

# Report of the first HIV/AIDS Civil Society Forum

Brussels, September 5 & 6, 2005

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



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## Introduction

The HIV/AIDS Civil Society Forum has been established by the Commission as an informal working group to facilitate the participation of non-governmental organisations, including those representing people living with HIV/AIDS, in policy development and implementation and in information exchange activities. The Forum includes 30 organisations from all over Europe representing different fields of activity (See annex A for list of organisations). The Forum acts as an informal advisory body to the European Think Tank on HIV/AIDS. In this first meeting, Forum attendants reviewed the second draft Communication on HIV/AIDS in the EU and Neighbourhood (see annex B) and provided substantial input for the final version.

## Report of the meeting on Monday September 5

Agenda: review of 2nd draft Commission Communication on Combating HIV/AIDS within the European Union and in the Neighbouring Countries, 2006-2009.

### General remarks

- Include attention to the diversity of the epidemic and the differences between old and new member states. Do not collate data.
- Include attention to co-infection with other STIs and Hepatitis B and C.
- Include a specific paragraph on human rights.
- Mention all affected groups: MSM, migrants and national minorities, sex workers, trafficked women, Roma and Sinti, prisoners, drug users, PLWHA.
- Include a sound monitoring and evaluation system with concrete measurable indicators.
- Mention NGOs as (main) actors in the action plan, when relevant.
- The linkage between prevention and care should be made in the document.
- Pay attention to the nexus between social exclusion, poverty and HIV/AIDS.
- Develop a social framework for reducing vulnerability and risk.
- Include positive prevention for PLWHA.
- Include the GIPA principle throughout the document.

## 1. Leadership and advocacy

*Text:*

- Separate the aim on leadership and on human rights. New aim: to promote strong and accountable leadership at all levels.
- EC, as pro-active leader in this field, has to make serious effort to include attention to HIV/AIDS on the agenda of all EU and international important meetings, particularly in contacts with neighbouring countries. In doing so, it should strongly support evidence-based approaches like harm reduction.
- The EC should also promote active leadership at the national levels on tackling HIV/AIDS.
- The EC should enforce that all member states develop national HIV/AIDS plans.
- The EC should be a more active leader in negotiating prices for ARV.

*Action plan:*

- The EC should seriously consider if a European conference is needed, taking into consideration that many events are already taking place and that it could be more useful to add-on and link to these initiatives.
- The EC should be involved (possible as co-sponsor) in the Eastern European HIV/AIDS Conference in Russia in May 2006 and the International Conference on Harm Reduction in Poland in 2007.

## 2. Human rights and stigmatisation

*Text:*

- A paragraph should be added on human rights and stigmatisation.

- Aim: to promote human rights and tackle stigma and discrimination.
- This paragraph should include the following recommendations made at the Informal Consultation on HIV/AIDS last June 13 on what the EC should do:
- Include the human rights for PLWHA in all its anti-discrimination regulations. The EU has a special responsibility in antidiscrimination regulations in general.
- Guarantee free movement of labour and people, including PLWHA. This should exclude travel restrictions and mandatory testing for PLWHA.
- Expand its guidelines for data protection and patient-privacy to PLWHA. The EU should develop guidelines for surveillance which guarantee that no individual information on a patient is needed. The data used can be anonymous.
- Put human rights of PLWHA on the agenda whenever possible in the international arena, specifically in contact with Russia. Human rights should be part of all political declarations.
- Support in very practical ways training on the issue of human rights for new members of the EU and neighbouring countries. These should include the human rights of PLWHA.
- Hold a survey every few years to monitor HIV, health and equality issues. This is important in order to have a clear view on what is going on in the countries and to adjust policy to it.
- In addition, the EC should include monitoring of criminalisation of PLWHA.
- The document should redefine a framework of equality and human rights.
- The EC fundamental rights agency (correct name?) should also monitor human rights in relation to HIV/AIDS.
- EC action is needed on guaranteeing access to insurance for PLWHA.

### **3. Involvement of civil society**

#### *Text:*

- Specify the broad definition of 'civil society', since in itself it is not enough to guarantee that CBOs and service providers are recognised and involved.
- Stress the equality in the partnership between the EC and civil society: partnership is more than involvement.

#### *Action plan:*

- In national action plans on HIV/AIDS, the EC should request member states to indicate how NGOs will be involved and how they will be financed.
- Instead of action number 2 (training for NGOs on ARV), include a mapping exercise at the national levels on NGO needs. Based on a need assessment, the EC can define what kind of training is needed.
- Consider training for policy-makers on how to involve NGOs as real partners.

## 4. Surveillance

### Text:

- There is a need for surveillance of other STIs and Hepatitis B and C.
- Mention that all testing and surveillance should be anonymous, voluntary and never mandatory.
- There is a need for monitoring of AIDS-related causes of death.
- Strengthen second generation surveillance.
- Develop a system to link all initiatives in the field of surveillance.
- Before national and European surveillance data are published, NGOs should be involved in the final review to ensure that accurate data are used.

### Action plan:

- NGOs have to be included among the main actors for action 5, 6 and 7.

## 5. Prevention of new infection

### Text:

- Aim number 2 should be rephrased as follows: Ensuring that all men and women, especially youth, have access to education, and services necessary to develop life skills required to reducing their vulnerability.
- Aim number 3 should be rephrased as follows: Scaling up access for injecting drug users to prevention, education, substitution treatment and harm reduction services in the community and prison settings.
- Aim number 4 should be rephrased as follows: Addressing the specific needs and requirements of migrants and national minorities, MSM, sex workers, trafficked women, Roma and Sinti, prisoners, drug users & HIV-positive people in terms of non-discriminating access to information, prevention, treatment, care and support and ensuring quality services.
- Aim number 5 should be rephrased as follows: Supporting the evaluation of preventive methods and evidence based approaches.
- Add an extra aim on monitoring of coverage of services for vulnerable populations.
- Add an extra aim on access to prevention of vertical transmission.
- All the different groups affected should be mentioned in the text (see list in aim 4).
- Describe what prevention is and should entail: gender-sensitive, evidence-based, non-coercive, non-moralistic, including positive prevention.
- The EC should clearly express a European vision on prevention at international events.
- 5.3.2: rephrase last phrase: Special emphasis should be given to improving access of IDUs to public health services *in community and prison settings*, as well as to the legalisation *and scale-up* of substitution treatment for drug users in Europe.
- Mention a need for developing new prevention options and technologies.
- A number of data are incorrect, so check the last data, for example on syphilis and Chlamydia.

### Action plan:

- Involve the Civil Society Forum and NGOs in the development of the EU Campaign.
- There is a need for specific campaigns for specific groups.
- The plan for peer education should target specific groups and NGOs should be involved in the development of this activity.
- Follow the results of the pilot on heroin maintenance programs (pilot in Switzerland).

## Report of the meeting on Tuesday September 6

Agenda: continuation of review of 2nd draft Commission Communication on Combating HIV/AIDS within the European Union and in the Neighbouring Countries, 2006-2009.

### General remarks

- Language: intravenous drug users should become injecting drug users all through the document. Also, attention should be made to judgmental terms (such as illicit drug use)
- A section dedicated to harm reduction should be added
- A paragraph on reproductive health should be added
- The term vulnerability should be defined and applied through the document. All vulnerable groups should be referred to in the document (MSM, prison inmates, poor persons, drug

users, migrants and geographic minorities, homeless people and street kids, ROMA, people living with HIV and AIDS

- A section on human rights and patient rights should be added
- The introduction should better explain the aim of the document and to whom it is addressed
- A section on partnership with NGOs should be added
- A short explanation is needed (probably in annex) on inter DG collaboration on HIV, mapping of services, and guidelines to funding programs
- A section should be dedicated to the implementation of the policy document, follow up, monitoring and evaluation
- More transparency and clarity are needed regarding past commission's activities
- All chapters should contain clear commitments and action plans

## **6. Testing, treatment, care and support**

### General remarks

- As the title of the chapter includes testing, a paragraph on VCT (Voluntary Counselling and Testing) should be added.
- As the title also mentions care and support, the text should refer to care and support services
- It should be clear that comprehensive treatment and care is not limited to provision of ARVs. This applies to both the text in the introduction (page 11) and to section 5.4.4. – access to affordable ARVs.
- Add paragraph on prevention of co-infections and on treatment of HIV+ patients co-infected with TB, HCV or HBV
- Scale up of access to treatment may be necessary within the frame of a specific program.
- Discuss the promotion of a European standard of care, comprehensive of care, treatment and quality of services, and the dissemination of best practices.
- Add a section on drug substitution therapy as a necessary mean to scaling up access to and retention in treatment of injecting drug users.
- Resistance section. Add monitoring of Therapeutic Drug Concentrations (TDC) as a major component of developing resistance
- Add a section on reproductive health: Proposed text: "Most individuals affected by HIV are at child bearing age. Comprehensive reproductive care is a cornerstone of prevention and an important component of quality of life. Reproductive care includes: informative, non judgmental reproductive counselling, affordable sperm washing programs, free and voluntary access to safe abortion, and optimal treatment of HIV infection in pregnancy."

### Access to treatment of vulnerable groups

- The document should speak of access to comprehensive care. Treatment is broader than ARVs – it is a comprehensive care package: treatment of opportunistic infections, adverse events, co-infections, and substitution therapy as treatment scale up
- MSM, sex workers and migrants should be included among the vulnerable groups.
- The list of vulnerable groups should be changed as youth are not the most vulnerable group in relation to treatment.
- Drug substitution therapy should be mentioned as a necessary mean to scale up access to treatment in injecting drug users.
- Mention that treatment access should be done in non discriminating ways. For example, in some member states HIV+ prison inmates are segregated from the rest.

Action plan: Mapping of access to HIV treatment among injecting drug users and prison inmates

### Providing gender sensitive support .....

- Information should be available on availability and accessibility of HIV treatment
- In the title Adherence to ARVs should be changed to Treatment preparedness
- The issue of gender should be mentioned in the text and not in the title
- Concerns of "men and women and people living with HIV" should read "all individuals living with HIV"

- “Counselling and support for better adherence” should read “treatment counselling and support”
- Availability and accessibility of treatment.

#### Planning of services

- A section on implementation, follow up and monitoring should be added
- Text should be reflected in Action Plan.
- Measures to ensure sustainability of services should be added.
- There should be mention of the accessibility of services in terms of respect and dignity to people in the services
- Last paragraph: why is follow up of children born to HIV positive mothers important? If they are HIV positive they are followed up in the paediatric networks. If they are HIV negative, they are healthy.

#### Facilitating the access to affordable ARVs

- Title should read: “affordable HIV treatments”, these include treatment of OIs which, importantly, are not always reimbursed.
- Support for NGOs, because they are the link between the medical facilities and hard to reach populations.
- The role and leadership of the EU in price negotiations should be mentioned.

## **7. Research**

#### General remarks

- There should be a mentioning of the way results of the research program be transmitted to various figures, such as member states and policy makers.
- There should be a clear mentioning of the public health research program.

#### Aims

- There is no connection between the aims list and the text (i.e. no mention of public health research)
- Aim 3: research need to be driven not only by public health, but also by patient needs (the concept of community driven research)
- Aim 4: behavioural preventive methods are a too narrow definition. Instead there should be reference to the entire vast area of social, psychosocial, environmental and legal research

#### Recommendations for items under the heading of public health research:

- Treatment effects on risk behaviour
- Mortality causes
- Co infections: epidemiology, natural history, treatment
- European comparative research: evaluation of what is implemented in the different European countries, equality in access to care in Europe
- Research on harm reduction – novel compounds for drug substitution therapies, pharmacological interactions between antiretrovirals and street drugs etc.
- Legal research: travel restrictions and criminalization of HIV transmission in Europe
- Social research: vulnerability factors,

## **8. Neighbourhood**

Political commitments should be stated clearly, not as a coercive measure, but as possibilities to explore in agreement of the respective partners.

#### The Russian Federation

#### Text

Introduction should refer to existing problems, including insufficient treatment coverage, no access to harm reduction, violations of human rights.

#### Actions

- Add political leadership and technical assistance with evidence based methods
- Transparency on past activities (Kyprianu meeting) and future activities
- Mention the development of civil society infrastructure
- Mention Aid to regional collaboration
- Areas of action (if possible): harm reduction, prevention and care for prison inmates, control of HIV/TB co-infections, development of support mechanisms for PLWHA, fighting discrimination

#### Countries under the European Neighbourhood Policy

#### Text

- Refer to problems existing in the countries (i.e. no substitution therapy, discrimination of prisoners and children with HIV).
- Provide follow up on past activities

#### Actions

- The tone should be more proactive, not just invite countries to participate but to initiate discussion and show political leadership. Some countries would welcome an intervention.
- Enlarge the geographic scope of ENP, pursue agreements with more countries – Balkans, Central Asia

#### **Comment on surveillance**

The document mentions the EU intention to enlarge the scope of the HIV surveillance network to Russia and ENP countries. In some of these countries ethics and respect human rights and data confidentiality are dangerously lacking. There should be a CLEAR reference on how the EU can ensure that community investment is not used unethically. If such guarantees are not possible, it is advisable that the commission postpone or cancel the inclusion of such countries in the surveillance network.

See proposes changes to the Communication action plan in Annex C.

*This report was prepared by Lital Hollander from European AIDS Treatment Group and Martine de Schutter from AIDS Action Europe.  
Amsterdam, January 2006*