

Report of the 21st HIV/AIDS Civil Society Forum

Luxembourg, July 6 and 7, 2015

Meeting convened by the European Commission Health & Consumer Protection Directorate-General
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](#).

Table of content

| | | |
|-----|---|---|
| 1 | Opening | 3 |
| 1.1 | Welcome and introduction | 3 |
| 1.2 | Report and action list of last meeting | 3 |
| 1.3 | CSF co-chairs update on advocacy and other actions | 4 |
| 2 | The current state of HIV Policy in Europe: Update from the Commission including a presentation on the Health Policy Forum and its IT Platform | 5 |
| 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 | 5 |
| 3.3 | WHO Europe | 6 |
| 3.4 | European Monitoring Centre for Drugs and Drug Addictions (EMCDDA) | 6 |
| 4 | PrEP: Latest research and policy development | 7 |
| 5 | Prevention among MSM – Travelling gay men and other MSM, impact of smart phone applications among other issues | 7 |
| 6 | Home-testing | 7 |
| 6.1 | United Kingdom | 7 |
| 6.2 | France | 8 |
| 7 | Prevention among Youth | 8 |
| 8 | Keep HIV, HCV, TB and STIs on the agenda - EU presidencies | 9 |
| 8.1 | Latvia | 9 |
| 8.2 | The Netherlands | 9 |
| 8.3 | Slovakia | 9 |
| 9 | START trial | 9 |

| | | |
|------|---|----|
| 10 | Update on Harm Reduction Policies: UNGASS meeting on Drugs and relevant information from the Civil Society Forum on Drugs | 10 |
| 11 | Quality Action – Report and discussion on the Joint Action on improving HIV prevention in Europe | 10 |
| 12 | Women and HIV in Europe | 11 |
| 13 | Any other business | 11 |
| 13.1 | Regional program of ECUO within the framework of the Global Fund New Funding Model | 11 |
| 13.2 | European HIV and Hepatitis Testing Week | 12 |
| 13.3 | Closing remarks | 12 |
| | Action list | 13 |
| | List of annexes | 13 |

July 7, 2015

1 Opening

1.1 Welcome and introduction

Lella Cosmaro and Tamás Bereczky open the 21st Civil Society Forum and welcome all participants. As there are new members to the forum, they invite the attendees to introduce themselves. Tamás reads out a message from Marianella Kloka, who due to the referendum held in Greece, is not able to attend the meeting.

1.2 Report and action list of last meeting

Michael Krone reports on the action list of last meeting:

| What | Who | When | Status |
|--|-----------------------|-------------------|---|
| Send out the latest version of the agenda and the declaration draft | Michael | November 25, 2014 | Done |
| Send a letter to the new Commissioner describing Civil Society concerns and highlighting thematic areas to be worked on | CSF Coordination Team | ASAP | The issues was addressed in a face-to-face meeting on November 27 2014 |
| Contacting the Luxembourgian MoH on activities regarding their presidency in 2015 | CSF Coordination Team | ASAP | Done. Unfortunately there are no HIV related activities during the Luxembourg presidency |
| Follow-up with upcoming EU presidencies to get the Rome declaration adopted | CSF Coordination Team | ongoing | Done on Feb 16 |
| 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 | The topic is on the agenda of this meeting and a working group is being established and will meet during these days in Luxembourg |
| Keep testing in community based settings on the agenda by advocating in favour of it | CSF Coordination Team | ongoing | Mainly through the OPTTEST project but also through other project activities community based testing has been kept on the agenda |
| Work on argument strands and advocacy strategies directed to respective stakeholders to keep PrEP as prevention option on the agenda | CSF Coordination Team | ongoing | With the publication of the Ipergay and PROUD results argument strands were developed and distributed via different media. The topic is again on the agenda of this CSF meeting |
| Follow-up on advocating for a policy tool after 2016 | CSF Coordination Team | ongoing | This was done through monthly TCs with the Commission and launching a telephone conference with European network representatives on Hep C and Tuberculosis on April 28 |

| | | | |
|--|-----------------------|---------|---|
| 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 | Open letter addressed to Regulatory Authorities, WHO and Clinical Societies, Government/Payer Decision Makers on March 6 by several organisations |
|--|-----------------------|---------|---|

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:

| | |
|---------------|--|
| January 2015 | Report of the meeting with Commissioner Audriukaitis of 27 November 2014 was shared with the CSF members |
| February 2015 | Letter of the Co-Chairs to the former EU Italian Presidency, the current Latvian EU Presidency and the upcoming Luxembourg Presidency to follow up on the renewal and update of the 2004 Dublin Declaration with the European Parliament ENVI committee, as well as the respective Commission services dealing with HIV and the countries in question in copy. |
| | Release of the PrEP Manifesto, the open letter to pharmaceutical industries, European and national institutions to make PrEP available and accessible in Europe. |
| March 2015 | Hepatitis C: Open letter addressed to Regulatory Authorities, WHO and Clinical Societies, Government/Payer Decision Makers to demand that first generation PIs, Boceprevir and Telaprevir be replaced with safer and more effective HCV drugs. |
| | Participation of AAE and EATG representatives in the Eastern Partnership Ministerial Conference on Tuberculosis and its Multidrug Resistance (Report of the conference enclosed) in Riga/Latvia. |
| April 2015 | Letter of the Co-chairs of the HIV/AIDS CSF to the Czech Minister of Health on the Public Health Protection Law - 2015 amendment, Introduction of mandatory HIV testing of certain at-risk populations, to ask the Czech Government to reconsider and withdraw the proposal. |
| | Teleconference on joint advocacy at European level on HIV, TB and HCV in Europe with the participation of the most relevant European networks on HIV, Hepatitis, TB and drugs. |
| May 2015 | Letter of the Co-chairs of the HIV/AIDS CSF to the Commissioner on the introduction of mandatory HIV Testing in the Czech Republic in request of support our requests to the Czech Government. |
| | Letter of the AAE Steering Committee to the Ministers of the Cabinet of the Republic of Latvia, to request that the Latvian Government follow WHO guidelines on the use of antiretroviral drugs for HIV. |
| | The Czech Chamber of Deputies cancelled the mandatory testing provision from the Public Health Protection Act amendment, thanks to the joint lobbying effort of the CSF, EATG, AAE, NeLP and other supporters. |
| | Commissioner Andriukaitis answers to the letter of the co-chairs, sharing our concerns and indicating that the Commission supports Member States in implementing voluntary HIV testing programmes. |
| June 2015 | Aids Fonds and Doctors without Borders Netherlands collected 36 endorsements from Dutch and European organizations on the petition Beat the AIDS epidemic – Press for fair prices and better access to medicines. |
| | Request from Croatian CS for support as the only psychosocial support service for PLHIV and the biggest VCT site were closed at the same time. |

Tamás reports on the results of the survey that was sent out to the CSF members prior to the meeting:

- Stock-outs: At the time of the survey, there were no actual stock-outs reported. Apparently, the situation in Russia is still difficult, in particular when it comes to viral load diagnostics. Medication is often only available for a month and people report therefore about a pending threat.
- Usage of the ECDC data set: Responders suggest having the publications in more languages, to make them easier to read and less technical.

Discussion: Teymur answers that the publications are not published in other languages as that is too costly. A question also arose whether already stock-outs from Greece are reported which is not the case in the moment. Lella adds to her report on advocacy that also the PICUM letter on migration was supported. Some concern was expressed on the possibility of other countries follow the example of the Czech Government on the idea of introduction of mandatory HIV Testing.

2 The current state of HIV Policy in Europe: Update from the Commission including a presentation on the Health Policy Forum and its IT Platform

Matthias Schuppe updates the attendees on recent developments in regard of the European Commission's HIV dossier (see Annex 1). He announces that the external evaluation of the Commission Communication and Action Plan on combating HIV/AIDS 2009-2013 will be published soon. After running through the activities during the Italian and Latvian presidency the calls for proposals for projects on "early diagnosis and treatment of viral hepatitis", "early diagnosis of tuberculosis" and tender(s) on "Surveys and target prevention projects for training of health professionals" are presented. Matthias also announces that he leaves the HIV dossier by July 16 but will remain in the field with a new position of the health profiles portfolio.

Discussion: The discussion centres on the policy framework after 2016, when the current action plan will expire. Luís emphasises that the work on the new framework has to start this year in order to have a continuing one in 2017. After the failure of the Rome declaration, and since there is no follow-up during the Latvian and Luxembourgian presidency, there is a clear commitment from the Commission needed to work on it. Lella adds that health is not very high on the EU agenda at the moment and that joint efforts are needed. The CSF coordination team is therefore assigned to write a letter to President Juncker to ensure that HIV, viral hepatitis and Tuberculosis are of importance in the EU and neighbouring countries.

The second part of the EU update covered a presentation of the Health Policy Forum and its IT Platform. Alberto Gago Fernández introduces the opportunities of the platform that will go online towards the end of this year (see Annex 2).

Discussion: Main outcomes of the discussion were that the IT platform is an additional tool for communication. It is not a replacement for face-to-face meetings. The term 'stakeholder' also includes private companies such as pharmaceutical companies but it will be possible to tie certain topic related groups to specific stakeholders only. The question whether eastern European organisations are able to join the platform and subgroups could not be answered and will be taken back to the department to check.

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 starts for ECDC with the update from the agencies (see Annex 3) focusing on following topics: ECDC guidance on HIV/STI among MSM in the EU, ECDC Modelling project, Evaluation of HIV testing guidance, Dublin Declaration, Continuum of HIV care, and Mobile apps and HIV testing.

Discussion: A question addresses the planned meeting in September with NGOs and app owners to discuss opportunities for HIV testing promotion during European HIV Testing Week, whether it should be promoted to LGBT NGOs. Teymur confirms that there are still some vacant seats and that specifically representatives of NGOs from central and eastern Europe should be addressed. A comment related to the guidance on prevention among MSM that now should also include PrEP including the results from the Ipergay and Proud studies. Teymur mentioned that PrEP deserves their own guidelines, but for that ECDC needs to have a clear position and recommendations of the European Commission and the Member States. Another question tackled the scientific and epidemiological reason of the modelling project. The modelling is needed to have a better assessment on time of infection vs. time of infection and it is based on concentrated epidemics. Furthermore, there is no data in regard of how many people are infected during the primary stage of infection but would be very much needed.

3.2 UNAIDS

Henning Mikkelsen updates on the UNAIDS activities since last CSF meeting (see Annex 4). They held a consultation on the UNAIDS Strategy (2016-2020) for western Europe. He emphasizes that having had a regional consultation for western Europe is a step to show that UNAIDS has interest and concerns in this region as well, especially regarding the MSM and migrant communities. A week UNAIDS/WHO joint meeting was held on PrEP: in March, report should be available in one week. Quote from the meeting: “We have the evidence, we need activism to get there” – Luis Loures. UNAIDS also held a meeting on mobile apps for gay men, participants included MSMGF, LGBT and HIV organizations and for the first time industry was present. Report of the meeting will also be shared.

The meeting “Fear No More” on PrEP was co-organized by UNAIDS and EATG where the discussions were not only about mobilizing the community to demand PrEP but also about treatment issues in light of the finding of START study. Europe should stop the practice of treatment initiation tied to CD4 count.

There were two visits by UNAIDS to the Czech Republic on the issue of plans to introduce mandatory testing for “risk populations”. Henning would like to thank civil society to alert UNAIDS. The proposal was withdrawn but there needs to be support to find a solution to address these epidemics in CSE and eastern Europe. It might be repeated in other parts of Europe considering the increasing anti-LGBT movement, we need to be alert.

Similar to Luis, Henning is also worried about the lack of high-level commitment at the European level to the issue of migrants and HIV. There needs to be a statement and commitment – perhaps the Dutch presidency could come up with one - UNAIDS is committed to engage politicians (e.g. Michael Cashman) to get a high-level commitment in Europe.

Discussion: The issue of Belarus removing the mandatory testing for migrants rule was raised. There was lack of information about the background of this move. The communication of information between UNAIDS and CS could be improved. Concerns were raised about the lack of information from EECA region in this meeting. There was a feeling of getting disconnected with the region, the EECA region should get back on the agenda of CSF meetings. Henning suggests that CSF invite someone from the Moscow office to the meeting. Ideas on how to push Europe high on the agenda would be very helpful for the CS, any update would be welcome. In the context of the issue of migrants and HIV it was raised the need of an interparliamentary group.

3.3 WHO Europe

Antons Mozalevskis reports on WHO activities. There were WHO country visits to Georgia, Armenia and Albania to provide technical support to GF transition activities. WHO also provided support on guidelines for viral hepatitis in Georgia and Turkey; a WHO manual is also being developed. Several new guidelines are under development: HBV treatment, HCV update, consolidated strategic information guidelines, ARV guidelines update, and technical update on PrEP. They are available for download (including a QR code).

WHO is also producing a global health sector strategy. There are regional consultations going on. A 3-day meeting for Europe was convened in Copenhagen last month. The Report is to come. Participants agreed that these strategies are relevant and necessary but the feasibility of the targets were questioned: there should be a balance between aspirational and feasible targets. There was an expressed need for regional action plans that should be prepared in parallel with the strategy. 2 separate reference groups on HIV and viral hepatitis should be set up. The timeline of the strategy development: first regional presentations of the draft, in 2016: general assembly to approval, September 2016 regional approval.

3.4 European Monitoring Centre for Drugs and Drug Addictions (EMCDDA)

Roland Simon reports on the European Drug Report 2015 and trends in drug consumption and activities related to infectious diseases among people who inject drugs (see Annex 5). His presentation included updates on the heroin market, OST coverage, trends in treatment of opioid problems, the use of cocaine, amphetamines and NPS, responses to outbreaks in Greece and Romania, HCV antibody prevalence among injecting drug users, overdose deaths and the preventing of overdose deaths through naloxone, drug consumption rooms, and the Best Practice Portal of EMCDDA.

Discussion: Drug use and overdosing in prison was one of the topics arising in the discussion. Roland reports that there is an increasing willingness to look into this problem, especially from health staff in prisons. In general, there is a decrease of injecting drug use in the EU member states that might not be necessarily the fact in eastern Europe, also in terms of the use of NPS (New Psychoactive Substances) which, in general, sets new challenges in terms of different risk profiles. In western Europe heroin is no longer to be considered a “sexy” drug. Chemsex is a topic, also for EMCDDA and Hepatitis C is high in

the Agencies' agenda. (An insight publication on HCV treatment will be published in October)

4 PrEP: Latest research and policy development

Francesca Belli reports on the latest developments in France regarding the Ipergay study (see Annex 6), based on the presentation she gave during the last Civil Society meeting. The activities now focus on Enquête Flash PrEP, an internet and paper survey on PrEP, the informal use of PrEP (4,5 % in the Ipergay study, the awareness raising and promotion of PrEP within the communities, the temporary recommendation of usage (RTU) and the role of the Minister of Health of France in the discussion so far. Francesca also reports on the Fear No More meeting in Brussels, organised by EATG where European stakeholders got together to discuss next steps in terms of biomedical prevention and to develop a PrEP action plan.

Discussion: Primarily, the need and the promotion of PrEP in the communities were discussed. It is necessary to have the communities on board, not only the gay community but also other key populations. Also, it was emphasised to address the TT members although it is not a decision making body. There are some implementation studies planned, in Antwerp and Amsterdam, also Germany thinks about an implementation study next year. Slovenia seems to have a good chance to introduce PrEP. It was raised that all countries with projects on PrEP implementation in the pipeline should work in collaboration so data can be shared as soon as possible. The PrEP manifesto needs a rewriting (Tamás asked for suggestions that should be sent to the CSF chairs and/or to the coordinator of the EATG Prevention Portfolio - Gus Cairns). A video by NOMS/Hispanosida and later by Nick Feustel with a view to the PROUD study were shown.

At the end of the discussion the issue on guidance on PeP was raised and it was highlighted that the implementation of PeP is still very difficult in various countries. It was also recommended promoting models on access to PeP for key populations. ECDC did not produce anything specific on PEP but there are WHO guidelines.

5 Prevention among MSM – Travelling gay men and other MSM, impact of smart phone applications among other issues

Per Slaaen Kaye reports in his presentation from the European expert group on prevention among MSM and focuses specifically on travelling MSM and the impact of mobile dating apps on prevention (see Annex 7). Although there is uncertainty whether MSM have more partners due to apps, there is a significant increase in reported gonorrhoea and syphilis among MSM from 2010. Also, it is uncertain whether there is an increase in sexual activities among MSM or if there has been a shift from other internet platforms to geospatial apps. However, there is evidence that the patterns of recreational drugs have changed, and that apps do appear to be playing a role in organising and finding group gatherings of MSM for sex which include the use of recreational drugs. Per concludes with proposed responses to the challenges, including the need for a bi-annual conference connecting practitioners, scientists and other stakeholders in the MSM prevention field and an improved collaboration of Checkpoints at European level.

Discussion: The importance of collaboration with app providers was emphasised, in particular in terms of sending out prevention messages and promotion of testing services. It was also stressed that this collaboration might not be easy, as it was not easy to negotiate with bar and club owners in the beginning of the epidemic and that is why CS should be involved in these negotiations. Teymur mentioned the lack of eastern European NGOs in the mobile apps project.

6 Home-testing

6.1 United Kingdom

Eleanor Briggs quickly introduces National AIDS Trust that is a policy and advocacy organisation but not a service provider. She presents about the experiences in self-testing in the UK so far (see Annex 8). There were studies (THT, NAT) that showed that self-testing would increase the uptake of testing, especially popular in the black African community. There were also several concerns about self-testing but illegal test use was also prevalent. In 2014 the law came into effect and tests first became available in April 2015. BioSure is the only company providing tests for Great Britain (Northern Ireland excluded). The test is 99% accurate with a three-month window period. Linkage to test confirmation, and to further care and services is provided through links to websites that come with the test.

Discussion: A good part of the discussion centred on discrimination and stigma, whether self-testing overcomes stigma and discrimination as no obstacles to go to testing facilities need to be passed or whether it actually increases stigma and discrimination since the users don't have to grapple with these phenomena and also with self-stigma. On top of that it was suggested that maybe the linkage to care is even more improved due to these barriers. Basically, this is another tool, another option for people that would not go to a testing facility and the more people use it, the less stigma could go along with it. In any case, the linkage to care was specifically stressed in implementing the self test. Discussed was also the quality of tests with an accuracy of 99 %. This is a blood test but there is strong likelihood that there will be a swab test pretty soon.

6.2 France

Francesca Belli presents on the situation of self-testing in France (see Annex 9). France performs 2nd highest number of tests (after Austria) but reaching the wrong populations. AIDES' action to promote testing – increased uptake of testing: most tests are done during outreach. Self-testing is considered a new tool for reaching people. 20 thousand kits will be given out in a pilot project by the community. Moreover, a 24-hour hotline is also in operation to answer questions.

Discussion: For the present there is no WHO self-testing guidelines but WHO guidelines are updated every 2-years and new evidence is always integrated in them. Self-testing should be integrated into the global WHO guidelines. The amount of tests to be performed (20 thousand) is considered to be too low, Francesca explains that first they need to test if there is demand for self-testing. The approval and quality of tests is discussed. In the French project the producer is a French company and the project was local but the tests have the CE label. However, the CE label only means that the production procedure is checked but doesn't necessarily include correct label information. This needs to be checked as these products are also available online. The quality of information and instructions are important in case of self-tests. In the NL there is a network built to collect information about availability, methodology and quality of tests. The issue of false positive tests is raised; there is fear of loss to follow-up, so there needs to be a better linkage to care. These worries are understandable but they can be solved by having proper guidelines and label information on the limitations of the tests and also information on linkage to care. The bigger problem is still the large number of undiagnosed people. If we are to reach the 90-90-90 targets, we must address the issue of over-medicalization of HIV-testing in most European countries. This is one of the barriers to reach the aim of 90% diagnosed and it is the most difficult to reach. There needs to be monitoring, guidelines on the efficacy, reliability of different approaches. Self-testing should be one of these approaches. Price can also be a huge barrier, not just for testing but also to put diagnosed people on treatment. Affordability (pricing) should get back onto the agenda of the CSF. It is also noted that false-positive tests are more common in high-prevalence settings and can be avoided by proper training.

Francesca points out that the price of HIV-tests is not much different from other tests available in pharmacies. But different strategies are important: NGO, pharmacy, public health all needed to get near the 90% target.

7 Prevention among Youth

Eleanor Briggs (UK) introduces her presentation on the “Boys who like boys” survey (see Annex 10) with the campaign video. The survey was conducted as new diagnoses among young MSM have doubled in the last 10 years in Britain and there was a need to find out where young MSM get their sexual education from. The survey got 1000 completed responses. The findings in general showed that young gay men lack knowledge on HIV and sexual health and relationships, and that they would use school education, sexual health clinics as source of information.

Eleanor's presentation is followed by Fidan Karimli's report on HIV/AIDS prevention among youth in Azerbaijan, describing the barriers to sexual and reproductive health education for adolescents and young people, the advocacy work in this field in Azerbaijan as well as the involvement of youth organisations in prevention (see Annex 11). Fidan also refers to international collaboration, for instance the HIV/AIDS international conference, that aimed to create a space for youth organizations from different countries, especially European and Eastern Partnership countries to share and exchange the best experiences on combating HIV/AIDS in different communities and to assist to future partnerships as well as the 1st Baku International Youth Health Forum.

Discussion: The discussion touches the issues of access to health education and increasing challenges due to conservative movements in societies, the need of youth-adequate testing facilities and access for testing youth in the first place as well as the need of drug education for young people in order to decrease infections. There is a Eurasian network for young people

and there are good tools for sexual education available in the internet (in several languages by the German BZGA). The CSF coordination team is asked to share these links. It was stressed that young people also should be addressed in EU policy framework (as a special group) like the Action Plan. On the other hand, it is pointed out that in countries with concentrated epidemics efforts should be covered by the national budget for sexual education, while HIV prevention budget should be used for the people in need which are key populations. In general, young people should be involved in prevention efforts, young people are needed in the forums of HIV work, and more disaggregated data in terms of drug use and young people are required. Fidan requested the CSF coordination team to explore the possibility to have more youth organisations (e.g. European Youth Forum) joining the HIV CSF Forum.

July 7, 2015

8 Keep HIV, HCV, TB and STIs on the agenda - EU presidencies

The second day starts with presentations about previous EU presidencies (Latvia), and updates from upcoming EU presidencies (the Netherlands and Slovakia). Since there is no representation from Luxembourg, there is no report in regard of their presidency in the second semester of this year.

8.1 Latvia

Aigars Cepitis gives his presentation on the related activities during the EU presidency (see Annex 12). TB was prominently on the agenda of the Latvian EU presidency with a ministerial conference on tuberculosis and multi-drug resistant TB. Activities regarding HIV/AIDS were supported by the presence of AIDS Action Europe (Steering Committee meeting) and their meeting and discussions with civil society and ministry and hospital representative.

8.2 The Netherlands

Anke van Dam and Martin van Oostrom report about the Dutch activities around UNGASS on drugs. There is a strong support of the Dutch government for decriminalisation and harm reduction. Also the IAC 2018 will take place in Amsterdam and there's planned focus on eastern Europe and central Asia. There are currently also advocacy efforts on affordability, highlighted by a joint letter of organisations, organised by SANL and delivered to the Ministry of Foreign Affairs of the Netherlands. There is good collaboration between civil society and government organisations in the Netherlands and therefore hope for achievements during the presidency and also in view with the AIDS conference.

8.3 Slovakia

Iveta Chovancova reports that the Slovak presidency is planning an event on TB. It would be important to get communicable diseases, including hepatitis, on the agenda.

Discussion: It seems very difficult to bring together a high-level meeting on HIV in Europe. It was pointed out that CSF needs to improve the interaction with the EU Presidencies as in 2016 we will have the new policy framework and the review of the Dublin Declaration. It was suggested that testing and affordability could get highlighted through the Dutch presidency, which will be in a good position to start a conversation on pricing. Also NGO support and low prevalence regions (CSEE) are mentioned. The group also proposed to invite presidencies to the CSF meetings.

9 START trial

Tamás introduces the 5 questions that should start off discussion on what the implications of the START study results are.

Discussion:

Guidelines will be adapted to the findings of the START study: WHO is updating its guidelines and most likely EACS will do so as well. However, besides guideline updates there is also need for advocacy within the community. We need to improve health literacy among PLHIV. The community needs to be informed about the advantages of starting therapy as soon as possible after diagnosis. There is also the issue of affordability of medications and putting everyone diagnosed on therapy. There are huge differences within regions and country by country on prices and also on how much a country can afford. In some countries different hospitals pay different prices for the same drugs. There could be a huge role here for generics, but even the community is divided over the use of generics. There is a clear need for training and literacy on generics. There is a

huge difference between EU and non-EU countries regarding generics. Outside the EU, countries are in need of Indian generics to reach universal access. Trade regulations imposed by the EU might be the biggest obstacles. One suggestion is to put generics on the agenda of the upcoming CSF meetings. The issue of pricing strategies and the lack of transparency of pricing are also discussed. There are differences in prices between countries and even between listed prices and the price a country actually pays for the medication. Members suggest a position paper on pricing from CSF and also as a move there is suggestion to present a complaint to the European court for breaking the rules of transparency. There is clear need to find information on the actual prices countries are paying for HIV and hepatitis medication.

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

Maria Phelan gives her presentation (see Annex 13) about preparations for the UNGASS on drugs taking place in New York in April, 2016. An interesting detail is that April 20 is the global marijuana movement's "light a joint" day. There was a request from the Egyptian chair that positions should be sent from regional perspective. The EU countries are not very happy about it. The EU will consolidate its position by mid-October. Civil Society has time till then to influence this process and provide input. Also the human rights council session feeds into the process; there is a high-level meeting on human rights and drugs in Geneva in September. UNAIDS PCB will sit together in October, putting pressure on UNAIDS to be more vocal in drug issues. On the EU position, Maria highlights that a treaty reform has been pushed from the Latin American states but the EU hasn't joined that. A Civil Society Task Force has been established (the members' list is to be found on the New York NGO Committee website). There is an online questionnaire developed by the CSTF. CSF members are encouraged to participate in this process, deadline is July 31, 2015. Maria also suggests that the CSF coordination team writes a letter with its position to the Horizontal Working Party on Drugs (HDG) which might not read the letter; however it is important that they hear that European civil society cares about these issues. The VNGOC (Vienna NGO Committee on Drugs) is usually made up of organizations which are not in favour of harm reduction policies and it would be great to have other voices there. Maria also briefs about the "10by20" campaign. Funding for harm reduction services is only at 7% of the total needed and even that is under threat of cuts. The aim of the campaign is to get 10% of the money spent on law enforcement and imprisonment of people using drugs spent on harm reduction by 2020.

Discussion: There is clear evidence of the need for different drug policies. The question is how we can transfer knowledge to different settings of the international agencies to get them on board. In South American countries, the debate is much more mature than in Europe. A few countries with decriminalization of drug use (the Netherlands, Portugal) are not the main voices in these reports. There should be a change in the conservative approach of European scientific societies such as EACS or EASL in order to make declarations similar to that that was released IAS in Vienna. The WHO European region is the only region where injecting drug use is the predominant way of transmission of HIV. It is time for evidence-based policies and the respect of human rights of people who use drugs. Maria points out that during the CND a resolution was approved that was put forward by Russia. We need to make clear what we mean by a "human rights approach to drugs". Although there is a general feeling that the timelines are very tight to prepare for UNGASS 2016, there are many activities going on already. A meeting is going to take place in a few days in Budapest with organizations supporting reform. Another concern is that NGOs in the EECA region are not much aware of the upcoming UNGASS meeting. We need to make sure that NGOs are informed and they start a conversation with their governments aimed at aligning health policies and drug policies. Examples of countries such as Portugal or the Czech Republic should be used. The Dutch government is open to bring up this topic UNAIDS PCB met last week and they came up with a list of recommendations, available on the UNAIDS website. In general, advocacy for a strong European position at national and international level is needed. In order to do so, the members agree that a letter to President Juncker and to the Dutch government - which holds the EU-presidency in the first semester of 2016 - would be helpful. We should also send a letter the new Commissioner of DG Migration and Home Affairs and to the Horizontal Working Party on Drugs (HDG).

11 Quality Action – Report and discussion on the Joint Action on improving HIV prevention in Europe

In his presentation, Matthias Wentzlaff-Eggebert highlights the activities and results of Quality Action so far (see Annex 14). He notes that joint actions have their challenges: much depends on the relationship between organizations and

governments. 2 WPs of the QA are led by NGO partners. Quality improvement can be easily abused and only add additional work but no value: principles need to be in place to avoid “abuse”. As it involves a lot of self-reflection, safe environment is needed for those who participate. Participation has to be based on self-determination; people should only participate on their own decision. Besides the existing tools new tools were developed, SCHIFF is to be used for the programme level. There was higher participation of NGOs in the training part of the joint action.

The feedback from participants was positive; there is a general level of satisfaction among them and after the trainings people felt more confident. People think they benefitted from the level of involvement that they had. They made improvements and obtained improved stakeholders’ participation. They regard the investment in time as worth the effort. The key populations with whom the participating projects work with in general reflect the epidemiology of HIV infection in Europe. They also include people living with HIV (‘positive in prevention’) as well as intermediaries who can reach those affected.

There is still work in progress: the Charter for Quality in HIV Prevention and a Policy Kit are under development. The closing conference is planned in Berlin in February, 2016.

Discussion: Some of the members of the CSF are also part of the Quality Action. Their experience is also generally positive, they value the participatory aspect of the tools. There is suggestion for better marketing of Quality Action and the tools. It looks quite theoretical but once you start applying the tools, you find out how easy and useful they are for your everyday work. From their experience, NGOs participating in training feel well connected and national conferences and events are also successful. GOs, however, are not so active in participating and applying the tools, most likely due to their not so flexible structures.

Questions on the sustainability of the project are also raised. QA came at a wrong time when economic pressure was already very strong. There is also a general dissatisfaction with the present rules for participation in EU Joint Actions, which the CSF co-chairs have raised already several times. Everything - from the decision about participation in JAs to the selection of partners - depends on the national focal points (usually the Ministries of Health). Key populations are usually not represented.

12 Women and HIV in Europe

The presentation by Cristina Torró from Médicos del Mundo (see Annex 14) focuses on the challenge of visibility of women. There has been a decrease in HIV in women in the EU countries that is connected to same decrease in sub-Saharan Africa. In the EECA region, the infection rate is increasing among women as well. Globally, young women are the most affected. There is still missing data on late presentation, ECDC will work on the male/female ratio data. They already have the raw data, still to be analysed. The CSF could ask for such an analysis and also advocate for different prevention tools. There is a need for support from men for the proper representation of women in the HIV movement.

Discussion: When gender issues are raised, there should be discussions about other genders such as trans* people. Gender issues are talked about but usually not reflected in programs (e.g. Global Fund). The social vulnerability of women is well-documented but women in general are not a key population; anyway, women in key populations are more affected and vulnerable than men. Sexual education with special focus on women should be included in general sexual education programs and not divert focus (financial support and commitment) from key populations. There is a need for disaggregated data on women in key populations (e.g. women in prison). When women issues are discussed, other aspects such as violence or providing care for children should be included in the discussions. Concerning the different prevention tools, it is noted that women and PrEP discussions are starting to happen in the UK.

13 Any other business

13.1 Regional program of ECUO within the framework of the Global Fund New Funding Model

Olya Aleksandrova gives her presentation about the goals and objectives of ECUO’s regional application (see Annex 15). She describes the background of the situation and highlights the main problem areas of the EECA region: access to HIV care and treatment, sustainability and low-level access for key populations. The regional program of ECUO aims to enhance the effectiveness, accessibility, sustainability and scale-up of HIV treatment programs in eastern Europe and central Asia (EECA region) with special emphasis on key populations.

Discussion: The discussion starts with the situation in different countries regarding access to treatment, which in some places is only about 10%. People raise their concerns about access in the conflict zones in Ukraine and whether there should be more attention paid to this situation. Olya adds that the situation in other countries is even worse. The Global Fund strategy for the region ends in 2017. There are efforts to develop a new strategy for 2017-21. There are consultations ongoing on health system strategy, community system strategy, countries in critical situations, transition of countries, gender, human rights and key populations. The gender issue in Ukraine is not being addressed because gender programmes are not funded.

13.2 European HIV and Hepatitis Testing Week

Mariana Vicente from EATG gives a presentation of the European Testing Week that she will also present at the Think Tank meeting. ETW 2014 was a huge success and HIVinEurope decided to include hepatitis C testing in ETW 2015. Different logos have been developed for this year: for HIV testing only, for hepatitis testing only, and for the combination. It is already possible to Sign-up for ETW2015 on the dedicated website.

Discussion: People raise their concerns that hepatitis tests are much more expensive than HIV tests and this could be a great barrier during the testing week activities. Mariana adds that similarly to what happened last year, some donations might be made in support of the initiative, including the supply of HCV tests.

13.3 Closing remarks

Michael Krone (AAE) reminds the CSF members to fill in the evaluation form. Furthermore, he brings the attention of the members on the call for the new CSF co-chair for AAE, which has already been launched; deadline for the submission of applications is August 3. Anyone interested in the position who has questions regarding the tasks and workload involved is invited to approach Lella in person or via e-mail. Tamás adds that as his term is also over at the end of 2015 and there will be a call for the EATG co-chair as well.

The possible dates for the next CSF meeting are November 23-24; the meeting will most likely take place in Luxembourg.

Tamás asks the members to send any important information to the mailing list or to post them on the Facebook page, as sharing information is crucial to our work.

Lella closes the meeting.

Action list

| What | Who | When |
|---|-----------------------|-----------------------------|
| Write a letter to Juncker together with viral Hepatitis and Tuberculosis networks and groups | CSF Coordination Team | September 2015 |
| Share links in regard of sexual education | CSF Coordination Team | as soon as possible |
| Send the list of national focal points | CSF Coordination Team | as soon as possible |
| 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 |
| 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 |
| Ask ECDC for a Technical Report on Women and HIV. | CSF Coordination Team | Autumn 2015 |

List of annexes

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

Annex 2 - EU Health Policy Forum

Annex 3 - ECDC Update to EU Civil Society Forum

Annex 4 – Update from UNAIDS

Annex 5 - EMCDDA activities related to infectious diseases among people who inject drugs

Annex 6 - PrEP and global mobilization

Annex 7 - Dating Apps – flirting with disease?

Annex 8 - HIV and self-testing in Great Britain

Annex 9 - Self-testing in France

Annex 10 - Boys who like boys - A study of where young MSM learn about sex, relationships and HIV

Annex 11 - HIV/AIDS prevention among youths in Azerbaijan

Annex 12 - Latvia EU Presidency Events

Annex 13 - Update on UNGASS on Drugs

Annex 14 - Women and HIV in Europe

Annex 15 - Regional program of the East Europe and Central Asia Union of PLWH within the framework of the Global Fund New Funding Model