to DG Home since there have been already several activities with regard to the UNGASS High Level Meeting. The Coordination Team explains that the drafting of the letter to various recipients was an outcome of the last CSF meeting where the CSF on drugs representative asked for support of the ongoing activities. The letter to the Commissioner of DG Home was explicitly mentioned as helpful to strengthen the European position on harm reduction and drug policies in general.

- After the last CSF meeting there has been email exchange between ECDC, Cristina Torr  and the CSF Coordination Team with regard to the ECDC report on women. There was the idea to have a petition from the CSF for a specific ECDC report. As it turned out, ECDC does not have the capacity to produce such a specific report on women but could produce some graphs with the data it has collected. Cristina Torr  and Michael Krone will follow-up with Anastasia Pharris (ECDC) to address which specific information on gender is needed, and asking ECDC to provide these pieces of information.

1.3 CSF co-Chairs update on advocacy and other actions

Lella and Tamás update the CSF on advocacy and other actions during the months since the last CSF meeting in July 2015:

July 2015

July 8 – Urgent call to action

The CSF Coordination Team delivers to the EC representatives and the Think Tank members an urgent call to action during the second day of the TT meeting, requesting immediate start of the work towards a new policy framework. The CSF calls on the European Commission to show leadership and continue to work on the impact assessment, offering collaboration from the part of European civil society organisations working in the field of HIV, viral hepatitis and tuberculosis.

The work of the CSF was presented on occasion of the AIDS Impact Conference in Amsterdam, on July 29, 2015 during the symposium “Doing the right things right – Guidance, Standards and Quality in the European response to HIV and co-infections” which was co-hosted by AIDS Action Europe.

September 2015

Sep 8-9 – Participation of Lella Cosmaro as Civil Society representative to the ECDC HIV Continuum of Care meeting held at ECDC in Stockholm, to bring the CS and community perspective to the discussion.

Sep 14 - Joint letter to President Juncker, signed by the HIV/AIDS Civil Society Forum, AIDS Action Europe, EATG, Stop AIDS Alliance, TB Europe Coalition, Correlation, Plus, ELPA, to call on the EC political leadership and support to ensure immediate start of the work on a comprehensive EU-Eastern Partnership Policy Framework which paves the way for the elimination of HIV, Tuberculosis and viral Hepatitis in the EU and Eastern neighbourhood.

Sep 21 – Letter of the EATG about the hearing at the E.P. of EMCDDA Director, Mr. Alexis Goosdeel, on September 22. The letter emphasised points of attention for the new director including: decriminalization/depenalisation of people using drugs, correct implementation of the ECDC and EMCDDA guidance on Prevention and control of infectious diseases for the people injecting drugs, increased involvement of people using drugs and civil society in the work of EMCDDA, consumption rooms, naloxone use by peers, medical prescription of drugs such as heroin.

Sep 22 – Collection of signatures for a petition regarding the Daraprim scandal at the time when Turing Pharmaceuticals, the pharmaceutical investment vehicle of Mr. Martin Shkreli, purchased the rights to the drug pyrimethamine, a lifesaving treatment for people suffering from AIDS sold under the trade name Daraprim, which was followed by a 5000% price increase of the medicine, to ask for the immediate discontinuation of the cynical and unethical conduct of Mr. Shkreli and Turing Pharmaceuticals. The campaign resulted in obtaining almost 1000 supporters in a matter of days, and then the situation resolved without sending the petition. Continued work around pricing and intellectual property regulations is definitely needed.

Sep 25 – Acknowledgement of receipt of the letter sent to Commissioner Juncker by the Secretariat-General, informing that the letter has been transmitted to the responsible for Health and Food Safety. Mr. Vytenis Andriukaitis.

Sep 29 – Participation of two representatives of the CSF Coordination Team (Ann Isabelle von Lingen and Michael Krone) to the “Brainstorming workshop” on future directions regarding HIV/AIDS in Luxembourg.

October 2015

Oct 2 - Participation of Luís Mendao as civil society expert to the Gastain European Health Forum, to contribute experience in access to medicines and the importance of patient involvement in the context of accessible health systems.

Oct 15-16 – Participation of civil society representatives (Anke van Dam, Silke Klumb, Daniela Rojas Castro, Lella Cosmaro...) to the ECDC Dublin Declaration Advisory Group meeting held in Stockholm, to contribute the NGOs perspectives.

Oct 20-22 – A delegation of the EATG and several CSF representatives attended the European AIDS Clinical Society conference in Barcelona. Tamás Bereczky held a lecture about the patients’ perspective of the HIV and related epidemics in Europe, which was very well received, and led to an almost 100% increase in the number of subscribers to the HIV Europe Policy Facebook page. Also, there were several discussions with new contacts and stakeholders that may ripen into working relationships with the CSF.

Oct 30 – Reply from Commissioner Andriukaitis to our letter to President Juncker sent on Sept. 14. The Commissioner informs the signatories of the letter that the Commission is considering all options on how best to tackle HIV, TB and HCV, also taking into account the new legal context created by Decision 1082/2013/EU and the mechanisms it established. The letter also assures about future involvement of civil society in future discussions.

November 2015

Nov 6 - Circulation for the collection of endorsements of the position paper “Health matters: EU political leadership needed to end HIV, TB and Hepatitis C in Europe” developed by TB Europe Coalition, the European AIDS Treatment Group, AIDS Action Europe, Stop AIDS Alliance and Correlation. The briefing is to be used for advocacy with EU Members states and EU institutions (European Parliament, European Commission and Council) in the coming period.

Nov 18 - Letter of concern sent by the HIV/AIDS Civil Society Forum to the Commissioner of DG Home, to the Dutch Government and the Dutch AIDS Ambassador, calling for a strong European position in the preparatory process for the UN General Assembly Special Session on the World Drug Problem in 2016. The HIV/AIDS CSF supports and encourages the work to make the UNGASS on Drugs meeting a historic event to improve the dignity and lives of people who use drugs. It will be sent to the Horizontal Working Party on Drugs (HDG) within the next week.

Discussion: Isabell Eibl points out that discussion at European level and national level are somehow disconnected and that we need to increase the impact of the CSF at the national level. She asks CSF members for thoughts on how EU HIV CSF could more effectively connect civil society with public authorities level to address structural problems. She underlines that in her country Austria, NGOs often do not work together, as funding competition overshadows possible joint action. It is extremely difficult to engage civil society and transfer action and activities discussed in European fora to the national level. In Italy, Lella Cosmaro (as CSF representatives) sends information to a substantial mailing list and notes that overtime information coming from the European level is ‘absorbed’. The fragmentation at state level is stressed and is noted that there needs to be more leadership from Think Tank members too and the European level.

Action Point: The CSF then requested the Coordination Team to put this issue on the agenda of the next CSF meeting for further and broader discussion.

2 The current state of HIV Policy in Europe: Update from the Commission

Herta Adam reports about the recent developments within the Directorate General for Health and Food Safety since the last CSF meeting. Matthias Schuppe has moved from his position as Policy Officer in the Health Threats Unit and is now working on country profiles. He was replaced by Velina Pendolovska. She underlines that the Commissioner wants to be more attentive to country needs and to places where the EC can add value. Country profiles would help identify commonalities to work on in smaller country groups (rather than having to move 28 countries) facing similar challenges.

The Action Plan will expire at the end of next year. The Commission is consulting stakeholders and evaluating what needs to be achieved in all respective areas by 2019, taking into consideration targets set at international level. The strategy of the Juncker administration is to be evidence and target driven, to act big on big things and small on small things. The Commission will focus on activities to reach these targets rather than preparing a new Communication, which is resources consuming and not necessarily productive. The Commission asks the CSF to be more precise and operational in its recommendations of what needs to be done. The European Commission updates the CSF on the implementation of the EU Cross-border health threats decision. In particular, it notes that the joint procurement agreement has been signed by 22 EU member states and that a few other countries are considering joining. The agreement means that EU Financial Regulation can be used to procure medicines at larger scale for participating countries, which facilitates the procurement process This is an achievement given the obstacles to be overcome, including opposition by some member states.

The European Commission notes that the Health Security Committee (HSC), which consists of EU member states health ministry representatives is a tool to reach the objectives regarding HIV and co-infections. It was noted during the discussion that the Think Tank members then ought to be connected with the HSC. The CSF asked if it would be possible to know who the country representatives are.

Velina concludes the Commission’s update with a short report of the EC Brainstorming Meeting organised by the EC in September 2015, which was attended by Ann-Isabelle and Michael as CSF representatives (see Annex 1 attached to the minutes of the meeting by the European Commission).

Discussion: The discussion centres on the policy framework and the joint procurement agreement. The CSF members highlight the recommendations from the Communication evaluation to draft a new Communication. They underline the importance of an updated policy framework, consisting of a EU member states long-term political commitment and agreement on strategic directions and targets, as well as of Commission policy document and action plan outlining how targets will be achieved. It should address gaps in the EU and how to improve the response to HIV together with neighbouring countries in the Eastern part of Europe where the epidemic is raging. Political leadership of the European Commission does make a difference in those situations where counter-productive policies are being discussed. The Commission should signal the continued importance of addressing HIV and co-infections based on evidence and respect of human rights via a policy document. The Communication has also allowed for increased civil society involvement in policy discussion at national level. It also ensures continuity and consistency in the response (for instance, without a political prioritisation would the EUROCOORD project still be funded?). A mere Commission working checklist would not be sufficient. The EC officials stress that it is crucial to convince their hierarchy of the need for a new policy framework and what it should address. The CSF will follow up on this.

Regarding the Joint Procurement Agreement, the EC emphasised that the agreement can only secure procedures to be prepared for an outbreak of a serious cross-border threat to health. It determines decision making processes and practical arrangements to ensure that pandemic vaccines and other medical countermeasures are available and that the member states can benefit from correct contractual conditions. Tuberculosis was mentioned during the negotiation. In the case of Sofosbuvir, since there is no real competition it is questionable whether a joint procurement would actually lead to lower prices. The CSF asked for the list of country representatives in the committee deciding on medicines and vaccines procurement.

3 The current state of HIV Policy in Europe: Updates from the agencies

3.1 European Centre for Disease Prevention and Control (ECDC)

Teymur Noori reports on the 2015 Dublin Declaration monitoring process and the Dublin monitoring priorities for 2016; the mobile apps meeting, the ECDC continuum of care meeting; the European HIV Test Finder as well as upcoming ECDC meetings (see Annex 2). With the key population reports and the evidence briefs, ECDC published some important information, including behavioural surveillance data, completed by the From Dublin to Rome: ten years of responding to HIV in Europe and Central Asia and the HIV continuum of care special reports. The meeting on mobile apps in October 2015 sought to understand the implications of mobile apps on STI/HIV prevention among MSM. The meeting conclusion is that practical guidance is needed to use this technology as an effective outreach tool.

In 2016, the ECDC will use the continuum of care angle and focus on shortcomings in prevention, testing and treatment. He refers to major gaps in prevention programmes for most at risk groups and their coverage. The lack of targeted programmes, as well as the persistence of criminalising laws and policies are noted as counter-productive. The ECDC will reemphasise on prevention as prevention. Testing is still not happening at the scale and in a targeted manner as it should, with a large number of people at high risk not getting tested and diagnosed. The undiagnosed account for a high number of new infections. It is also noted that some laws limit the uptake of testing. ECDC will collaborate with the OptTEST project work package on linkage and retention in care to address the issue of quality of care.

Uptake of treatment is problematic in Eastern European countries with low rates of viral suppression. The persisting high costs of treatment are also raised as an issue. Stigma and discrimination - while difficult to monitor - continue to be the main obstacles to key populations accessing prevention, testing and treatment. The CSF therefore requests the coordination team to organise a group work session on stigma and discrimination during the next CSF meeting. There could also be a report on best practices to overcome stigma. Teymur then presents the European HIV Test Finder, a tool through which testing facilities can be found by city (actualisations and updates are welcome) and notes that the Test Finder obtained free ads during the European HIV Testing Week on smartphone applications such as Grindr, Hornet and Planet romeo.

Discussion: The issue of stigma and discrimination is addressed repeatedly during the discussion. It is difficult to evaluate which programmes on stigma reduction work. In 2014, ECDC integrated questions but the predictable results did not provide much added value. Also, innovative ways should be explored to work better with GPs to reduce stigma. Besides the stigma issue and whether a specific report should be produced, participants discuss how and by whom the questionnaires should be filled in in future. It is noted that in some countries civil society and government representatives already collaborate in responding to the ECDC questionnaire, and that the first page of the report should indicate whether civil society was part of

the process. An investigation of treatment good practices and quality of life could be useful. Could it maybe be performed with the support of the public health programme?

3.2 UNAIDS

Brigitte Quenum explains the UNAIDS strategy development process, the key features and content overview as well as goal framework, targets and result areas of the UNAIDS 2016-2021 global strategy. She touches upon the result areas with reference to the selected strategic development goals Good Health and Well-being; Reduced Inequalities; Gender Equality; Just, Peaceful and Inclusive Societies; and Global Partnership with specific recommendations for each SDG (see Annex 3).

Henning Mikkelsen adds to Brigitte's report about the UNAIDS 2016-2021 strategy and focuses in his presentation on regional priorities, leadership and action, gaps and challenges in Europe, game changers to get Europe on the fast track to end AIDS, regional opportunities and accountability and in his last slide emphasises on the specific challenging situation in Eastern Europe and Central Asia (see Annex 4). Henning announces the tentative days of the UNAIDS High Level Meeting: June 8-10, 2016.

Discussion: Aigars Ceplitis raises some concerns regarding the strategy saying that it will be not sustainable where countries spend less than 3% of GDP on health care. There should be a mechanism that compels member states to spend at least 5%. This is also of importance while countries are switching to insurance based health care systems like it is the case in Latvia. Also the concern is raised that at country level several problems indicate that the 90-90-90 goals are too ambitious and cannot be reached. Luís Mendão stresses that if we fail to have a new Communication as a policy framework organising the response to targets in Europe, we will be in need of a UNAIDS office in Europe.

3.3 WHO and EMCDDA

At the end of this session Tamás points out that due to Martin Donoghoe's absence there is no update from WHO for this CSF meeting and since Dagmar Hedrich is arriving later, the update from EMCDDA will be rendered next morning during her presentation on Access to DAAs.

4 Road map to a new policy framework and action plan

Lella Cosmaro introduces the session by reviewing the steps that were taken from 2012 to renew the Communication that expired in the end of 2013. She presents the following advocacy activities and efforts of the EC that resulted in the extension of the Action Plan. The last 8 slides of her presentation show the status quo of activities with regard to the situation after 2015 and next steps to be taken (see Annex 5).

Discussion: The EC emphasises the importance of strengthening the commitment of health authorities in the country. Civil Society should fight at the national level that this commitment is taken seriously. Of importance is also the implementation of the current Action Plan and the question of how we can obtain the same results without a Communication. There were a number of crisis situations before the Communication and Action Plan existed. A Communication is not a precondition to the European Commission's commitment. Furthermore, the European Union is challenged by some countries in its reason of being at the moment. It makes it difficult to argue on health issues within the Commission when there are pressing fundamental issues. There should be joint actions at operational level, based on the evidence that is provided by the agencies. The question is not only what the Commission can do but also what the member states and, in that context, what Civil Society can do.

Civil Society representatives argue that a policy framework, including a Communication, is needed to ensure continuity and that HIV is not disappearing from the agenda due to other pressing health issues as it was the case with Ebola or in case of bioterrorism or populist responses. The EC is disappearing at the time it is most needed. This has been the reflection since 2012. Civil society has given some examples of possible EC interventions. Some structural funds could be used for building capacities in the member states for the early elimination of health threats. It is pointed out that Civil Society plays a crucial role at European level to change conditions at national level to its better. The involvement of key populations in the response to HIV has been and will be of major importance. The response from the Commissioner to the joint civil society's letter to President Juncker was encouraging on this point. Moreover, the evaluation of the Communication revealed the importance of this policy framework and the involvement of CS. The CSF is disappointed that the EC seems to be reluctant to take a strong position in a situation where it is very much needed. In Germany, the ministry just decided to work on a new policy framework due to the new developments and the UNAIDS and WHO new strategies. This is not only very helpful but also needed with

regard to the challenges in the upcoming years to eventually end AIDS.

5 Policy implications of new treatment guidelines and scientific findings

After lunch break this session was shortened due to the extension of the discussion on the policy framework. Tamás introduces the topic summarising recent developments, including the PROUD and Ipergay studies with regard to PrEP and the findings of the START trial. The findings resulting in new guidelines from the agencies have important implications on national treatment guidelines since it is basically indicated to start treatment as early as possible. A lot of advocacy needs to be done at national level to convince the governments to adopt the guidelines and contribute to the last two of the 90-90-90 goals. Tamás opens the discussion round with the question how the guidelines are implemented in the countries.

Discussion: Apart from the point of time of treatment, quality of provided treatment still seems to be a factor. Some patients in Hungary are apparently still on Combivir. Also in Latvia, medicines of lower quality are prescribed. In the course of the discussion, the joint procurement agreement comes up again. It is suggested to make a list of medicines that should be stopped. A participant also suggests that ECDC could maybe help to estimate the number of persons who should be on treatment to better understand the financial gap more precisely when considering new treatment guidelines.

Chris Lambrecht noted that in the case of Belgium, it looks like the treatment guidelines will be updated but that it will take time. He also noted the need to educate on what viral load and viral suppression mean in practice.

Velina asks her colleague Jean-Luc Sion, who was involved in the development process of the Joint procurement agreement under the Cross-Border Health Threats Directive, to talk about the specifics and the relevance in terms of HIV medicines. Jean-Luc Sion stresses that it can only be used for cross-border health threats, not chronic diseases. HIV, TB and HCV can be considered for inclusion in the Decision. He explained that a minimum of 4 countries are required to start a joint procurement discussion. The first tender will be about protective equipment, the first call in December. Future calls could be for BSG vaccines, tuberculosis because some member states have trouble getting response from companies (at 4 countries interested); antitoxins diphtheria (4 countries interested); Hep C (3 countries interested). These joint procurements would be discussed at the next joint procurement meeting on 16 December.

All documents relating to the agreement are published on the department's website, including an easy to read explanatory note: http://ec.europa.eu/health/preparedness_response/joint_procurement/index_en.htm.

6 Eastern Europe and Central Asia – Needs, challenges and strategies to support CSO in EECA countries

Elena Romanyak introduces the session with a presentation on recent developments in the region. The session was planned to be joined by Vinay Saldanha from the regional UNAIDS office in Moscow via video conference. Due to technical problems, the connection could only be established via telephone.

Elena reports about the 29 countries in the region with regard to key operation outlines, the situation of drug users with 16 countries in Eastern Europe and 2 in Central Asia providing OST, challenges referring to unreliable data and underfunding, the decrease of harm reduction projects in Russia from 2006 to 2015 and the challenge of sustainability and transition (see Annex 6).

Vinay confirms the results from Elena's presentation and adds that latest data show that 1.000.000 people are living in Russia with HIV and that the cumulative number of people who died from AIDS is at 250.000. The rapidly growing epidemic still affects predominantly drug users. Also, women who are sexual partners of drug users are affected. However, it is still a concentrated epidemic. There are some progresses in the region, in particular in Ukraine with regard to testing and treatment programmes. It was noted that the Global Fund does not monitor trends in access.

Discussion: The discussion centres on the participation in the 2016 EECAAC conference in March in Moscow. Several organisations called for a boycott of the conference in Russia given the hostile attitude of the Russian government towards drug users and harm reduction, as well as LGTBI rights with anti-sexual laws on propaganda. Another group, consisting mainly, but not only of Russian NGOs, asks for an international presence at the conference to strengthen evidence based discussions and as it is a platform for dialogue. UNAIDS is interested in getting strong international presence at the European Conference and underlies that this needs to be a dialogue and that there should be support for civil society.

Participants should get the Russian government to say what policy changes it will introduce.

Harm Reduction International explains that the fact that people on OST will not be allowed to participate raises questions. UNAIDS has expressed its position on this matter but the Russian government will not change that policy. UNAIDS noted that there will be interventions from Moldova, Kyrgyzstan and Belarus, as well as from UNAIDS on harm reduction and OST.

AIDES states that they support participation but that there are concerns to what will happen to outspoken NGOs in Russia after the conference. It is also important to ensure that Russian organisations, e.g. LGBT organisations, will be able to maintain their work after the conference and will not face negative consequences as it has been the case in the African continent after AIDS conferences. Some participants (was it UNAIDS??) noted that in previous conferences there has not been retaliation as a result of statements at the conference.

AIDS Action Europe and EATG, while understanding the concerns and call for boycott, have decided to participate in the conference to support the communities and their members in the region. Open dialogue and discussion outweigh the legitimate concerns that other organisations express.

The Eastern Europe UNAIDS regional office will be invited to the next CSF in June.

7 Migrants with irregular status

Ferenc presents the outcomes of AIDS Action Europe's EHLF (European HIV Legal Forum) project on migrants with irregular status. He summarises the development of the project starting with the results of the pilot project and its conclusions, then the new composition of the EHLF with 10 countries for the period 2014 and 2015, the updated questionnaire, objectives, conclusions and outcomes of the project so far (see Annex 7). In general, preliminary results show that the situation is not improving at all, for instance in the UK where lately hospitals tried to call on people to find out who they are, which questions the accomplishment of access to treatment for undocumented migrants. Mandatory testing in Hungary has been introduced only recently as part of the so called refugee crisis legislation. The CSF Coordination Team is asked to follow up on advocacy with regard to mandatory testing in Hungary and elsewhere. Future plans of the EHLF in 2016 foresee the extension to 15 countries, as well as the establishment of a project on HIV and labour.

Discussion: There has been a lot of advocacy using public health in addition to human rights arguments, but the situation is nevertheless deteriorating. The topic of migration is overpoliticised and worsened by the current asylum crisis. It was emphasised that we should not mix up the current asylum seekers situation with migrants with irregular status. It is clear that collaborations across organisations and public agencies are needed to ensure evidence and rights based policies. It was also stressed that collaboration with PICUM, Doctors of the World, FPA is crucial.

There was a short update on the developments on mandatory testing for asylum seekers. Rita Bence from the Hungarian Civil Liberties Union noted that an amendment to the Hungarian health law was recently introduced to allow the Chief Medical Officer to declare some specific screenings as necessary in case of mass migration and accompanying public health emergencies. So far, the Chief Medical Officer has been reluctant to declare a public health emergency. Silke Klumb from Deutsche AIDS-Hilfe reported that in some Länder there has been mandatory testing. However, labs cannot catch up with testing where it is mandatory for refugees. Saxony gave up on that. Moreover, the AIDS Council advises against HIV testing in first check-ups because of anonymity issues etc.

Christina Torro from Médecins du Monde/Doctors of the World suggested to use the German statements and to include expulsion of seriously ill persons in the AIDS Action Europe project. She referred to a study on the permits to stay in a country for medical reasons and the expulsion of persons living with HIV to countries where in fact they have no access to effective treatment. ECDC is working on guidance for prevention and assessment of migrants but it underlines that such guidelines are not for the current crisis.

November 24, 2015

The second day of the meeting starts with news from AIDES, whose representatives announce that in France PrEP will become available and reimbursed by the MoH.

8 Keep HIV, HCV, TB and STIs on the agenda: EU Presidencies

The discussion focused on the Dutch EU Presidency because there is no representative from Luxembourg and Malta in the CSF and Iveta Chovancova from Slovakia had to cancel at short notice. The government will follow up on the medical device and in vitro diagnostics file. Overall, the government has chosen a low profile on European affairs. The World AIDS Conference in 2018 though will be of high European interest focusing on the situation in EECA countries. Anke van Dam noted that there is a plan of action; AFEW will support it and ensure that people from the EECA region will be able to join.

Discussion: Henning suggested that the AIDS High Level Meeting in New York, the first high level meeting since 2011, should be used by the Dutch presidency to reflect on the situation in Europe. This is of high importance in particular to support the EECA countries. The HLM could also be used to lobby for an EU statement with new targets for Europe. Lella reports that Malta intends to take over the Rome declaration. As far as Lella is informed, the Malta government has already connected with Slovakia and the Netherlands to adapt and endorse the declaration.

9 Update on Harm Reduction Policies: UNGASS meeting on Drugs and relevant information from the Civil Society Forum on Drugs

Ola Szubert from Harm Reduction International reports on the International Harm Reduction conference in Malaysia and the Kuala Lumpur Harm Reduction Decade Declaration, the UNODC briefing paper on decriminalisation of drug use and possession for personal consumption and conclusions, the 2020 UNAIDS targets for drug users regarding HIV, the Civil Society Recommendations for the EU consolidated position for the UNGASS 2016 Outcome Document and possibilities for the EU to involve the CSF on drugs in its work on the UNGASS and other areas of drug policies (see Annex 8).

Discussion: It is stressed that there are various ways at national and organisational level to get involved as pointed out on the last slide of the presentation, especially in signing the UNGASS recommendations from Civil Society which is a strong document not only against the death penalty but also for the prevention of infectious diseases and a comprehensive package in general to make harm reduction a driving principle of national and international approaches to drug use. Moreover, it would be worth trying to join the Civil Society task force although there are limited seats. It is also mentioned to identify two or three countries that could create an alternative declaration, which would be more progressive than the UN consensus. Ferenc adds that the NGO delegation of the UNAIDS Programme Coordinating Board is also preparing papers for UNGASS, the High Level Meeting in New York and the World AIDS Conference in Durban.

Dagmar Hedrich from EMCDDA notes that the EU position at UNGASS adopted by Coreper (6 November) makes reference to the conventions, human rights and civil society, informed consent and strong statement against death penalty. It supports a comprehensive package for prevention. All in all, the EU statement provides a good starting point for EU delegations.

10 Excursus: Policy Framework

At the request of several CSF members, the topic of the policy framework and the future of the CSF were again put in the agenda. CSF members again pointed out that a policy framework is of high importance and that the CSF will not stop advocating for it, also by addressing members of the European Parliament and also national politicians.

The CSF asks the EC for indications on the future of the CSF. There is a need to clarify next steps to ensure a constructive discussion on this issue in July. Some members feel that we should address the dependency of the CSF on the European Commission to meet. We should also discuss collaboration with the TB, HCV, LGBTI etc communities, as we are trying to engage with the EU CSF on Drugs. It was suggested that the focus could be vulnerabilities to the diseases rather than just the disease itself.

The position of the EC remains the same: solutions and evidence based interventions are needed and will be pursued and implemented, rather than pursuing a policy framework. It is stressed that a decision has not been made yet. The idea to involve MEPs is countered by the assessment that they have no competence in the area. However, a participant notes that they have a political and awareness-raising role.

11 Community based voluntary counselling testing (CBVCT) – Reports from Italy, Portugal and Finland

There are three reports about CBVCT from Portugal, Finland and Italy. Pedro Marquez starts with his presentation on CBVCT in Portugal: Achievements and Challenges by his organisation GAT (see Annex 9): He speaks about the general HIV situation in Portugal, GAT CBVCT activities directed to MSM, drug users and migrants and their experiences, about their mobile unit to provide low threshold outreach CBVCT, about obstacles to and inequalities in access, the Portuguese community based screening network, test results and achievements of the activities and remaining challenges.

Sini Pasanen from Positiiviset continues with the work on CBVCT in Finland. There are several organisations providing CBVCT addressed to MSM, sex workers and drug users. As in Portugal there is low-threshold out of office testing provided, for instance on the Russian border where a lot of truck drivers are waiting to pass the border. With the results of the testing activities she also points out the high number of people reached who have never been tested before and that targeted testing is very cost effective. Interesting are also the carrying out of tests and counselling explicitly by HIV positive people and the notification of clients of their results via text message on cell phones after pre counselling (see Annex 10).

The last speaker of this session is Lella Cosmaro who introduces to the CSF members CBVCT activities carried out by LILA in Italy. Lella focuses her presentation on the results of CBVCT activities in Milano during 2015 presenting data on the target groups, number of tests performed and venues of the activities, also with regard to linkage to care; interesting conclusions and suggestions for improvement are indicated (see Annex 11).

Discussion: To reduce the number of undiagnosed people CBVCT is a very good instrument but there are a number of challenges including funding, to be addressed. It was noted that some organisations had to rely on Companies' donations for the European Testing Week. There is a lot of experience and knowledge within the community. It was suggested that a Joint Action could usefully build on these experiences, provided that bottlenecks of this instrument are dealt with. It was suggested that EU Structural Funds could maybe be used to co-fund such initiative. It was mentioned that the absorption of EU funds is quite low and therefore organisations should be guided to use these funds. What should be focused on, as there are activities already in some cities, is credible scientific work on recent primary infections, with guidance and investment on concrete action research.

Loreta from Demetra Lithuania announces that the first checkpoint will open on December 1 (with international donors and pharma support), based on the model of the Athens Checkpoint .

12 The current state of HIV Policy in Europe: Update from EMCDDA and Access to Direct Acting Antvirals (DAA)

Dagmar Hedrich from the European Monitoring Centre for Drugs and Drug Addiction combines her update from EMCDDA with her presentation on access to DAAs for drug users (see Annex 12). She refers to the latest European review of EMCDDA, published in September 2015, and reports on estimates of the prevalence of injecting drug use, prevalence of injection among clients entering treatment with opioid as their primary drug, HIV prevalence among injecting drug users – studies with national and subnational coverage 2013-2014, the health and social responses to drug use related country reports and interactive map, significant level of drug treatment provision, variable levels of syringe provision, NSP-sites: geographical coverage and performance, a risk assessment on HIV/HCV prevalence, transmission and prevention coverage in 30 countries, HCV antibody prevalence among PWID 2012–13 and trends in age structure of clients entering treatment by primary drug. Dagmar continues her presentation with access to Hepatitis C treatment for injecting drug users and introduces the interactive site <http://www.emcdda.europa.eu/topics/pods/hepatitis-c-treatment>. On access to DAAs, EMCDDA carried out a survey from May-July 2015 with replies from 21 Countries on new DAAs (reference price) and previous generation DAAs from 16 Countries producing data on the size of the population in need , HCV medication pricing and issues to be addressed. Dagmar notes that while there are harm reduction policies, the investment is still not high enough. She notes that according to the systematic review (Wiessing et al 2015) there is a high number of undiagnosed among the PWID and that only a fraction has access to the new DAAs. Now that we have interferon free treatment, we should focus on getting people diagnosed. At the end Dagmar draws attention to the conference on Women and Drugs on November 24, 2015 in Lisbon.

Luís Mendao then reports about the recent experience in Portugal in negotiating DAAs prices and access to DAAs. One of the key elements of success was that all stakeholders were involved and that different communities were brought together. The aim of the negotiation was to treat everybody, amongst other things to make it attractive for the pharma business. F3 and F4 fibrosis grades and co-infections are prioritised and people at risk of transmission but all have right to treatment. The price of drugs should follow the burden of disease, recognition of affordability, huge epidemic and willingness to treat gives

different schemes of pricing: these three issues were the key. To get to the achievement was the result of a lot of meetings, fights and demonstrations. Since Gilead has on the key pangenetic drug sobosbuvir a monopole, it took a huge deal of negotiations with the company and with the MoH.

13 Any other Business

- In between the sessions, Lella and Tamás are bid farewell by the CSF for their amazing work as co-Chairs. Chris Lambrechts thanked the two on behalf of the CSF members and the CSF Coordination Team.



- Wojtek also announces his resignation from the CSF from the next year on.
- Eleanor shortly reports on the Berlin meeting on PrEP in Europe. It was a fruitful meeting that was set up to coordinate activities with regard to PrEP in Europe. It includes advocacy efforts at national level linked to the gay pride activities in the summer.

Action list

| What | Who | When |
|--|-------------------------------|-------------------------------------|
| Follow up with ECDC to have specific information papers on HIV and Women | Cristina Torró, Michael Krone | 1 st quarter of 2016 |
| Put on the agenda of the next CSF meeting the topic how to engage CS at national level and connect with GO representatives | CSF Coordination Team | Preparation of the next CSF meeting |
| Organise a group work session during the next CSF meeting on how to address stigma and discrimination | CSF Coordination Team | Preparation of the next CSF meeting |
| Follow-up on mandatory testing of undocumented migrants in Hungary? and elsewhere | CSF Coordination Team | within the next months |
| Put the topic of Migrants with irregular status on the agenda of the next CSF again to present the final results of the EHLF | CSF Coordination Team | Preparation of the next CSF meeting |

List of annexes

Annex 1 – Ad hoc consultation: Follow-up on June Think Tank/Civil Society Forum Meeting

Annex 2 – ECDC: Update to EU HIV/AIDS Civil Society Forum

Annex 3 – UNAIDS: On the Fast Track to end AIDS

Annex 4 – UNAIDS: UNAIDS 2016-2021 Strategy

Annex 5 – Road map towards a new policy framework and action plan

Annex 6 – Needs, challenges and strategies to support CSO in EECA countries

Annex 7 – European HIV Legal Forum: Migrants with irregular status

Annex 8 – Harm Reduction International: Update on Harm Reduction Policies

Annex 9 – CBVCT in Portugal

Annex 10 – CBVCT in Finland

Annex 11 – CBVCT in Italy

Annex 12 – EMCDDA: Update and Hep C treatment for injecting drug users