The EU HIV/AIDS Civil Society Forum

Report of the 7th EU HIV/AIDS Civil Society Forum
Brussels, April 8-9 2008
Meeting convened by the European Commission Health & Consumer Protection Directorate-General with co-chairing of AIDS Action Europe and the European AIDS Treatment Group

Contents

Introduction

The HIV/AIDS Civil Society Forum (CSF) has been established by the 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. See annex A for the participant list of this meeting. 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. This meeting of the CSF focused on new Swiss counselling guidelines on infectiousness and condom use, financing of AIDS programmes in the Eastern region and priorities of the CSF, among others.

1 Opening

Opening of the meeting by Nikos Dedes; introduction of the members of the CSF; adoption of the preliminary agenda by the participants.

2 Reports from last meeting

The report of the last meeting was adopted. It was stated that future reports should get distributed earlier.

3 Follow up on action list last CSF meeting

Task	Responsibility, Status
(Re)circulate reports of previous CSF meetings	Done.
(Re)send European action plan and communication paper to CSF	Pending. Wolfgang
Send out draft monitoring report Dublin declaration to CSF	Jeff Lazarus stated that the draft report was circulated some weeks ago. The final version will be finalized next week.
Follow up with letter about issues raised by commissioner Kyprianou	Pending. Nikos proposed that we draft a letter to the new commissioner, since Mr. Kyprianou left the position, Wolfgang should start a collaboration with the new person
Draft letter on awareness campaign to ministries of all countries represented in the CSF	?
Ask KNTG about agenda TB community	Pending. will be a topic for the next meeting of the CSF
Distribute report on positive prevention to CSF	Done.
Check with ECDC whether undocumented people are included in European Action Plan	Pending. Wolfgang will check this with ECDC
ARV affordability – making follow up (based on feedback from the TT)	Nikos (to put suggestions forward and facilitate follow up)

	Nikos says that the German Government did not get back to the CSF and this should be put on the agenda.
Follow up on migration recommendations – dissemination of materials and submission of draft action plan (suggested by the initiative's steering committee)	Done: recommendations had been sent to all EU 53 ministries of health (Peter, EATG secretariat); A task team will be created to strategize future steps.
Follow up with Slovenia's EU Presidency regarding possibility to organize a meeting on MSM	Will be put on the agenda (Jeff Lazarus)
Disseminate report of the European seminar on legislation and judicial systems in relation to HIV	Pending; NAT representative (Eleonora or Yusef);
CSF to receive draft recommendation for the follow up after the European seminar on legislation and judicial systems in relation to HIV	Pending; Yusef
Disseminate report of the European seminar on gay health	Done
Disseminate reports of the UNAIDS consultation on criminalization	Pending: The CSF expressed that the circulation of the report would be useful.
Follow up with the Commission regarding timing and further process of the Council's draft recommendation on prison and drugs	Raminta; ongoing
Circulating the list of CSF members, their representatives, emails and field of interest	Done. Othoman says that he not get the mails from the mailing list
Spreading information about CSF	Ongoing
Dissemination to the CSF its mission statement	0ngoing
Preparing proposal regarding the CSF action plan and its linkage with the Commission's Action Plan	CSF representatives in TT the action plan should get circulated will be discussed during the meeting
Proposing one or two hotels for the CSF to stay during the next meeting	Pending, this is more difficult than expected; hotels are expensive and should be booked well beforehand, CSF members are requested to send information about their hotels to the mailing list
Sharing the GF briefing papers on TB	Pending. Mick (needs to be reminded)

4 New Swiss Counselling Guidelines on infectiousness and condom use under various circumstances

Presentation by Daniel Bruttin, Director of the Swiss Aids Federation (see annex B), followed by a discussion. Daniel introduced the Swiss National AIDS Commission (EKAF); explained the composure of the body (mostly physicians, few PLWHA), and its tasks (advice to governments; development of guidelines, etc.). Latest example of the work of this body is the guidelines on HIV transmission and viral load, published under the title: “HIV-positive individuals without additional sexually transmitted diseases (STD) and on effective anti-retroviral therapy are sexually non-infectious. “ Core message of the guidelines is, that HIV+ individuals with suppressed viremia are not infectious, if the following criteria are fulfilled: The HIV-infected individual complies with the anti-retroviral therapy (ART), the effects of which must be evaluated regularly by the treating physician; The viral load (VL) has been non-detectable since at least six months (i.e. viremia is suppressed); There are no additional sexually transmitted diseases (STD) present.”

Daniel explained that the paper wouldn’t change prevention messages; the main concern of the paper relates to the specific needs of serodiscortant couples, wishing to have a child (and not about prevention messages for other populations). The EKAF produced the guidelines in order to stop conflicting counselling messages by physicians and to stop criminalization. The EKAF did not talk to other stakeholders before it published the paper, this might have been a big mistake.

Daniel outlined the problems with the paper from the perspective of the Swiss AIDS Federation: Physicians have to do the counselling, this is difficult, it might be challenging for some physicians to talk about sexual relations; counselling should be delivered by trained personnel; the guidelines say that the HIV negative partner takes the decision, the Swiss AIDS Federation opposes that and beliefs that the decision has to be taken by both partners. Daniel informed about steps already taken (satellite symposium in Berlin) and future steps:

June 2008; closed symposium with at UNAIDS/Geneva (Daniel and Dennis Haveaux will follow up whether there are any possibilities for participation of CSF members)

Sunday, 03. August 2008; Satellite symposium during the IAC in Mexico City.

A vivid discussion took place after the presentation. An overview on first reactions clearly demonstrates a wide variety of reactions - there is certainly no consensus among the members of the CSF, the paper opens a door to many other questions:

- Reading the paper was a thrilling experience, this is important; in our country we made conservative statements about the “ifs” and “buts”. (Denmark)
- How does the paper refer to gay populations? (France)
- The paper produced some outrage among physicians; we very much welcome the discussion but the way the paper was produced and published was not very helpful. (Belgium)
- Some physicians were enthusiastic; the administrations did so far not answer to queries. (Poland)
- The media did not speak about the issue, we did not know whether we should come up with our own statement, it’s still too early, there are no information about anal sex, what are the criteria of good treatment in our country? At the end we’ve been against the Swiss statement. (Morocco)
- More information about these issues is needed. AIDS Action Europe collects all relevant information at the Clearinghouse. (http://www.aidsactioneurope.org/index.php?id=55&tx_ttnews[pointer]=1&tx_ttnews[tt_news]=238&tx_ttnews[backPid]=97&cHash=49dfc333bd)

- The guidelines are good news for counsellors and PLWHA alike. We now have a paper to refer to. The message will reduce double standards in counselling; the paper sends a strong message towards normalization of HIV, at the end of the day it will reduce stigma and discrimination, since exaggerated fear of infectiousness is a big source of discrimination of PLWHA nowadays face, for example at work places. (EATG/Germany)
- A proper process would have been good but we have to admit, that this would have lasted for years. We still have doubts since it's difficult to manage correct information delivery by the media. Yet, we should always fight for the truth and for scientific evidence; let's not destroy the message delivered by the messenger. We need that information and we have to move forward. We need scientific knowledge. We must take this into account in public health strategies, promote early access to treatment and we need to do more about primary infection. (Portugal)
- We did send out a press release but no newspaper wanted to adopt it. The paper needs more discussion. Not to release this information is problematic. 85% of HIV+ person in our country have undetectable viral load. (Sweden)
- The message hit the first page of the main paper newspaper but was received with silence; no further discussion in the media. (Denmark)
- We will publish a short statement within the next 2-3 weeks, stating that the EATG welcomes a public debate and announcing a satellite that will take place during the Glasgow conference in autumn. There is no consensus about the guidelines in our organization. (EATG)
- We followed with a conservative statement in the beginning. We had discussions with key organizations in our countries. We have to define what can be answered and not. We have to admit, that the statement does already have its impact on the practice of counselling from physicians. (Netherlands)
- The paper refers to practices that already take place. It forces a debate on sexual health and matters, which is a taboo in many countries. We will come up with an official statement together with the government; difficult discussions are taking place; the Swiss paper entails great news for all HIV+ people. (Germany)
- The messages should get coordinated: sexual relationships without condoms addressed at a QOL issue can be counterproductive and damage other safer sex practices. (TAMPEP)
- The paper took us by surprise, we needed time to respond. This was, so far, the event of the year. (WHO Europe)

Some open questions and remarks were formulated during the discussion:
Switzerland does have rather ideal conditions that might not correspond to places in other regions.
The paper does not distinguish between MSM and hetero sex, why? There might be a higher frequency of anal sex between MSM.

- There are open questions about the core elements of the statements (correlation of viral load in blood and semen).
- Ton emphasized the need to distinguish between the political arguments and the evidence, there is no website where this information is available; for the quality of the debate we should put this information together. The AAE Clearinghouse could fill this gap.
- The guidelines relate to persons in stable relationships: what is the definition of a stable relationship? What does this mean for real-life scenarios?

- We have to balance the messages to be sent to HIV+ people. We have to discuss how to move forward. A roadmap should be developed: what is happening where?
- Data among MSM in Denmark indicate that 35% had unsafe sex with partners without knowledge of HIV status. Low infectiousness will have its impact on the community; there will be fewer stigmas, but in terms of prevention we don't know much about that.
- Communication of primary infection symptoms needs to be added in work plan and capacity building.
- Daniel Bruttin mentioned a list of open questions from Canadian advocates/activists that had been sent to the Swiss AIDS Federation. He will share the questions with the group.

5 Financing of AIDS programs and NGOs in the Eastern region

Wolfgang informed the group about financing mechanisms of some specific AIDS programs at EU level, especially the Public Health Action Program: certain funds are available for core funding for NGOs. Money is available, the call is still open. Structural funds are negotiated between governments and commission. The presentation was followed by a discussion about the Global Fund funding criteria and possibilities to create new mechanisms to guarantee funding for programs that will not survive due to the changes of the GF criteria. Arnaud pointed out how substantial the donation of the EC to the GF is. This commitment should be increased. 22 countries in the EU region benefited from these funds. Yet, a fast growing number of countries will not be applicable for the GF money, because the criteria are becoming stricter. Ton asked whether there is an EU strategy to have the GF soften their criteria. He points out that Global Fund will very likely not move; to change the GF might not be very realistic: what we need is an alternative EU mechanism; there is a serious political problem in Europe unless this is solved. Is the EU trying to find a new mechanism?

Nikos reminds the group that many of the G8 countries are EU member states. The commission does have negotiation power. A parallel funding mechanism has to be established. Either the commission negotiates the criteria or installs a new mechanism. Nikos mentioned the "Interservice Group on HIV/AIDS", where different bodies within the EU can talk to each other. Ton pointed out, that this body should have a broader representation within the CSF.

Wolfgang reminds the participants that this discussion is about policy that goes beyond EU countries. The right person to get in contact about this would be the new Commissioner. The Interservice Group on HIV/AIDS is an internal body; it is not known whether the group had dealt with these issues so far. He agreed that the communication to the Interservice Group on HIV/AIDS should get strengthened and assured that he will take the concerns of the CSF to the group.

Corinne and Raminta repeated that more funding is needed. Either the funding criteria should change or the focus should be on direct funding. DG Sanco should put pressure on the commission. There should be an effort from the commission to start new mechanisms for funding, especially for community funding for services, advocacy etc.

6 Update on implementation of EU-Action Plan

Wolfgang did not give a formal presentation about the implementation of the EU Action plan; there is a need to get first the Commissioners opinion on the renewal of the new action plan, since it will be under the Commissioners mandate. There wasn't much activity, due to the change in office, but there will certainly be some work done during the next few weeks.

The new commissioner, Ms. Asigniou, will very soon be appointed by the EU parliament. Wolfgang announced that she is going to attend the EECAAC in Moscow in May, where she is supposed to deliver a speech during the opening session of the conference. Currently, there are uncertainties and it will take some weeks to find out what the plan is. Wolfgang is sure that there will be a reference to the action plan during the conference. He assured us that a table with comments from the CSF will be forwarded to the new commissioner as soon as appropriate, very likely by mid-May.
Wolfgang says that the format of the new EU policy on HIV/AIDS has not been defined. This work should be done by the new Commissioner. A review process will address lack of achievements, decisions need to get taken decide, where and how to follow up.
Raminta expresses her gratitude that the Commissioner will come to Moscow and offers to help deliver input for briefing papers. Local NGOs would very much like to have a meeting with the Commissioner.
Wolfgang assured that he would come back to us on that.
Wim raises the question whether it's possible to have an endorsement of the current action plan by the new commissioner?
Wolfgang says that we are free to do what we want but emphasized to put this on hold for a couple of weeks. It's now a moment to get the commissioner well prepared the Moscow Conference. It would not to be wise to do this right now. Wolfgang promises to keep the CSF updated on new developments.
Ton points out that we should start to communicate by sending a welcome letter.
Luis says that the action plan is an approved, official document; it would be not acceptable to put it on hold.
Wolfgang reminds in reply that the discussion is about priorities for future developments of the action plan.

7 Health Programme 2008-2013

Presentation by Cinthia Menel-Lemos from the Public Health Executive Agency (PHEA) (see annex C) on the second program of the Community Action in Public Health.
The three main objectives of the program are:

- Improve citizen's health security
- Promote health
- Generate and disseminate health information

Participants in the program are EU member States; EFTA and EEA countries; cross border and neighbouring countries, candidate and accession countries.
The program is implemented by the annual work plan of the commission; supervised by a program committee with help by an executive agency (PHEA). The overall budget is € 46.365.000.
The 2008 work program has a new structure, consisting of call for proposals for projects, call for tenders, joint action with member states, operating grants and conference grants.
Grant may be given to public or private bodies
Deadline for proposal submission: 23.05.2008
Peer review evaluation: 09-20.06. 2008 (participation most welcome)
Evaluation committee meeting: 03-04.07.2008
Program committee: 21-25.07.2008
NGOs that are applying have to prove that they are independent from industry. The aim is to support NGOs that are active in public health at EU level; this should of course always be consistent with EU policy. One public health conference for each presidency can get financed.
Further information is available under:
Public Health Portal: http://health.europa.eu

SANCO Web Site: http://ec.europa.eu/health
PHEA Website: http://ec.europa.eu/phea

Discussion:
Chris raises the issue that regulations and formalities are a big concern for NGOs. How come that so many NGOs fail in the process to deliver project proposals? What are the main problems?
Cinthia: mean average score for NGOs is lower than academic etc. Scientific writing is not as good (10% less); the Commission is aware of the problem and is currently developing training for the submission of applications, this will specifically target NGOs and organisations with low participation or success rate.
Nikos raises the questions whether an assessment on the projects is submitted: what are effects and results of the projects?
Cinthia says that to measure the effectiveness of programs is difficult. In the past there were only processor output indicators but not impact indicators. The Commission would like to set these indicators, and this is stressed during the negotiation of the project.
To ensure better participation of NGOs, one solution would be to involve different actors, and interchange expertise between the different actors, they should work together.
Martine raises the question about the specific conditions for the exceptional 80% co-funding by the Commission. The problem is that the Commission does not accept already existing co-funding as such.
Cinthia: the conditions for exceptional co-funding are outlined under 3.1. Different sources for co-funding can be allocated, but funding has to start right when you start the program, this cannot be done retrospectively. The sources of external funding should be identified during the submission phase and be confirmed when the organisation receives the invitation to negotiate the grant.
Wim wants to know what independence from industry means and whether organizations with some funds from industry can apply?
Cinthia says that NGOs are recommended to sign the ("WHO Charter") declaration of independence; the Commission will check whether the NGO has signed this declaration, and when there are documents which can be consulted in the organisation websites that state their independency. The percentage possible for funding of pharmaceutical Industry is not defined.
Othoman raises the question about the eligibility criteria for North African Countries?
Cinthia says that the eligibility criteria is based on the existence of an agreement between the countries and the EU, and that for non EU countries to have benefit from an application, they could only be involved as collaborating partner. .
Jacob wants to know, whether there are still problems to the handing out of money to NGOs?
Cinthia says that the first money will be received 45 days after the signature of the contract. Again, money has to get applied within 45 days after the submission of the interim report (one year); only at the end we have the balance: when there is proof that the money has been spend according to the grant agreement criteria of eligible costs.

8 Dublin Declaration / ECDC Migrants health report

Teymoor Noori from the European Centre for disease prevention and Control (ECDC) outlined in her presentation (see annex D) the components of the ECDC migrants and infectious disease report.
Important steps towards the call for this report was the Portuguese Presidencies commitment on migrant issues, the conclusion on the European conference on Health and Migration, the Commissioners speech at the Lisbon Conference and the Council Conclusions from December 5 and 6, 2007. The report will be embedded into a monitoring framework and the Dublin Declarations areas of action (33 actions divided into 5 areas). One of the guiding principles will be to make use of the already existing indicators

developed in the reports for UNGASS, EU Action Plan; EMCDDA; the framework currently already consists 60 indicators.

Discussion:
Arnaud raises the question about a report on countries in Central Asia (Scope of the Dublin Declaration covers EU 27 + 3 and Central Asia)?
Teymoor says that this was discussed with Mr. Huebel from the Commission. The commission was pretty clear that we don't have a mandate covering this.
Jeff Lazarus reminds us that there are other agencies that might be interested to do this, if the mandate of the ECDC only covers 27 countries.
Teymoor says that the Commission requested to create a framework, the ECDC wants to have input from CS and UNAIDS.
Ton says that tremendous work on migrant issues has been done by the community. It would be good to include relevant people from the community.
Teymoor requests us to speak with Susanna Jakab in order to clarify possible role collaboration. This isn't the end of the process
Jeff Lazarus informs the group of a meeting between ECDC and WHO about the creation of a database / surveillance systems. The meeting will take place on the 17 April; there are still some issues to be discussed.
Yusef points out that the responsibility of monitoring lies on the member states and that would be very useful to have guidance to the member states. There are right and wrong ways to do the monitoring.
Yusef wants to have a discussion, that monitoring is not only the subject for bodies like ECDC.
Raminta congratulates the participants on the joint initiative between ECDC and WHO EURO and draws a line between UNGASS and Dublin. There are specific issues that are not covered at the UNGASS reports; migrants are not reported in UNGASS, other neglected groups are prisoners (who inject drugs). It would be very important to consider the additional value of these indicators. What we want is qualitative data, and not only quantitative data.

9 Brief report from ECDC consultation in Stockholm

Jacob briefly reported from an ECDC consultation that took place in Stockholm. The ECDC had set out indicators for MSM. Results of most recent studies are incorporated. Aim of the meeting was to develop indicators to monitor MSM (number of male partners; incidence of anal intercourse, testing behavior etc.).

10 Any other business - Important events and meetings

26-27 May 2008 informal global consultation on MSM in Slovenia (WHO-EURO).
Around 30 people will be invited to attend this meeting. The agenda is not finalized; representatives from the Government of Slovenia will be there, including representatives from international bodies, like UNAIDS, WHO etc. Aim of the small meeting is to bring stakeholders together. Questions to be discussed will very likely be:
Why is national data on MSM relatively so poor?
What goes on in different regions (epidemiology/MSM)?
Information exchange: what are other stakeholders/countries doing?
Development of next steps (develop agenda for a meeting/consultation that might take place during the French presidency)
28 May 2008 NGO meeting in Slovenia
Arnaud informs us that a meeting dedicated on NGO participation will take on the day following the informal consultation on MSM.
01-02 August 2008, meeting on MSM, IAS Mexico City

Ton informed us about a meeting on MSM in Mexico City; the meeting will take place on Friday or Saturday prior to the Mexico Conference.

Quality Assurance in HIV/AIDS Prevention in Europe
Organized by the German BzgA together with WHO Europe. This meeting takes place October 22-24 in Berlin. It is by invitation only. Martine will give further input, since she will attend a meeting next Monday, where more information will be available. Martine will lobby for involvement/invitations to the CSF.
UNAIDS Program Community Board Meeting
Licia informed us about the upcoming UNAIDS Program Community Board Meeting that takes place in Thailand, April 24-25, 2008. The CSF discussed whether the CSF should send a letter with support for the recommendations, that are included in the community report and the arguments mentioned there. The war on drugs in Thailand did cost many people's life, what can the CSF realistically do, since the board was not shifted to a place where the rights of drug users are respected?
It was decided to send a letter to the PCB members with some explanations about the European approach towards drug users, in respect of their fundamental rights, questioning as well the place for this particular meeting.
Vitaly should get asked to propose a draft letter. Raminta will get in contact ASAP. If we have the letter for the CSF on the second day of CSF meeting we can ask the signatories from the organizations present at the meeting.

11 Travel restrictions

The international task team on HIV travel restrictions has its first meeting in February. UNAIDS is involved. Andreas will circulate the minutes. Peter is a member of the task team and is participating with the working group on long term travel restrictions. The database created is a strong advocacy tool. There will be a satellite session and maybe a plenary at the Mexico IAC. A satellite is also organised at EECAAC. Recommendations will be available in July; then an open advocacy group will be created. UNAIDS will finance the database and data collection. The results will be discussed at the CSF.

12 Community recommendations for migrants

Rhon informed that several CSF members met to discuss how the Community recommendations for migrants were used by different countries. The recommendations are now only available on the EATG website, without opportunity for NGOs to endorse. There is a need for a taskforce to monitor the recommendations. There is no up-to-date knowledge about policies on universal access for migrants in Europe. AIDS & Mobility will be contacted. The Public Health Executive Agency (PHEA) is setting up a web-based database where information from different projects is collected, migration and HIV are topics included. There will be a matrix analysis for synergies and gaps for all migrant projects (11 funded). PHEA will send a reference on a new regulation of asylum seekers and refugees right to health. Wolfgang explains that treatment or health care is pure member states competence. Emergency funds are available, but for special situations only. It would be useful to have a clear view on what a universal access commitment should look like. Slovenia is preparing a statement on universal access for UNGASS, as EU presidency. EPHA (European Public Health Association) will hold late May in Sweden conference on health and migration. In conclusion, the topic is considered a priority. A working group will be formed. Rhon is prime contact.

13 Priorities CSF

All CSF members have prepared a list of priorities in their countries, as well as for the CSF. See the details in annex E. The detailed report will be on the agenda of the next CSF, now the focus is on main issues.

13.1 National priorities

On the one hand there are quite some similarities between blocks of countries and regions. MSM, IDUs, migrants, universal access, human rights angle, pressure on services, money is being diminished.
Specific issues for countries: for Morocco the Trips issue.

13.2 CSF priorities

The results are quite similar to what members expect from the CSF and what the priorities should be.

Fight for universal access for prevention, treatment, care and support, especially for vulnerable groups

We need to make an inventory of what we know that allows/ensures universal access among these specific groups. We lack a common vision on how to translate experiences in concrete policies and programmes. We need to bring together NGOS and PLHIV, but also academic and public and international institutions. Look at good practice examples that really work, and invite them to CSF.
Look at pricing of treatment. An example: Second line treatment is as expensive as first line treatment 10 years ago. There is the issue of patents for new medication. CSF can make a statement about prices.
The German Ministry of Health identified 3 pilot countries for bilateral price negotiations. The EC can not interfere, has to do with internal market. But can advice on possibilities and use influence.
Migration issue: people being deported to countries where medication is not accessible. Look into treatment possibilities, report on it.
Pricing and affordability are issues, but also accessibility for different groups.
We should have pharmaceutical industries as a partner in the process, have them at the table. We should have meetings where civil society is included.
There is information available from WHO on lack of treatment for people that need it in our region.
We don't have enough research on vulnerable groups, especially in the EU neighbouring countries.
In conclusion, the CSF considers it a main priority to focus on vulnerable groups and pricing of ARVs. We should work more based on documentation available and identify what's lacking. A lot of information will become available with UNGASS and other meetings.
The CSF will focus on the broader Europe region of 54 countries and from that perspective we could make general remarks on what happens in rest of the world.
Two working groups are formed:
Universal access, focus on vulnerable groups: Rhon (lead), Peter, Luis P., Licia.
Universal access, focus on Pricing of drugs: Mirjam (lead), Wim, Othoman.

Give NGOs and PLHIV a voice in EU policy on HIV and related issues

We have intensive CSF meetings, but then go back to our work, in between meeting it has been proven difficult to follow-up. AIDS Action Europe's vision is that more could be done with the outcomes of these meetings. Policy is not only made within EU structures, but also in European parliament, by our country representatives in TT and at home. Perhaps we need press releases after every CSF, to send out to all Parliamentarians. CSF representatives should have contact with the TT representative of their country.

Maybe an informal meeting lunch in between CSF and TT meetings could be organised. AIDS Action Europe is searching for means to support the CSF better, and ensure better follow-up in between meetings. This should enable us to have more impact. EATG agrees this direction to take. The CSF Co-chairs will be helped much with the creation of the working groups.
Not all issues that affect PLHIV are under DG Sanco responsibility, many health issues, like in relation to migrants, are defined by other DGs. HIV doesn't seem to be on their agenda. How doe we get other DGs to pro-actively think about HIV? The DG Sanco inter-service group on HIV/AIDS was not active for over a year now. A meeting will be planned before summer, and this point will be on the agenda.
A key obstacle is that the EU policy is an action plan without a budget. How much effort do we want to spend in creating a new policy without a budget? We will not have a budget before 2013 when the next EU budget will be determined.
It might be helpful to get an extra day reimbursed for CSF meetings, to enable for exchanging and shaping the views of civil society.
We have to look into official linkage with the CSF on drug policies and the CSF of DG Trade.
In conclusion this issue will be taken up as priority. We should look into methods and funding on how to work better, link to other EU institutions and make better use of partners around the table, strengthen relations with NGOs at country and European level.
A working group on GIPA is formed: Andreas (lead), Henrik, Wojciech.

Strengthen human rights of PLHIV and most affected groups, including fighting discrimination and stigmatisation
If we don't break the circle around stigma and discrimination, we can't progress, we can't get people to test and get early treatment.
A working group on human rights, stigmatization and criminalisation is formed: Yusef (lead), Andreas, Corinne, Raminta.

Promote linking and learning and creating more financial support for NGOs
Does the CSF have a role in strengthening NGOs and capacity-building work? How does it relate to networks like AIDS Action Europe and EATG? We should not repeat their work. AIDS Action Europe should continue with technical meetings, whereas the CSF can put forward more the political messages. Should we focus more on civil society groups in Eastern Europe and Central Asia and the Mediterranean and their problems with lack of funding? The CSF should focus on the political issue related to this.
In conclusion the role of CSF should be to be advocate on the political level, to strengthen NGOs with special attention to Eastern Europe and Central Asia.
A working group on strengthening of NGOs in Eastern Europe is formed: Raminta (Lead), Arnaud, Luis P., Vlatko, Michal, Liliana, Igor, Michaella, Wojciech

Priorities in relation to the way we work
We should have a better prepared agenda with backgrounders, work more on strategic planning and be more operational and involve broader EU Parliament, Council etc. more in our work.
There are severe time, budget and capacity restrictions in the CSF ambitions. But the working groups could play a great role in preparing the backgrounders, formulate what CSF should do and prepare the discussion in the meeting.

14 Coming EU-presidencies

Slovenia presidency: will chair a WHO meeting on MSM. Arnaud has connected this to a Gay meeting for NGOs, as follow-up of the Gay Health seminar organised last year.
The coming 3 presidencies will not have HIV directly on the agenda, hopes are on Sweden only. We have to be realistic, not every Presidency can or should have HIV on agenda. Sometimes we need to make alliances if related topics are on the agenda, for example prisoner health. But when we look at the new EU action plan, that might be good moment to have HIV on the agenda. Can the CSF and TT take place in Sweden instead of Brussels? Probably not, due to financial regulations, Wolfgang will check. He informs that we first need to see what the new Commissioner thinks about the timing for the action plan and new policy.
France: no clear commitment from Ministry of Health. But Ministry of Foreign affairs has prioritised HIV and civil society.
Czech Republic: Slogan: Europe without borders. Health is not a topic. Rumour that ageing will be the priority. But strong lobby to get drugs high on the agenda.
Sweden: National AIDS Commission informed that National Board of Health and Welfare was commissioned them to come with some topics, they are keen in having a meeting on HIV. Andreas will keep the CSF updated.
Spain: no information yet.
In conclusion we decide to send an open letter to the 3 upcoming presidencies at the latest in June, to suggest taking on the topic of HIV. Arnaud will make a draft.

15 UNGASS

Will focus on review on where we are with universal access. UNAIDS report is almost finalised, Raminta is involved. We know that quite some countries have submitted reports, but not all. CSF members present update on the focus of their country.
Slovenia: Miran is working with the Ministry on preparing a statement. Priorities: nothing related to universal access.
Sweden: Andreas will be part of delegation. Hoping for travel restrictions work as main topic, on civil society and/ or political level.
Tampep: Licia is invited as representative of Tampep next week on briefing on vulnerability of sex workers by UNAIDS and UNFPA to UN ambassador in preparation of June UNGASS.
UK: government representative will promote universal access. Historically, EU was pretty united against US points of views, government was concerned that unity was not there any longer. But since there won't be a declaration by participating countries at UNGASS, the uniting process will not happen.
Germany: Civil society report of umbrella of AIDS NGOs focuses on migrants and prisoners. German government process report is poor. A shadow report will be issued by Action against AIDS on universal access.
Norway: prevention work regarding testing.
Finland: Ministry hasn't started. Sexual and reproductive health and rights might be on the agenda.
Portugal: focus on universal access.
Netherlands: Ministry of Foreign affairs has human rights high on agenda. Ton will be on delegation and other civil society delegates. Stop AIDS Now! has a lobby office in Brussels and they are in contact with the people preparing the statement on behalf of EU.

In conclusion a subgroup of people is created that will follow-up: Andreas, Ton, Mirjam, Othoman, Yusef, Licia, Rhon, Miran, Ivo, Michal, Wojciech, Corinne, Ton, Raminta, Wim, Murdo. If confidential information is sent around, state that on top of message.

16 Candlelight memorial day

Presentation by Ivo Prochazka, Czech Republic, see annex F.
There are more than 1000 candlelight coordinators. 200 events organised last year. General coordination by Global Health Council. This year the event takes place on May 18. There is a 6 month mobilisation campaign. Promotion pack materials are available. Europe is not well represented with activities. Event in Czech Republic since 20 years.
HIV Sweden applied, has been coordinator in earlier years, but communication this year is still pending on who's elected as coordinator. An international advisory established, to have better process in the future.
Mirjam is shocked that the event is sponsored by Abbott, who is denying treatment in Thailand. Luis P. explains that their event is sponsored by whole pharmaceutical industry, since it is a big event. Would be unrealistic not to accept the money. France has not taken on this initiative. AIDES has boycotted Abbott because of the situation in Thailand.
Other countries, like Belgium, have AIDS Memorial Day, that has similar objectives.

17 Hepatitis C treatment access for IDUs

Short overview of situation in Central and Eastern Europe by Raminta. See annex G for the presentation.
There are severe barriers to HCV treatment like limited free of charge diagnostics. HIV/HCV co-infection: Eastern Europe particularly infected, because of epidemic mainly among injecting drug users. There are limited reports about causes of death. Liver failure is one of leading causes among PLHIV. Treatment for co-infection is a huge problem, especially in Belarus. Lack of attention to HCV in prisons.
Actions needed:

- Strategies at national level and EU wide action
- Supportive environment for services that reduce vulnerability
- Comprehensive care and cooperation

What can the CSF do? It's World Hepatitis Day in May. The CSF could issue a statement and make press releases. CSF members could look into integrating Hepatitis into their own work. The Commission could integrate the topic in its HIV strategy and the new communication. The European Parliament has political leadership, we could ask them in a letter to address on World Hepatitis Day. We can also address our concerns in a letter to the Think Tank.
Discussion with the CSF:
Transplantation of liver: there is much to learn from the Spanish experience.
At harmreduction.org you can download the referred publication.
In France 60% of injecting drug users are co-infected.
In the Netherlands there are gay men with co-infection with Hepatitis C: this opens the debate about sexual transmission. In Spain also their have been some cases.
In Germany up to 20% in prisoners are living with Hepatitis C. Treatment is mostly delayed until the prisoner is released. If there is no universal access to all treatments for drugs, including maintenance programs, we can avoid only HIV transmission and not Hepatitis C transmission.
In Central Europe we can't talk about universal access without more attention to HBV.
More R&D (research & development) is needed on the motor of transmission.

EHRN is one of the leaders putting this topic on the agenda. We will invite the new president of the International Hepatitis Association, Charles Gore, to next CSF meeting.
19 May is World Hepatitis Day (one day after Candlelight Memorial Day this year).
The International Harm Reduction conference will have 2 sessions on Hepatitis (WHO Europe involved).
We should put pressure on pharmaceutical industry because of high price of available treatment.
Lithuania had court cases related to Hepatitis C treatment in prisons.
Hepatitis C treatment accessibility for general population is an issue even in the EU (waiting lists, co-payments).

In conclusion the CSF agrees with the proposed actions. Some additional proposals need more elaboration: R&D, pharmaceutical pressure pricing, awareness among Civil society groups addressing government and professionals.
A working group is formed for follow-up actions and statements: Raminta (lead), Luis M., Murdo, Arnaud, Peter, Michal.

18 UNAIDS PCB letter

Raminta, Licia, Peter prepared the draft. There is agreement on main issues in letter. Raminta, Andreas, Peter, Wim will make the final version.
Vitaly will step down as PCB representative after this meeting, German representative Sonia Weinreich will follow-up. She will be invited to next CSF meeting.

19 Letter regarding Thailand

Raminta presents a letter from the CSF to UNAIDS PCB board members from Europe expressing concern regarding the war on drugs and requesting PCB members to condemn and call for elimination of violations of human rights and development of evidence-bases drug services.
A copy will be sent to the TT, Parliament, Commission. Raminta, Luis M. and Peter will finalise the draft.

20 Any other business

Chris raises the issue that working with the pharmaceutical industry is often difficult and controversial. We could develop an ethical code for the CSF. Chris will prepare a backgrounder for next CSF.
Vlatko has sent an email to the CSF to support a petition. If you haven't signed it, please do so.
Othoman informs that Egypt has condemned gay HIV positive men to 3 years in prison. Testing results were used as proof in court. Othman will check with local partners which action they wish us to take and come back to CSF. Wolfgang will forward relevant information to colleagues in charge of relations with Egypt.
The CSF on drugs was established and had a first meeting December 2007. Raminta will send the minutes. It operates quite different from our CSF. Key issues discussed: report for EU drugs action plan and recommendation on prisons and drugs. Next meeting in May: new EU drugs action plan will be on agenda. CSF observer status was requested, but denied.
The CSF should discuss prevention technologies, especially vaccines and microbicides. Will be on agenda of next CSF.

21 Follow up/Action list

What	Who	When
Enquire possibilities to participate in the closed symposium on counselling guidelines at UNAIDS in Geneva, June 2008	Responsibility Dennis Haveaux; Daniel Bruttin, Swiss AIDS Federation, UNAIDS	ASAP
Circulate the list of questions on counselling guidelines from the Canadian activists	Daniel Bruttin; Swiss AIDS Federation	ASAP
Put relevant data on counselling guidelines on the AAE clearinghouse	Martine	ASAP
Circulate the announcement of a satellite on the Swiss Guidelines during the Glasgow Conference	Wim	ASAP
Improve communication to Interservice group on HIV/AIDS, inform the Interservice group about the CSF.	Wolfgang	ASAP
Welcome letter to new Commissioner	Ton, Nikos	April
Table with CSF priorities to new Commissioner	Wolfgang	ASAP
Information about possibilities to provide input into briefing papers for the Commissioners visit of the Moscow Conference, visit with local NGOs	Wolfgang	ASAP
Information about the technical meeting between WHO and the German ministry, participation of CSF?	Martine	ASAP
Draft letter to the UNAIDS PCB	Raminta, Vitaly	ASAP
Follow up on the MSM NGO meeting in Slovenia	Arnaud	ASAP
Follow up on the MSM meeting prior to the IAC	Ton	ASAP
Follow up on the ECDC/WHO EUR meeting on 17. April	Jeff	ASAP
Circulate minutes meeting task force travel restrictions	Andreas	ASAP
Present outcomes data collection on travel restrictions	Denis	Next CSF
Send reference new regulation asylum seekers	Cinthia (PHEA)	ASAP
Action group on community recommendations migrants	Rhon (lead)	ASAP
Open letter to 3 upcoming Presidencies	Arnaud	June
UNGASS subgroup for follow-up	?	ASAP
Priorities CSF detailed report	Ton	Next CSF
Start working group on vulnerable groups	Rhon	ASAP
Start working group on pricing	Mirjam	ASAP
Start working group on GIPA	Andreas	ASAP
Start working group on human rights	Yusef	ASAP
Start working group on strengthening NGOs Eastern Europe	Raminta	ASAP
Invite Charles Gore to next CSF meeting	Raminta	Next CSF
Start working group on Hepatitis C	Raminta	ASAP
Send letter UNAIDS PCB	Raminta, Andreas, Peter, Wim	ASAP
Invite new PCB representative Sonia Weinreich to CSF	?	Next CSF
Send letter to Thailand	Raminta, Luis M., Peter	ASAP
Prepare backgrounder on ethical code	Chris	Next CSF

Support petition Vlatko	All	ASAP
Inform CSF on action related to Egypt	Othoman	ASAP
Send minutes of CSF on drugs	Raminta	ASAP
New prevention technologies on agenda	?	Next CSF

Annex A: List of Participants

ARILDSEN	Henrik	HIV Europe/ NordPol
AZAD	Yusef	National AIDS Trust
BERGLÖF	Andreas	RFHP Swedish Association for HIV-Positive People
BIJL	Murdo	IAVI
BJÖRKENHEIM	Corinne	Finnish AIDS Council
BRUSSA	Licia	TAMPEP
BRUTTIN	Daniel	Swiss AIDS Federation
COENEN	Ton	AIDS Action Europe
DEDES	Nikos	EATG
DEKOV	Vlatko	HOPS
GHERMAN	Liliana	Soros Foundation Moldova
HAFF	Jacob	STOP AIDS
HAGEBÖLLING	Mirjam	Action against AIDS
ILIC	Dragan	JAZAS
LAMBRECHTS	Chris	SENSOA
KAITE P	Charis	RUBSI
KLAVINS	Sandris	AGIHAS
MELLOUK	Othoman	ALCS
MENDAO	Luis	GAT
MINALTO	Michal	Social AIDS Committee
PEJKOVIC	Miso	CAZAS
PINZÓN	Luis Carlos Escobar	Deutsche AIDS Hilfe
PROCHAZKA	Ivo	Czech AIDS Help Society
PUJOL I ROCCA	Ferran	Projecte dels NOMS - Hispanosida
REYNOLDS	Rhon	African HIV Policy Network
SCHUTTER, DE	Martine	AIDS Action Europe
SIMON	Arnaud W.	AIDES
SMIRNOV	Sergey	Regional public organisation "Community of People Living with HIV"
SOBOLEV	Igor	Estonian NPLWH
SOLINC	Miran	SKUC-Magnus
STUIKYTE	Raminta	EHRN (formerly CEEHRN)
STEFANESCU	Michaela	RAA
TOMCZYNSKI	Wojciech	ECUO
VANDEVELDE	Wim	EATG
WIESSNER	Peter	EATG
OBSERVERS		
HAMERS	Françoise	ECDC
HAVEAUX	Denis	UNAIDS
LAZARUS	Jeffrey	WHO-EURO
MENEL-LEMOS	Cinthia	PHEA
NOORI	Teymoor	ECDC
COMMISSION		
PHILIPP	Wolfgang	SANCO C4
GUDFINNSDOTTIR	Gudrun	SANCO C4

Annex B: PowerPoint Presentation Daniel Bruttin – Swiss AIDS Federation

Slide 1

Daniel Bruttin

Director of the Swiss aids federation

I am…

…social worker, supervisor, manager.

I am not…

…a physician or scientist!

Slide 2

The Swiss National AIDS Commission (EKAF)

Aprox. 20 Members and guests:

Physicians

PWA's

Scientists (law, political, social, medical)

Swiss Aids Association

Swiss National Centre for Retroviruses

Slide 3

The Swiss National AIDS Commission (EKAF)

1. Advice for government
2. Guidelines

For Example:

HIV-positive individuals without additional sexually transmitted diseases (STD) and on effective anti-retroviral therapy are sexually non-infectious

Slide 4

The Core Message:

"An HIV-infected individual on an anti-retroviral therapy (ART) with completely suppressed viremia (in the following: "effective ART") is sexually non-infectious, i.e. he/her cannot pass on the HI-Virus through *sexual contact* as long as the following conditions are fulfilled:

1. The HIV-infected individual complies with the anti-retroviral therapy (ART), the effects of which must be evaluated regularly by the treating physician;
2. The viral load (VL) has been non-detectable since at least six months (i.e. viremia is suppressed);
3. There are no additional sexually transmitted diseases (STD) present."

Slide 5

The Recommendations also say :

The main indication for ART is still a medical reason not prevention

Prevention messages don't change

Legal practice has to be modified in future referring to the fact of assault

Only in stable partnerships there is the possibility for an informed consent, so the guidelines are only made for people living in partnerships

Slide 6

Physicians have to give information to or discuss with the couple (both of them):

The conditions for not being infectious (see above)

The Importance of Therapy compliance for the relationship

Sexual relations outside of stable partnership

For Heterosexual Couples: Conception or contraception

Slide 7

Why did the EKAF publish the guidelines?

1. Conflict between official message („use condoms") and physicians message („no harm if you are under ART")

Slide 8

And yes:

..The EKAF did not talk first to other policy makers in other countries or with UNAIDS and WHO

2. Criminalization of PWA shall be stopped, if they are not supposed to be infectious

Slide 9

Two more "ifs and buts" from the Swiss aids federation :

1. Counselling ideally comprises two parts: Medical counselling by a physician
2. Psychosocial and legal counselling by a regional advice centre
3. The decision to do without condoms must be taken by the couple together

Slide 11

And to make it more difficult or maybe in another way: "Go back to real life".

"Let's talk about other prevention strategies, that are used by a lot of people, HIV positive or negative."

Abstinence/fidelity/negotiatedsafety/lesspartners/ serodisclosure/serosorting/safersex/dipping/ strategigpositioning/PEP/PREP/HIVTesting/ STIcontroll/circumcision/microbizides

Slide 13

Statement found in a blog, made by a man living with HIV for many years:

"After reading the EKAF Guidelines, this is like a complete change in my life.
For the first time I have the feeling: "I will survive HIV!"

Thank you!

…There are few people who are affected by the Guidelines

It is a complicated message with a lot of „ifs and buts"

Slide 10

For the second part of counselling, the Swiss Aids Federation has created the

"Swiss Aids Federation – Advice Manual: doing without condoms during potent ART"

1. Principles of counselling
2. Counselling content in medical consultations
3. Counselling content in consultations with Regional Advice Centres

Slide 12

What's next?

Satellite symposium with discussion in Berlin at "Münchner Aids Tage" in march 08 has been held
Closed Symposium organised by the EKAF in June 08 in Switzerland for international players
Satellite Symposium at "WAC" in Mexico, Sunday, 3.8.08
More discussions everywhere

Annex C: PowerPoint Presentation Cinthia Menel-Lemos – PHEA

Slide 1

EU HIV/AIDS Civil Society
Brussels 8 April 2008

Slide 2

Health & Consumer Protection Directorate-General

Development of Community Action in Public Health

Basis in Article 152 of the Treaty:

Incentive measure designed to protect and improve human health', 'excluding any harmonisation of the laws and regulations of the Member States'.

1993-2002	Eight separate action programmes: health promotion, cancer, drug dependence, AIDS and other communicable diseases, health monitoring, rare diseases, accidents and injuries, pollution-related diseases
2003-2008 € 353.77 million	Community Action Programme for Public Health: • Health Information • Health Threats • Health Determinants
2008-2013 € 321.5 million	Second Programme of Community Action in the field of Health: • Health Security and Safety • Health Promotion (including Health Inequalities) • Health Information

Slide 3

Health Programme 2008-2013
Objectives

- Improve citizens' health security
- Promote health – including the reduction of health inequalities
- Generate and disseminate health information and knowledge

Slide 4

Health Security

- Protect citizens against health threats
  - develop EU and Member State capacity to respond to a cross-border threats
  - support development of vaccination policies
- Improve citizens' safety
  - patient safety
  - risk assessment
  - organs, substances of human origin and blood
- What is new?
  - Particular focus on cross border health threats
  - Development of Community reference laboratories
  - Action on patient safety through high-quality healthcare

Slide 5

Promoting Health

- Foster healthier ways of life and the reduction of health inequalities
  - increase healthy life years
  - reduce health inequalities

Slide 6

Promoting Health

- Nutrition and Physical Activity
  - A comprehensive strategy: 2007 White Paper.
  - Product reformulation: 2008 reduce salt

- co-operation on cross-border care
- Promote healthier ways of life and reduce major diseases and injuries by tackling determinants
  - Action on key health determinants - tobacco, alcohol, nutrition, drugs
  - social and physical environment
- What is new?
  - Regional policy as key factor in reducing health inequalities
  - Focus on health ageing and children's health
  - Co-operation between health systems

Slide 7

Promoting Health

- Sexual health and HIV/AIDS
  - Action plan on AIDS (2005) for EU and Neighbourhood countries
  - Access to ARV treatment
  - Linking to Member States and Stakeholders: Think Tank and Civil Society Forum
  - New Action plan on AIDS (2009) for EU and Neighbourhood countries
- Accidents and injuries:

2007 Council recommendation on good practice across Member States

Slide 8

Promoting Health

- Alcohol
  - EU alcohol strategy (2006): focus on vulnerable groups, high risk drinking, drink driving, workplace
  - Coordinating Member State good practices; Committee on National Policy and Action
  - Stakeholder platform: European Alcohol and Health Forum
- Drugs
  - Focus on prevention and harm reduction
  - Recommendation on drugs and prisons (2008)
  - Integrated approach across addictions: Polydrug use

Slide 9

Promoting Health

Multi-faceted tobacco control approach

- Binding legislation (Product & Advertising directives)
- Non binding legislation (Council recommendations)
- Participation in international TC initiatives (FCTC);
- Help: Integrated communication campaign across all Member States :

Slide 10

Promoting health

- Health inequalities:

  policy leadership and good practice
- Settings:

  Workplace/-force health strategy planned for 2009
- Environment and health:

  indoor air quality, noise, etc.
- Initiative on child and adolescent health – 2008/2009

- Media (TV spots and Internet)
- Website in 22 languages
- Series of national events
- PR activities

Slide 11

Promoting Health

- Health inequalities:

  policy leadership and good practice
- Settings:

  Workplace/-force health strategy planned for 2009
- Environment and health

  indoor air quality, noise, etc.
- Initiative on child and adolescent health - 2008/2009
- Chronic disease prevention:

  heart health, asthma-allergies, etc

Slide 12

Promoting Health

- Chronic disease prevention:

  heart health, asthma-allergies, etc

- Health Policy Forum
  - regular consultations and exchange of experiences with stakeholders (public health, health professionals, health services) in the field of health
  - 2 meetings in 2008
- Open Forum

  key element as an annual conference and exhibition event

Slide 13

Health & Consumer Protection Directorate-General

Health Programme: Budget

(not including EFTA contribution)

	2008	2009	2010	2011	2012	2013	TOTAL 2008-2013
Operational budget	45,2	47	45,7	47,3	49,7	51,5	286,4
Administrative budget	1,4	1,5	1,4	1,5	1,5	1,6	8,9
Public Health Executive Agency	4,1	4,3	4,3	4,4	4,5	4,6	26,2
TOTAL	50,7	52,8	51,4	53,2	55,7	57,7	321,5

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Slide 14

Participation

- Member States
- EFTA / EEA countries (under conditions of EEA agreement)

  In accordance with bilateral or multilateral agreements:
- Candidate and accession countries
- European Neighbourhood Policy countries
- Western Balkans included in the stabilisation and association process
- International co-operation with third countries and relevant international organisations, for example OECD and WHO

Slide 15

Participation in the Health Programme is open to a wide range of organisations, including:

- Research institutes and universities
- Public administrations
- Non-governmental organisations
- Commercial firms

Slide 16

Implementation: actors

- Annual work plans are prepared by the Commission (priorities and actions to be undertaken and the criteria for Community contributions).
- The Commission is supervised by a Programme Committee -Members States - (approves the annual work plan and is informed on all actions and projects funded through the Programme).
- The Executive Agency (PHEA) assists in the technical and financial implementation of actions.
- National Focal Points provide national information relay points on the Programme and provide local support to potential applicants.

Slide 17

Logistics

- A work plan will be published each year – the first in February 2008. This will include a single call for proposals with different end dates for the actions.
- Calls for tender will be issued throughout the year.
- The Public Health Executive Agency (PHEA) will carry out all the operations necessary for the management of the work plan 2008.
- National Focal Points will act as a point of referral in each of the Member States to interested participants.

Slide 18

Work Plan 2008:

- First year of the new programme
- Approved on 27 February 2008 (2008/170/EC)
- Published in the Official Journal on 29 February 2008 (L 56/36)

Slide 19

Work plan 2008
Overall approach

- Wider consultation process
- Streamlined, more focussed objectives
- Diversification of financing mechanisms

Slide 20

Wider consultation process

- Public mailbox:
  sanco-workplan2008@ec.europa.eu
- Programme Committee
- Stakeholder groups
- 2009: on line?

Slide 21

Wider financing mechanisms

- Ensure full stakeholder participation in the Programme to organisations which take forward the health agenda
- Intention to use new mechanisms as widely as possible from 2008

Slide 22

Overall budget by financing type

Financing instrument	Total amount for 2008 in EUR	Percentage of operating budget
Call for proposal	28 541 000	62%
Call for tenders	9 300 000	20%
Joint Actions with MS	2 300 000	5%
Operating grants	2 300 000	5%
International organisations	2 300 000	5%
Health Conferences	700 000	1.5%
Eurostat	700 000	1.5%
Scientific Committees	254 000	0.5%
Operating budget	**46 365 000**	

NOTE: UP TO 20% VARIATION IS POSSIBLE BETWEEN EACH FINANCING TYPE

Slide 23

Call for proposals

- Grant may be given to a public or private body based in one of the participating countries.
- Goal: co-funding of Cross-border sustainable projects in line with the EU agenda.
- Financial contributions by the Community will cover up to 60% of project costs (exceptionally: 80%).
- Selection and award criteria detailed in the work plan.

Slide 24

- Not for research projects (DGT RTD) or infrastructure projects (DG REGIO) and NO “national” projects (Crossborder).
- External evaluation of project submitted.
- 2008: one call published on 29 February. Deadline for submission 23 May 2008.

Slide 25

Calls for tender

- Service procurements to cover specific Programme objective (studies, IT Tools).
- Financing offered at 100%.
- Calls for tender will be launched for specific actions throughout the year,

Slide 26

Joint action

- Specific actions may be financed by the Community and one or more participating countries.
- May be offered to a public body or non-government organisation designated by

preferably in the first half.

participating country.

- Community contributions may be up to 50% (or 70% if there are at least 10 MS involved or 3 MS where the lead partner is from a post-2004 accession country.
- Areas for 2008: rare diseases, capacity building and health indicators.
- Participating countries have been invited to present proposals for joint actions.
- Selection and award criteria are detailed in the work plan (simplified).

Slide 27

Operating grants

- These will be offered to a non-government organisation or specialised network to cover core functioning costs.
- Organisations must be independent of industry and conflicting interests.
- Member organisations must be presented in at least half the Member States with a balanced geographical coverage.
- Community contributions may be up to 60% (exceptionally 80%).
- Selection and award criteria are detailed in the work plan.
- Areas for 2008:
    - To NGOs primarily active in public health at EU level, which contribute to EU health policy.
    - To NGOs or networks as seed money in sexual health networks and HIV/AIDS prevention networks.

Slide 28

Conferences in public health

- Presidency conferences
- Maximum one per Presidency
- Up to 50% of the budget awarded as a lump sum
- Other conferences
- Up to 50% of the budget awarded as a lump sum
- Offered as call for proposals on a competitive basis
- Aims should be in line with overall Programme objectives
- Conferences must have a European-wide dimension and be organised by a public or non-profit making body

Slide 28

Cooperation with international organisations

- Action is in line with Article 12 of the Programme text, which encourages co-operations with international organisations in areas of joint interest.
- Funding will be through direct agreements to cover specific areas agreed with the respective organisations.
- Financial contributions can be up to 60% of the costs for each action.
- In 2008, direct agreements are intended to be agreed with WHO, OECD and the Council of Europe.

Slide 29

Slide 30

Other financing mechanisms

- Sub delegation to EUROSTAT
- Possibility of administrative agreement with Joint Research Centre
- Allowances for the operation of scientific committees
- Expenditure on administrative management of the Programme
    - Workshops
    - Expert meetings
    - Publications and other communications activities
- Contribution to the Framework Convention on Tobacco Control

Slide 31

Slide 32

Slide 33

Slide 34

Further Information

Public Health Portal
http://health.europa.eu

SANCO Web Site
http://ec.europa.eu/health

PHEA Website
http://ec.europa.eu/phea

Annex D: PowerPoint Presentation Teymoor Noori – ECDC

Slide 1

European Centre for Disease Prevention and Control
Teymoor Noori

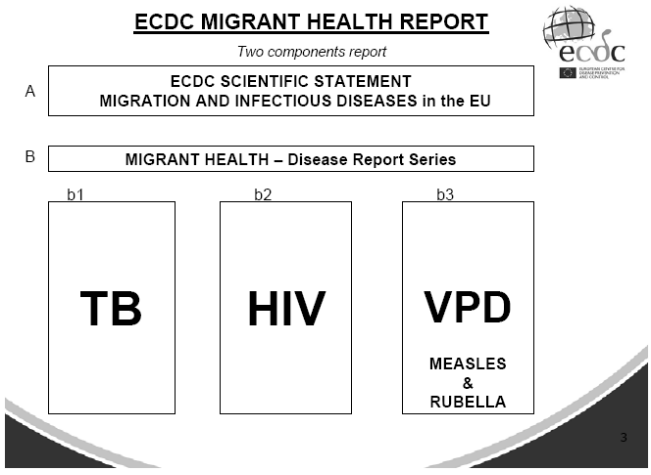
Slide 2

Call for an EU Migrants & Infectious Disease Report

- Portuguese Presidency work and conclusions of European Conference on 'Health and Migration'
  - o Recognizing TB, HIV and other infectious diseases as a priority within migrants
- Commissioner speech at the Lisbon Conference
  - o Specifically calling for action from ECDC on TB and HIV in relation to migrants
- Council conclusions 5 and 6 December 2007
  - o WELCOMES the activities of the ECDC in the field of migrant health and looks forward to the report on migration and infectious diseases to be delivered in 2008.

ECDC background work on migrant health started in 2007, reinforced in 2008 & to be continued in 2009

Slide 3



Slide 4

Disease Report Series – Tuberculosis

- Scope and objectives: to provide a situation analysis on burden, control and interventions for TB in migrant and foreign born communities in the EU
- Situation analysis (Review of epidemiology and interventions at EU level)
- Forecasting model to estimate impact of TB in migrants and model interventions (user friendly interface)
- Systematic review of interventions

(screening, contact tracing, vaccination, intensified case finding)

Slide 5

Disease Report Series - HIV

- Epidemiological review:

  determine burden of HIV in migrant communities
- Testing policies across Europe:

  identifying practices and barriers to testing
- Access to prevention, treatment and care:

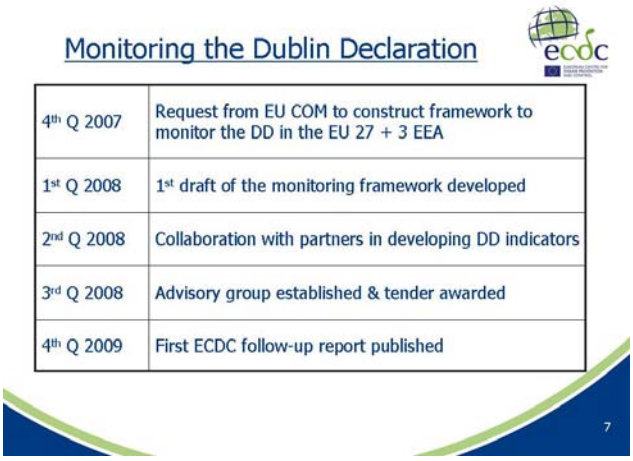
  policies and barriers

Slide 6

Disease Report Series – Measles & Congenital Rubella

- Situation analysis:
  - Assessing the specific burden of disease
  - Identifying determinants of low coverage
- Models for intervention:
  - Guidelines for communication plans – public health perspective
  - Guidelines for improving vaccination coverage from a health care perspective

Slide 7



Slide 8

Dublin Declaration Monitoring Framework

- Guiding principle – make use of existing indicators (UNGASS, EU Action Plan, EMCDDA, etc.)
- Framework currently consists of 60 indicators
  - Almost all are existing indicators/data sources
  - 50 % consists of UNGASS/NCPI indicators
- ECDC involved in UNAIDS MERG TWG on Indicator Development & Revision
- ECDC/UNAIDS Regional M&E Retreat/Training

Slide 9

Dublin Declaration Areas of Actions

Consists of 33 actions divided into 5 areas of actions:

- Leadership
- Prevention
- Living with HIV/AIDS

- Partnership
- Follow-up

Slide 10

Area of action: Leadership

Actions	Involved sectors	Indicators	Means of collecting data	Existing indicator/ data source
1. Promote strong and accountable leadership at the level of our Heads of State and Government to protect our people from this threat to their future, and promote human rights and tackle stigma and ensure access to education, information and services for all those in need	MS, Civil society	a) A national HIV/AIDS policy adopted (UNGASS 2)	Part A, section I. & II.; and part B, section I. of the UNGASS NCPI Country survey	Yes
		b) Per capita spending on national HIV/ AIDS prevention programs (as measured by proportion of GDP)		No
		c) The total amount of funds annually pledged and contributed to the Global Fund (also measured as proportion of GDP)	GFATM	Yes
2. Encourage and facilitate strong leadership by civil society and the private sector in our countries in contributing to the achievement of the goals and targets of the Declaration of Commitment	MS, Civil society	a) Civil society participation as measured by UNGASS NCPI (UNGASS 2, NCPI)	Part A, section I., question 1.8; part B, section II., questions 1-6 of the NCPI	Yes
		b) Percentage of the national/ regional HIV/AIDS budget spent on activities implemented by civil society in the past year (UNGASS 2)	Part A, section II., question 4 of the NCPI	Yes

Slide 11

Area of action: Prevention

Actions	Involved sectors	Indicators	Means of collecting data	Existing indicator/ data source
10. Scale up access for injecting drug users to prevention, drug dependence treatment and harm reduction services through promoting, enabling and strengthening the widespread introduction of prevention, drug dependence treatment and harm reduction programmes[2] (e.g. needle and syringe programmes, bleach and condom distribution, voluntary HIV counselling and testing, substitution drug therapy, STI diagnosis and treatment) in line with national policies	MS, Civil society	*Coverage* a) Percentage of IDUs who received an HIV test in the last 12 months and who know their results (EMCDDA B7, UNGASS 8)	EMCDDA survey UNGASS Report 2008	Yes
		b) Percentage of injecting drug users reached with HIV prevention programmes (EMCDDA – NSP, UNGASS 9)	EMCDDA survey UNGASS Report 2008	Yes
		c) Percentage of injecting drug users that have access to drug dependence treatment (EMCDDA B15)	EMCDDA survey	Yes
		d) Percentage of injecting drug users that have access to needle & syringe programmes (EMCDDA)	EMCDDA Annual Report	Yes
		Impact e) Percentage of injecting drug users who are HIV/HBV/HCV-infected (ECDC & EMCDDA prevalence data, UNGASS 23)	ECDC HIV prev. database EMCDDA survey UNGASS Report 2008	Yes

Slide 12

Area of action: Prevention contin.

Actions	Involved sectors	Indicators	Means of collecting data	Existing indicator/ data source
16. Control the incidence and prevalence of sexually-transmitted infections, particularly amongst those at the highest risk of and most vulnerable to HIV/AIDS, through increased public awareness of their role in HIV transmission, improved and more accessible services for prompt diagnosis and efficient treatment	MS, ECDC	*Coverage* a) Number of countries that have national programmes to control STI	Part A, section III., question 3.1 of the NCPI	Yes
		Impact b) Number of reported cases of Chlamydia per 100,000 population	TESSy	Yes
		c) Number of reported cases of gonorrhoea per 100,000 population	TESSy	Yes
		d) Number of reported cases of syphilis per 100,000 population	TESSy	Yes
17. Fund, improve, and harmonise surveillance systems, in line with international standards, to track and monitor the epidemic, risk behaviours and vulnerability to HIV/AIDS	MS, EU COM, ECDC, WHO & EMCDDA	a) Number of countries able to provide national and individual data on HIV and AIDS case reporting	TESSy	Yes
		b) Number of countries able to provide HIV prevalence data for most-at-risk populations (WHO/UNAIDS)	European HIV preval. database	Yes (for IDU - EMCDDA annual report)
		c) Number of countries conducting behavioural surveillance in the general population and in most-at-risk populations (WHO/UNAIDS)	ECDC survey (for IDU, see EMCDDA survey)	Yes

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Area of action: Living with HIV/AIDS

Actions	Involved sectors	Indicators	Means of collecting data	Existing indicator/ data source
21. By 2005, provide universal access to effective, affordable and equitable prevention, treatment and care including safe anti-retroviral treatment to people living with HIV/AIDS in the countries in our region[1] where access to such treatment is currently less than universal, including through the technical support of the UN through the global initiative led by the World Health Organisation and UNAIDS to ensure 3 million people globally are on anti-retroviral treatment by 2005 ("3 by 5"). The goal of providing effective anti-retroviral treatment must be conducted in a poverty-focused manner, equitable, and to those people who are at the highest risk of and most vulnerable to HIV/AIDS	MS, WHO, UNAIDS, Civil society	***Coverage*** a) Percentage of adults and children with advanced HIV infection receiving antiretroviral therapy (UNGASS 4)	UNGASS Report 2008	Yes
		b) Proportion of HIV infected IDUs on ART of all people on ART	WHO	Yes
		c) Existence of national policies, strategies and guidelines for ART programmes (WHO core indicator 1)	Part A, section IV., question 1 of the NCPI	Yes

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Area of action: Partnership

Actions	Involved sectors	Indicators	Means of collecting data	Existing indicator/ data source
27. Involve civil society and faith-based organizations, as well as people living with HIV/AIDS and persons at the highest risk of and most vulnerable to HIV/AIDS infection in the development and implementation of national HIV/AIDS prevention and care strategies and financing plans, including through participation in national partnership forums	MS, Civil society	a) Civil society participation as measured by UNGASS NCPI (UNGASS 2, NCPI)	Part A, section I., question 1.8; part B, section II., questions 1-6 of the NCPI	Yes (cross reference 2a)
28. Work with leaders from the private sector in fighting HIV/AIDS through workplace education programmes, employee non-discrimination policies, provision of treatment, counselling, care, and support services, and through engagement with policy makers on the local, national and regional levels	MS, ILO, Private sector, Trade unions, Civil society	a) Percentage of transnational companies that are present in developing countries and that have workplace HIV policies and programmes (UNGASS, Global indicator 3)	UNGASS Report 2008	Yes
		b) Percentage of international organizations that have workplace HIV policies and programmes (UNGASS, Global indicator 4)	UNGASS Report 2008	Yes

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Area of action: Follow-up

Actions	Involved sectors	Indicators	Means of collecting data	Existing indicator/ data source
33. We commit ourselves to closely monitor and evaluate the implementation of the actions outlined in this Declaration, along with those of the Declaration of Commitment of the United Nations General Assembly Session on HIV/AIDS, and call upon the European Union and other relevant regional institutions and organisations, in partnership with the Joint United Nations Programme on HIV/AIDS, to establish adequate forums and mechanisms including the involvement of civil society and people living with HIV/AIDS to assess progress at regional level every second year, beginning in 2006	MS, Civil society, EU COM, WHO-EURO, UNAIDS, ECDC	a) Advisory group established in order to monitor the Dublin Declaration	Meeting reports	Yes
		b) Number of countries that have submitted UNAIDS with a UNGASS Country Report	Country reports published	Yes
		c) A biannual European Report of the Dublin Declaration published	EU report published	Yes

Annex E: Civil Society Forum Priorities

Main Problems in the countries

Macedonia

1. To ensure financial sustainability and good availability of the preventive services (outreach for most at risk)
2. Dispersion of the methadone programs in capital city
3. To open needle exchange programs in prisons

Finland

1. Main challenge for NGOs is long term funding. Little prevention resources available for targeted MSM work
2. Neighbourhood area cooperation in HIV prevention a lot of cross border exchange to Russian Federation & the Baltic status occurs & is expected to grow in the future
3. Positive prevention need to develop the concept further. HIVAIDS expertise within the public health care is insufficient
4. Overall: keep HIV on the agenda

Slovenia

1. Homophobia
2. Sustainable funding
3. Gay health is in a crisis, make health services more accessible for MSM

AAE

1. Providing European NGOs with information
2. Support NGO capacity to be involved on a national level
3. Involve local/ national NGOs in European policy

Belgium

1. Better coordination of policy and activities on a national level
2. Deal with the rise of infections with MSM
3. Increase availability of Mono PEP

Portugal

1. How to implement universal access mainly among vulnerable groups migrants IDUs MSM and minorities
2. Quality reliable and usable epidemiological dates

Sweden

1. Stigma / discrimination
2. Criminalization
3. Harm reduction (IDU)
4. Undocumented persons (access to care/ treatment)

Denmark

1. Governmental funding for prevention for slowly decreasing
2. Funding for prevention at regional/ municipal level is chaotic and partly vanished since structural reform in 2007
3. MSM facing big HIV-problems
    - Unsafe sex increased 20 – 30 % from 2002 to 2006
    - HIV incidence increased in recent 5 years period compared to former 5 years period (heterosexual stable, IDU declining)

Denmark 2

1. Stigma / discrimination
2. Criminalization
3. Testing
4. Workplace issues

??

1. Maintaining the low HIV incidence by strengthening the prevention programs
2. Ensuring sustainability of GF programs after Grant/s end
3. Ensuring a good combination of positive prevention and social services for YPLHA (vocational training, social integration, professional integration, education, etc.)

Morocco

1. Access to second line treatment (IPRs, Trips, USFTA) and paediatric pharmaceuticals
2. Treatment of co-infections especially hep b and c
3. Stigma against PLHIV and most at risk populations
4. Access to prevention (MSM +++, IDUs, sex workers, migrants)
5. Rights of sexual minorities

Cyprus

1. No data on MSM
2. No LGBT society in Cyprus
3. Stigma/ discrimination towards PLHIV and MSM
4. Legislation in Cyprus does not give protection against discrimination on grounds of HIV positive status

Netherlands

1. HIV on the rise among MSM
2. Late diagnosis & stigma among Sub Sahara Africa
3. Stigma & discrimination PLHIV
4. No integral policy

Lithuania

1. Policies and services in prisons
2. NGO capacity development
3. Quality, scale, Funding & diversity of low threshold services, first of all to IDUs also SW and MSM (in the future migrants)

EHRN

1. Drug policies (enabling environment and human rights)
2. Making harm reduction services available, sustainable, accessible and being more than HIV prevention (including HCV, overdose, access to ART)
3. Strong and sustainable CS role in drugs and HIV dialogue in Europe especially CEE and Central Asia

???

1. HIV related stigma and migrant populations
2. Late presentation of migrant men

Latvia

1. Treatment interruption of several ARV again taking place in the beginning of the year (bad coordination between decision makers)
2. MH not listening to AIDS NGOs messages seriously enough
3. Difficulties accessing EU projects (NGO needs to have its office etc.)

France

1. Access to earlier testing & better care for MSM and migrants
2. Quality of Life of PLWHA (including being able to speak safely about one's status)
3. Defending health rights are being threatened by current government (including right treatment for undocumented migrants & quality harm reduction for IDUs)

Priorities for Civil Society Forum

Macedonia

Prepare and adopt mission statement

Finland

1. Priorities need to be defined for membership period for ex early diagnosis
2. Ongoing processes should be identified & developed: presidencies, ECDC, conferences on specific topics national AIDS coordinator meetings
3. Action plan is needed, strengthening of EU's commission's/ leadership on HIV

Slovenia

1. Act as a pressure group on EU and national governments
2. Networking opportunities, partnerships for EU funding
3. Working with media making more visibility
4. Advocacy

AAE

1. Sustainability & continuity of good programmes run by NGOs in C/ E Europe due to funding difficulties
2. Support involvement of its members at national level policy & program development
3. Real involvement of CSF in development of new EU HIV policy beyond 2009

Belgium

1. Make inventories & advocate for enabling conditions on a policy level for NGOs to have more impact
2. Improve communication with NGOs all over EU, with TT representatives EU parliament and the public in general
3. Build my on the national level for topics in the CSF

Portugal

1. Increase CSF capacity work
2. Prioritise the research agenda (NPT)
3. Involve officials and European Parliament

Sweden

1. Stigma/ discrimination
2. Criminalization
3. Harm reduction (IDU)
4. Undocumented persons (access to care/ treatment)

Denmark

1. Human rights/ law/ stigmatisation of MSM and PLHIV
2. Focus on MSM and other vulnerable groups, i.e. drug users, migrants

Denmark 2

1. Stigma discrimination
2. Criminalization
3. Testing
4. Workplace issues

Morocco

1. Promotion of the use of trips flexibility
2. Advocacy for the rights of sexual minorities and human rights in general

Cyprus

1. Stop preaching the professionals/ same people being always involved on the matter
2. Give HIV/ Positive people the chance to speak by giving them the right to participate on organizations that are fighting AIDS

Netherlands

1. Influence active policy on HIV in broader Europe with meaningful involvement of civil society
2. Increase financial support for NGO work
3. Improve integral policy EU on HIV

EHRN

1. CS in EE/ CA (role and funding)
2. Universal access for vulnerable (MSM, IDU, migrants, also sex workers, prisoners, ethnic minorities)
3. Making some kind of strategy and action plan for specific priorities and becoming more operational

??

1. Universal access for all to include migrants
2. Ensure treatment is free/ undocumented migrants accessing treatment should not face deportation / failed asylum seekers

EATG

1. Barriers to universal access to TPCS in WHO53 with focus on undocumented migrants MSM and IDU
2. Affordability and sustainability of HIV/ HCV/ TB treatments and services in EU 27
3. Closer collaboration between CSF and European institutions (EC, EP) and international organizations

Latvia

Not experienced enough to give input

IAVI

1. Strong emphasis on political and policy lobby
1. Guiding principle CSF focus human rights and ethics
2. Per agenda item/ topic preferably supports with references to empirical studies
3. Meeting topics preferably supported with smart objectives to strengthen pragmatic outputs/ outcomes

France

1. Improve our agenda/ far more preparation for the present actions
2. Acknowledge our role as enabler of exchanges in between NGOs and adapt our agenda accordingly
3. Get the EU parliament & the EU council involved (invite them)

Tampep

1. Monitoring the rights based approach to HIV policy development of the public health
2. Promote better coverage of quality services for vulnerable groups
3. Lobby and advocacy with the EU on universal access to health an prevention and care for migrants particularly by vulnerable groups of migrants

Total

1. Fight for universal access on prevention, treatment, care and support for all, but especially vulnerable groups, IDUs MSM, people in prisons, sex workers, migrants/ illegal migrants
    - Vulnerable groups * Rhon © Luis Peter Licia Jakob
    - Pricing drugs * Mirjam © Wim Othoman
    - Need to work more on documents

2. Give NGOs & PLHIV a voice in the EU policy on HIV and related issues (research)
    - This comes out of our way of working
    - Use the meetings more to better link back to influencers at home
    - Communicate better with parliament
    - Informal meeting between country representatives & CSF
    - Positive prevention
    - GIPA * Andreas © Henrik Wojtech
    - We focus on the issue not hindered by the lines between the departments
    - Stronger link with other fora

3. Strengthen human rights of PLHIV and most affected groups, incl. fighting criminalization & stigmatization * Yusef © Andreas Corinne Raminta Daniel

4. Promote linking & learning & financial support for NGOs
    - Funding & involvement of NGOs in political process focussing on eastern Europe Raminta © Igor Wojtech Luis Arnaud Vlatkow Lilianne Michel Michal
    - Focussing on the political pressure

Way of working

1. Better prepared/ better agenda with background documents
2. Work with smaller groups & have people more involved
3. Work on strategic plan & be more operational
4. Involve EU for example parliament & EU council

Suggestions

1. Work this out with conclusions & have a look at it next time again. Then finalize it
2. Specific country needs (Trips, Positive prevention): someone from country work on it for CSF
3. More joint effort in putting things on agenda

Annex F: PowerPoint Presentation Ivo Prochazka – Candlelight memorial day

Slide 1

The International AIDS Candlelight Memorial Program

International Advisory Board
Civil Society Forum
April 2008

Global health begins here.

Slide 2

Overview

- World's first public and international HIV/AIDS event
- Honouring affected lives and mobilizing communities
- Started and led by civil society
- 1,200 Candlelight Coordinators in 119 countries
- In 2007, 2,000 events reaching hundreds of thousands

Slide 3

History

- Started in 1983, San Francisco, United States
- Confusion and misconception, mysterious disease
- Four young gay men – Bobbi Campbell, Bobby Reynolds, Dan Turner, & Mark Feldman
- Putting a "face on the disease"
- Mobilization Against AIDS (1983-2000)
- Global Health Council (2000-present)

Slide 4

Mission

The mission of the International AIDS Candlelight Memorial program is to honour and support all those who have been affected in some way by the global HIV/AIDS pandemic and to fulfil our vision for a world free of AIDS
by mobilizing communities to action.

Slide 5

More Than a Memorial

- Raise public awareness
- Educate about HIV/AIDS
- Advocate for policy change
- Foster partnerships, community dialogue
- Improve skills for leadership and community mobilization

Slide 6

How the Memorial Works

- Every third Sunday in May
- World AIDS Day Launch – 2008 Malawi
- Coordinator Registration & Packet
- Six-month Mobilization Campaign
- Opening Ceremony
- Final Reporting

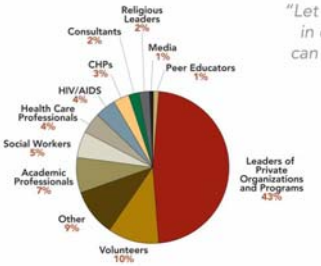
Slide 7

Slide 8

Memorials Around the World

Slide 9

Community Coordinators

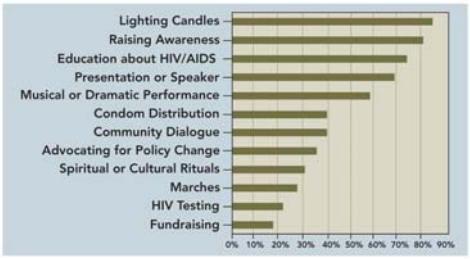


"Let these candles shine in our heart, so that we can be able to make the right decisions."

– Kahabi Isangula Ganka, Candlelight Coordinator, Tanzania

Slide 10

Memorial Activities



Candlelight Staff

- Maurice Middleberg, Vice President for Public Policy
- Sarah Albert, Public Outreach Director
- Todd Lawrence, International Outreach Coordinator
- Julia Masters, Public Outreach Associate
- Sara Friedman, Editor, *Global AIDSLink Newspaper*

Slide 11

Sponsorship

- Ford Foundation's Global Initiative on HIV/AIDS
- Bill & Melinda Gates Foundation
- Abbott Fund
- Membership of the Global Health Council

Slide 12

Why Candlelight in the Czech republic

- Tradition of 20 years
- 1988 – first Candlelight – the first event of illegal gay (lesbian) raising movement
- Complementary public event to World AIDS Day, more oriented to PLWHA
- 1989 – one of the organizer was murdered Candlelight was his memorial, too
- 2007 – the first politician (human rights minister) supported the event

Slide 13

Useful contacts:

http://www.candlelightmemorial.org/

Regional coordinators:
Mzia Tabatadze (Georgia)
mzia@savechildren.ge
Ivo Prochazka (Czech republic)
ivo.prochazka@seznam.cz
Cristina Vladimirov (Romania)
cvladimirov@baylor-romania.ro

Registration:
http://www.globalhealth.org/forms/candlelight/community/index_2008.php

Contact for media: Laura Barnitz:
lbarnitz@globalhealth.org

Annex G: PowerPoint presentation Raminta Stuikyte - Hepatitis C treatment access for IDUs

Slide 1	Slide 2
Hepatitis C treatment access for IDUs: short overview of situation in Central and Eastern Europe Raminta Stuikyte, Simona Merkinaite, Eurasian Harm Reduction Network For Civil Society Forum on HIV/AIDS, April 2008	**Report about HCV in Central and Eastern Europe (CEE)** • Survey in 13 countries of the CEE region in partnership with national experts (Belarus, Bulgaria, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Russia, Slovakia, Slovenia, Ukraine); • Data from 2006 - Jan 2007; • Information on treatment guidelines; reimbursement policies' assess for IDUs, availability in prisons
Slide 3	**Slide 4**
High HCV prevalence throughout the region • Eastern Europe – high prevalence rates o From 70% to more than 90% (in studies from Estonia, Lithuania, Russia and Ukraine); • Central Europe – significantly lower o the Czech Republic, Hungary, Romania, Slovenia and Slovakia; • Prevalence of more than 60% in samples from Central Europe, indicating high HCV prevalence throughout the region o Bulgaria (79%), Poland (68.3%) and Romania (84.45)	**Low awareness and political commitment** • On national level o Only 2 out of 13 countries (Romania and Slovakia) have specific national plan or strategy addressing hepatitis; • There are no hepatitis focused recommendations/strategy on EU level o Declaration on hepatitis C adopted by European Parliament in March 2007. Lack of EU strategy identified as one of negative factors affecting lack of national action by activists in countries); • Estimates for the EU: delays in establishing prevention and treatment programs will lead to increase in treatment costs of additional 1,4 billion Euros. o Such estimates never done for Eastern part of Europe
Slide 5	**Slide 6**
High HCV prevalence throughout the region • Eastern Europe – high prevalence rates o From 70% to more than 90% (in studies from Estonia, Lithuania, Russia and Ukraine);	**Low awareness and testing availability for IDUs** • In most cases HCV is asymptomatic and is undiagnosed, especially among IDUs, who are not reached by services; • Free, anonymous and voluntary testing for

• Central Europe – significantly lower o the Czech Republic, Hungary, Romania, Slovenia and Slovakia; • Prevalence of more than 60% in samples from Central Europe, indicating high HCV prevalence throughout the region o Bulgaria (79%), Poland (68.3%) and Romania (84.45);	HCV at low-threshold facilities is frequently unavailable or limited and is poorly linked to established services for drug users. Testing at needle exchange or substitution treatment programs available in 5 out of 13 countries In some countries testing available at entrance to drug treatment (Czech Republic, Lithuania, Slovakia, Slovenia) and as part of HIV diagnostics • Poor pre- and post- test counselling. Any IDUs see diagnosis as "death sentence", have no or often wrong information about the infection
Slide 7	**Slide 8**
Insufficient coverage of targeted prevention • Less than 10% of IDUs have access to evidence-based harm reduction services in Eastern Europe, coverage better in Central Europe: the Czech Republic, Slovenia, in Eastern Europe – Estonia; • NSPs not diversified o in pharmacies available in 4 out of 13 countries • Only a few countries provide sterile injecting equipment apart from needles; • Negative attitude towards IDUs among health care professionals and service providers persists.	**Access to HCV treatment: guidelines** International guidelines clearly state that active drug use should not be an exclusionary criterion… Any assessment of treatment eligibility should be made on case-by-case basis – European Consensus Conference Jury, 2005 • Guidelines exist in 12 out of 13 countries adopted between 1998 - 2006 (pending for approval in Ukraine and new guidelines in Hungary); • Drug use - contraindication to HCV treatment in 9 countries - Belarus, Bulgaria, the Czech Rep., Estonia, Hungary (updated guidelines, 2007), Latvia, Lithuania, Romania and Slovenia); not mentioned in Russia and guidelines project in Ukraine; • Slovenia: "treatment recommended with cooperation with drug treatment specialists".

Slide 9	Slide 10
Problems within guidelines • No consultation with drug addiction specialists; • No mentioning how address drug dependency and hepatitis C together; • No guidelines on HCV/HIV co-infection management	**Access to HCV treatment for IDUs** • In practice some can be treated based on individual decisions by doctors – very few examples; • Abstinence for at least 6 months required o Bulgaria, Czech Republic, Estonia, Hungary, Lithuania, Slovakia; o Hungary - from 6 to 12 months; o Slovakia – requirement by health insurance companies
Slide 11	**Slide 12**
Access to HCV treatment for people on ST "Treatment of patients on opiod substitution therapy should not be deferred" – WHO Clinical Protocol for the WHO European Region • Access according to HCV treatment guidelines in Hungary (new guidelines, 2007), Romania, Slovakia and Slovenia; • In practice – more accessible than for drug users o in Bulgaria, Czech Republic, Hungary, Lithuania, Romania, Slovakia • Most often – limited and can be rejected by doctors (better access in Czech Republic where treatment is linked to harm reduction services, including ST) • Very limited data on actual number of people on OST in HCV treatment	**Barriers to HCV treatment** • Restrictively high price, reimbursement policies: • In countries where available - 20,000 to over 30,000 EUR for 48 weeks' treatment course (with PEG-IFN+RBV); • Partial reimbursement e.g. in Latvia (75% of price); • 'Ceilings' of how many people per year can get treatment funded by state or other sources e.g. Bulgaria 50-60 people per year, PEG-IFN+RBV to 80 people in Latvia; • Limited availability of PEG-IFN+RBV treatment • Not provided in Romania, Belarus; • in Lithuania until the beginning of 2007 provided to 120 people in case of non response to IFN or IFN+RBV treatment
Slide 13	**Slide 14**
Barriers to HCV treatment II • Limited free of charge diagnostics: • Not possible to get reimbursement for some tests like, confirmatory test, RNA and genotype tests; e.g. in Ukraine; in Russia antibody tests available through GPs, covered by health insurance, a person has to pay for all other tests; • "Ceilings" how many people can get free of charge diagnostics each year, e.g. in	**HIV/HCV co-infection** • HCV co-infection with HIV is common particularly among IDUs, who acquire both viruses from injecting drugs; • A study among people living with HIV and AIDS (PLWHA) seeking care showed high prevalence in the Eastern Europe o Estonia - 80%; Latvia - 61%; Russia - 52%; and Ukraine - 77–80%). (WHO Europe, 2006)

Lithuania due to centralized purchase of tests, by the end of 2006 there were no diagnostic tests available; • Stigma and discrimination against IDUs, especially on behalf of health care professions; • Lack of cooperation between drug treatment and infectious disease specialists and lack of information about HCV treatment among IDUs (supposedly low compliance, drug interaction, possible re-infection); • Limited access to additional care and treatment, substitution treatment (not available in Russia, Belarus, limited in Ukraine), mental health management and counselling on side effects, usually provided only by doctors appointing treatment and peer support limited	
Slide 15	**Slide 16**
Treatment for people with HIV/HCV co-infection • In some – for example Belarus – co-infection reported to be one of the criteria excluding people from HCV treatment; • In Russia – co-infection is the only way to get State funded treatment; • Becoming available in countries receiving funding from large donors: o In Belarus 40-50 people with HIV will receive HCV treatment in the framework of Global Fund grant o Ukraine – with the support of World Bank plans to enrol 200 people living with HIV in HCV treatment. As of Feb, 2007 the drugs still were not purchased)	**Lack of attention to HCV in prisons** • Average of 20–40% of prisoners are infected with HCV, rates of HCV among prisoners who inject drugs is usually two to three times higher than among prisoners who have no history of injecting drug use; WHO (2005). *Status Paper on Prisons, Drugs and Harm Reduction*, World Health Organization Regional Office for Europe, Copenhagen, 2005. • In many prisons, evidence-based prevention policies and strategies are absent; o currently no needle and syringe programs; o substitution treatment only in the Czech Republic, Poland, Slovenia. • Additional risks like tattooing, sharing of razors not addressed; • Most countries offer testing for HCV when symptoms occur; o In Slovakia suggested to all suspected, diagnosed, self-reported drug users o In the Czech R. mandatory to all suspected, self-reported drug users; • In most countries HCV treatment not available in prisons, due to lack of funds
Slide 17	**Slide 18**

Actions needed	**Actions needed II**
• National hepatitis **strategies on national level** and **EU-wide actions**: focused and systematic approach demonstrating political leadership and commitment; • **A supportive environment** for services that **reduce vulnerability** related to HCV and risk behavior, increasing access to health services; • **Protection of the human rights and legal interests** of those affected by HCV and the **meaningful involvement of drug users and people with liver disease** are essential components of effective policies and practices; • Implementation of **evidence-based, targeted preventive measures** • needle and syringe exchange and provision of other injecting equipment; drug treatment, including substitution treatment; education and counselling, low threshold, voluntary testing with pre- and post-test counselling for HCV; peer education and support; vaccination for hepatitis A and B	• **Treatment** of chronic HCV with the most effective drugs available **for all who need it, including drug users and clients of substitution treatment programs. Drug users should not be excluded from HCV treatment;** eligibility for treatment should be decided on a **case-by-case basis**; • **Comprehensive care and cooperation** of specialists, peers and their relatives**;** • The availability of preventive measures **in prisons** should be **equal** to that provided in the community; • It is crucial to implement these measures **simultaneously**, **make them affordable, accessible and effective** taking into account specific needs of drug users.

Slide 19	
For more information info@harm-reduction.org EHRN publications on HCV in English and Russian: • Hepatitis C infection in Europe (2007) • Hepatitis C Among Injection Drug Users in the New EU Member States and Neighbouring Countries: Situation, Guidelines and Recommendations (2007) • Hepatitis C Among Injecting Drug Users in the New EU Member States and Neighbouring Countries: Key Facts and Issues (2007) • Hepatitis C Among Injection Drug Users in the New EU Member States and Neighbouring Countries: Recommendations for Action (2006) All available at www.harm-reduction.org	

Minutes: Peter Wiessner (EATG) and Martine de Schutter (AIDS Action Europe), May 2008