# Report of the 17th HIV/AIDS Civil Society Forum Brussels, May 27, 2013

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









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# 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. See the participant list in annex A. All annexes to this report are only available online at the CSF page on the AIDS Action Europe website.

# May 27, 2013

# 1 Opening

Opening of the meeting by co-chairs Anna Zakowicz and Lella Cosmaro, starting with a brief round of introductions (see annex A).

# 1.1 Report and action list of last meeting

Martine de Schutter gave an update of the status of the action list of the last meeting:

Who	What	When	Status
CSF CT (Coordination Team)	Circulate compilation of national HIV strategies by Yusef Azad	ASAP	After a second round of feed-back from CSF members a compilation of responses from 23 countries was circulated through the mailing list.
CSF CT	Send stock-outs inventory to WHO/Europe		Done.
CSF CT	Develop an advocacy strategy at the European level based on stock-outs information	Before next CSF meeting	We have done the inventory twice. This information is not collected through any other mechanism than through the CSF and is therefore of much use to WHO. CSF co-chairs discuss with WHO treatment expert on how to structure a future inventory in order to include its outcomes in WHO reports.
CSF members	Use the ECDC Dublin report (when available) to advocate for improvements with national governments	Early 2013 when ECDC reports are published	Since the report was only launched at the date of this meeting, the date will be used from now on.
CSF CT	Send letter to Commissioner Borg to ask for new HIV Communication	December 2012	Done, CSF delegation will have a meeting with the Commissioner after the CSF meeting.
Wolfgang Philipp	Send summary of legislative and non-legislative instruments (similar to the Commission Communication)  ASAP  EC will update CSF members at this meeting about different options available.		EC will update CSF members at this meeting about different options available.
Anna	Share the community consultation on WHO ART guidelines for comments for CSF	ASAP	Done.
Anna	Share the information on WHO/EATG twitter on TasP that CSF members can	ASAP	Done.

	join		
CSF members	Check the ECDC Report on migrants and send any comments to ECDC in case civil society has a different opinion with respect to data given by their governments.	ASAP	Not done.
CSF CT	Ask CSF members Ireland, Greece, Latvia to update CSF on email list.	January	Update will be given at this CSF meeting since not much happened in between meetings.
CSF CT	Share EC Call for proposals - Public Health Programme	When launched	Done.
Sini Pasanen	Share ECDC Report on Finland	ASAP	Done.
CSF CT	Ask EC to organise CSF-TT lunch meetings in the occasion of future meetings	Prior to next CSF meeting	CSF CT will keep this in mind but this time it wasn't possible due to different schedules because of the High Level Meeting on Human Rights.

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

#### December 2012

- 05/12 Response of Karel de Gucht, EC, to our letter on the DCFTA EU and Moldova, ensuring that the negotiations will be supportive of public health and well-being of PLHIV.
- 14/12 Letter of CSF co-chairs to Commissioner Borg about the need to renew the European Commission Communication and Action plan on HIV.

#### January 2013

- 09/01 In response to an e-mail sent by the Greek CSF member requesting examples of compensation for people infected with HIV due to alleged state negligence, 5 CSF members shared information.
- 14/01 Letter to President of Ukraine and a number of other relevant Parliament committees, political parties, human rights
  committees etc. in Ukraine on draft law affecting freedom of speech and expression in Ukraine: draft law #8711 on prohibition of
  propaganda of homosexuality.
- 18/01 CSF members sent additional information to finalise the overview of recent national HIV strategies.
- 22/01 Reply from Commissioner Borg to our letter, informing us that the European Commission is planning to conduct an
  external evaluation of the current EU policy, which will serve as a guidance on how to take forward EC efforts. Borg committed
  to meet with a CSF delegation on the occasion of the High Level Meeting on Human Rights in May 2013. Such a meeting will
  take place today.

## February 2013

- Contact with the Cabinet of Commissioner Borg to request an earlier meeting, since the May meeting was deemed too late to discuss future HIV policy developments.
- 08/02 In response to a request by Portuguese CSF member to share national HIV testing guidelines or legal frameworks for HIV and Hepatitis or rapid test Point of Care testing, 16 CSF members shared their national or regional experiences.

#### March 2013

- 11/03 letter to Mr. Briol, Director of the EAHC, expressing concern about the possible lack of recognition of the value of the participation and involvement of community and civil society organisations in the 2013 Public Health Call for projects under the Call: "Improve access to early diagnosis of HIV/AIDS and timely treatment and care of most vulnerable groups and in priority regions".
- 15/03 Upon a request by Austrian CSF member for examples of fact sheets for judges and/or prosecutors, information from the UK and Czech republic was shared.
- 18/03 Meeting of CSF co-chairs in Brussels with Paula Duarte Gaspar, representative of EU Commissioner Tonio Borg's cabinet
  to discuss the future of the EU HIV policy and the issues to be addressed at the upcoming Human Rights conference. The
  meeting was also attended by Paolo Guglielmetti (DG Sanco) and Ann-Isabelle Von Lingen (policy officer EATG).

#### April 2013

17/04 Conference call of CSF Coordination Team with John Ryan, Paolo Guglielmetti and Herta Adams from DG SANCO to
exchange thoughts about the process towards the future HIV policy, the evaluation of the current Commission Communication,
the upcoming CSF meeting, and Human Rights Conference.

## May 2013

- 13/05 Call to the EU leaders and the EC to reaffirm their leadership and commitments on HIV/AIDS by approving a new strategy
  and action plan on HIV/AIDS (199 signatories). The document was sent to President Van Rompuy, Commissioner Borg,
  President Schulz, President Barroso, Minister Linkevicius, Ms. Creighton.
- 27/05 CSF delegation meeting prior to the opening of the Right to health, Right to life high-level meeting with Commissioner Borg to discuss future HIV policy.
- 27/05 To strengthen the CSF call to action, a petition from AHF was launched and an action today at the EC main building was held. A short video message to members of European Parliament will be prepared and CSF members will be interviewed.

# 3 Commission update (Recent HIV-related activities, further activities planned for 2013, Think Tank agenda)

Paolo Guglielmetti (DG SANCO) has taken over Wolfgang Philipp's position. He presented an overview of recent projects and joint actions funded through the EC Health Programme. See **annex B** for details.

He reported on the TT agenda as challenging and interesting, with a preview by WHO Europe on WHO new guidelines on access to treatment which will be launched at the IAS conference in July and updates from Italy, Portugal and Spain on national surveillance data with a special focus on illegal migrants, among others.

# 4 HIV & Human Rights: monitoring developments in the region (roundtable of CSF experiences)

This session provided a roundtable of CSF experiences. Several CSF members gave an update on developments regarding HIV and human rights in their countries. It was an important session in preparation of the Right to Health, Right to Life conference the day after.

#### 4.1 Ukraine

Hannah Shevchenko presented both positive and negative stories regarding HIV and Human Rights. The country has quite a strong legislation on HIV and AIDS, yet is currently facing legislative gaps, violations in health care settings and violations by law-enforcement authorities. She also gave an update on the legislative ban of homosexual propaganda. Although the proposed law was successfully opposed, another similar one was drafted and presented to parliament afterwards. See **Annex C** for further details.

#### 4.2 Latvia

Ruta Kaupe gave an update on the situation in Latvia. A campaign to urge the government to start HIV treatment at CD4 level of 350 instead of 200 was organised, which included a letter addressed to the government which was endorsed by 700 signatories and successfully delivered. For the first time the Latvian government reacted and recognised that Latvia should comply to European ARV treatment guidelines, promising to submit a proposal in parliament. Furthermore, a press conference was organised during the Candlelight Memorial Celebrations regarding this issue. Although no specific decisions have been taken as yet, the problem has been strongly addressed with good advocacy actions..

## 4.3 Tampep

Licia Brussa from TAMPEP presented a statement indicating the main on the main factors contributing to the vulnerability of migrant and national sexworkers across Europe, including criminalisation and human rights violations. She outlined fundamental rights for sex workers and listed the demand of the global sex workers rights movements for proactive measures that governments and responsible authorities must take to fulfil and protect these rights.

## 4.4 Switzerland

Harry Witzthum hopes that the referendum that will take place on September 22, 2013 concerning the amendment of the criminalisation of HIV transmission, will pass. Cantons started to introduce new prostitution laws. Apart from these laws, there is an increase of police crackdown on sex work.

In June, parliament discussions will take place again on access to health and health insurance for undocumented migrants. 8% of such vulnerable group cannot access healthcare and there is concern that this figure will rise due to a more repressive trend witnessed in the last period.

#### 4.5 Finland

Sini Pasanen pointed out that Finland currently has 2 criminalisation of HIV cases in supreme court, and judgement could take years. The Parliament argued that there is no ARV treatment available because of a lack of separate laboratories for research of cells and tissues of infectious diseases. A couple of years ago the ombudsman was called in and its decision has been that this is not acceptable, forcing government to provide ART.

#### 4.6 Greece

Marianella Kloka reported that the broader picture of the situation in Greece is the unstable situation and the 30% cuts in the health sector for the period 2009-2013. However, there are no stock outs on drugs for the moment. The ECDC's visits to Greece were a necessity due to the outbreak of HIV infections among IDUs.

Positive Voice has developed new materials and in the first 6 months of this year it has reached its target of 1000 tests among MSM.

#### 4.7 Russian Federation

Pavel Aksenov explained that in the Russian Federation ARV supplies are more or less OK at the moment. As from Dec 2012, procurements have been decentralized. Each territory of the country is now responsible for ARV stocks, prices, etc. It is likely that stocks will be available in the country until October. 50 Territories have not yet announced tenders for procurement of ARVs. Tenders in about 20 territories did not occur, so no applications from suppliers are expected. Expected problems: more requests for ARV, less adherence to treatment, price increase, extreme lack of ART. Public actions were taken by NGOs to try to get into dialogue. Last February, after a period of 3 years, a first attempt for dialogue between NGOs and the Ministry of Health was established.

#### 4.8 Morocco

Othoman Mellouk explained that the situation of undocumented African migrants is worsening: there have been arrests and police targets NGOs working with undocumented migrants. Migrants do have access to health care services, but when they are evicted, health care professionals lose track of them and treatment is interrupted.

# 5 The current and future state of HIV policy in Europe

Outcomes of the 2012 monitoring of the Commission Communication & the Dublin Declaration monitoring report - Teymur Noori, ECDC

Teymur Noori started with a presentation of some key outcomes of the 'Monitoring implementation of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia: 2012 progress report". See **annex D** for the details, some important data presented:

In relation to leadership and resources, data show that prevention funding is prioritised for key populations, but needle and syringe programmes in prisons are still very poor across the region, and ART for undocumented migrants is available in only less than 50% of countries.

Concerning financial resources, treatment accounts for more than 95% of all HIV spending in the region. So far the economic crisis has not adversely affected as yet domestic spending on HIV response (although it must be taken into account that that last data considered refer to 2011) but it did affect international spending.

As far as treatment is concerned, in 22 EU countries with data, coverage is above 85%, but outside the EU the picture is rather different. The fact that 46% of people in the region are diagnosed late creates big concern.

4 Thematic reports are being released today and all other reports will be published in June. Preparations have started for a 2014 progress report providing a 10 year overview.

Furthermore, Teymur Noori presented the Monitoring Report on the EU Communication and Action Plan. The main question raised was: Are the Communication objectives being met? See **annex D** for the details. Below are some of the conclusions presented:

In relation to quality of life and access to treatment, ART coverage has increased, but not everyone is receiving it. Access to services varies from moderate to good for people using drugs in the EU, but not outside the EU. There is no good measure of programme coverage for MSM. HIV prevalence is high in some categories of sex workers. Many countries do not provide ART to undocumented migrants. There is an overall decline of HIV transmission, but an increase among MSM.

The main conclusion is that overall progress has been made but much remains to be done. The report includes several recommendations to improve implementation of the Communication and Action Plan.

Next steps: the report is with the Commission for clearance and will be distributed afterwards.

#### Actions:

- CSF CT: circulate ECDC 2012 Commission Communication monitoring reports to CSF mailing list when released
- CSF CT: circulate ECDC 2012 Dublin monitoring report to CSF mailing list when released
- CSF CT: utilise the conclusions and recommendations from the Commission Communication and Dublin monitoring reports as input for CSF agenda and development of new EU policy framework

# 6 EU HIV/AIDS Policy & Action plan beyond 2013: EC plans and CSF involvement

Paolo Guglielmetti explained that the Commission is currently preparing to conduct an external evaluation of the Communication. The evaluation should be completed before the end of 2013 and will inform on future needs and directions. At the time being, the Commission is considering different political tools to give continuity to the present Communication, getting to conclusion at the end of 2013: an Action Plan not supported by a Communication, a new Communication or a Recommendation. A decision will be made based

upon the outcomes of the on-going evaluation. See annex E for further details.

#### Discussion:

WHO has a problem with the strategic information on treatment coverage: it gives an overly optimistic perspective because of the different methodologies adopted by member states. ECDC recognises that many member states do not use the WHO methodology, but nevertheless cannot dispute the way member states capture the data.

Paolo Guglielmetti underlined that there is political leadership and commitment on the part of the Commission with the objective to identify follow-up mechanism to the current Commission Communication. At present the mechanism has not yet been defined but the process has started.

#### Actions:

- CSF delegation: meet with Commissioner Borg after CSF meeting to discuss future HIV policy and civil society engagement
- CSF CT: follow-up with DG SANCO to ensure pro-active involvement of CSF in the development of a new political framework to follow the current Commission Communication

# 7 HIV & Human Rights: CSF key advocacy messages to bring to the human rights conference

The CSF co-chairs introduced the agenda of the High-level meeting in order to identify together with CSF members key advocacy messages that members would intend to bring forward to the different sessions:

During the opening session: Luis Mendao will address the following key priorities:

- the EC to concretely commit on HIV;
- undocumented migrants to have sufficient access to treatment and care;
- prices to be reduced in line with countries' GDP and HIV prevalence.

# 7.1 Session 1- The right to health

- National funding for harm reduction in Eastern Europe to be scaled up and progress to be made to protect the right to health of people using drugs;
- The many legislative barriers to access services need to be removed;
- Access to treatment, sterile equipment, condoms in prisons to be fully implemented, also in Western Europe (court case in Lithuania).

## 7.2 Session 2 – Making laws right

- Criminalisation remains a key barrier to access
- Prohibition of OST, criminalisation of sex workers, anti-MSM propaganda laws, mandatory testing cause vulnerable groups to hide and prevent access to healthcare.

## 7.3 Session 3 – Living with HIV

- Self-stigma;
- Get evidence based examples of what really works in countering stigma and discrimination;
- Better protection and care for people using drugs and migrants;

- Awareness raising campaigns addressed to the general population to disseminate the TasP concepts: treated people are not infectious;
- Push for more awareness campaigns against stigma and discrimination;
- Structural and environmental factors and removal of obstacles and policies;
- Prevention is more cost effective than repression.

# 8 EU presidencies

## 8.1 Lithuania July – December 2013 - Svetlana Kulšis

HIV is no priority during EU presidency, however drug policy will be. The 1st big event will be the HIV Forum July 21-27th . In June a campaign will be launched to attract attention of national leaders on HIV and harm reduction issues; a call has been prepared to sign a letter for action (already signed by NGOs in Lithuania and neighbouring countries).

## 8.2 Greece January – June 2014 - Marianella Kloka

After many changes in Government, Greek NGOs need to see if the work with new faces in the Ministry of Health can be improved. Greece has no national plan on HIV. NGOs like to see a meeting taking place; they will refer to the outcomes WHO and ECDC have produced to convince the government to get HIV on the agenda of the Greek EU presidency.

# 8.3 Italy July – December 2014 - Lella Cosmaro

Recently Italy voted a new government, which has not made declarations of commitment for the EU Presidency Semester. NGOs are approaching the new Ministry of Health officials to ask for the organisation of an event on HIV during the EU presidency. At the time being many issues need redefinition and it is difficult to make long term plans.

#### 8.4 Latvia January – June 2015 - Ruta Kaupe

Latvia has a weak resource capacity and is presently facing a reduction in HIV specialists. It is premature to set priorities.

# 9 Updates by EMCDDA, WHO/Europe and UNAIDS

# 9.1 EMCDDA – Dagmar Hedrich

Dagmar Hedrich presented an update on EMCDDA's activities and publications, including the just released European Drug Report 2013, which was highly appreciated by the CSF members. See presentation in **annex F**. In July EMCDDA will organise, in collaboration with ISCTE, the second edition of European Summer School, entitled: 'Illicit drugs in Europe, supply, demand and public policies '. See for more information http://www.emcdda.europa.eu/news/2013/fs1

#### 9.2 WHO/Europe – Martin Donoghoe

Martin Donoghoe updated the CSF on WHO/Europe's activities:

- The new consolidated guidelines on HIV/AIDS treatment care will be released in July. The guidance reflects evidence of the benefits of early entry to treatment and aims to boost the impact on ART by broadening the ART availability. The big change consists of the newly recommended CD4 threshold for treatment, which will be raised to 500. In the European region the guidance will be rolled out with a focus on low and middle income countries in Eastern Europe and Central Asia;
- Release of the Global update on HIV. Highlight of the report is that globally the number of people on ART tripled in the last 5
  years to 9.4 million. The positive message of having 15 million on treatment by 2015 is realistic. There is progress in every
  region, including Europe. Key point is that Europe is staying behind the rest of the world, concerning treatment coverage;

- A new initiative of WHO regards the elimination of mother to child transmission and of genital syphilis. In October a regional technical consultation will take place in Kazakhstan;
- The 1st ever global WHO collaborating centre on harm reduction has been established in Lithuania.
- WHO is about to publish new estimates on viral hepatitis for all EU member states, with specific estimates for key populations (IDUs, MSM).

## 9.3 UNAIDS – Susan Timberlake / Henning Mikkelsen

Susan Timberlake announced the publication of several new documents: a new guidance on criminalisation of HIV transmission; a new handbook for judges is to be released in a couple of weeks as well as indicators measuring stigma in communities. Furthermore a new tool for measuring stigma in health care services will be finalised soon.

Henning Mikkelsen pointed out that ensuring that in 2015 15 million people have access to treatment means that 5.6 million are still without treatment. They are the difficult ones: not easy to reach, discriminated key populations. We have to make sure they are included as well in treatment initiatives.

# 10 Any Other Business

Chris Lambrechts suggests to invite the HIVERA network (collaboration on HIV research across European borders) to give a presentation at the next CSF meeting.

## 11 Action list

What	Who	When
Circulate ECDC 2012 Commission Communication monitoring reports to CSF mailing list when released	CSF CT	When published
Circulate ECDC 2012 Dublin monitoring report to CSF mailing list when released	CSF CT	When published
Utilise the conclusions and recommendations from the Commission Communication and Dublin monitoring reports as input for CSF agenda and development of new EU policy framework	CSF CT	On-going
Meet with Commissioner Borg after CSF meeting to discuss future HIV policy and civil society engagement	CSF delegation	May 27
Follow-up with DG SANCO to ensure pro-active involvement of CSF in the development of a new political framework to follow the current Commission Communication	CSF CT	On-going

## 12 List of annexes

- Annex A: Participants list of the XVII-th CSF
- Annex B: Commission Update
- Annex C: Human Rights Protection of PLHIV in Ukraine
- Annex D: ECDC Update on Dublin Declaration and Commission Communication
- Annex E: EU HIV/AIDS Policy and Action Plan beyond 2013
- Annex F: EMCDDA Update