

Report of the 8th HIV/AIDS Civil Society Forum Brussels, 3-4 November 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



The EU HIV/AIDS Civil Society Forum



Contents

1	Opening.....	3
2	Report from last meeting.....	3
3	Follow up on action list last CSF meeting.....	3
4	Think Tank agenda.....	4
5	New Co-chair.....	4
6	Human rights.....	5
6.1	EU Equality Directive.....	5
6.2	People living with HIV Stigma Index.....	6
7	Testing.....	6
8	Travel restrictions.....	6
9	Recently launched publications.....	6
10	New EU Policy on HIV/AIDS.....	7
10.1	Strengths and weaknesses of the current Communication.....	7
10.2	Priorities for the new Communication.....	8
11	Ethical code.....	11
12	Updates on the EU Presidencies.....	12
13	Vienna – World AIDS Conference.....	12
14	Any other business.....	13
14.1	UNAIDS.....	13
14.2	European Agency for Health and Consumers.....	13
14.3	Cook case in Portugal.....	13
14.4	Working groups.....	13
15	Action list.....	14
16	Annexes.....	14
16.1	Annex A – List of participants.....	14
16.2	Annex B – presentation Yusef Azad (NAT).....	16
16.3	Annex C – presentation Kevin Osborne (IPPF).....	17
16.4	Annex D – presentation Ferran Pujol I Roca (BCN Checkpoint).....	19
16.5	Annex E - Travel restrictions.....	23

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 the planning of the development of the new EU Communication on HIV/AIDS, human rights and testing, among others.

1 Opening

Opening of the meeting by Ton Coenen; introduction of the members of the CSF; adoption of the preliminary agenda by the participants.

2 Report from last meeting

The report of the last meeting was adopted.

3 Follow up on action list last CSF meeting

What	Who	Status
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	?
Circulate the list of questions on counselling guidelines from the Canadian activists	Daniel Bruttin; Swiss AIDS Federation	Done
Put relevant data on counselling guidelines on the AAE clearinghouse	Martine	Done
Circulate the announcement of a satellite on the Swiss Guidelines during the Glasgow Conference	Wim	Will send info
Improve communication to Interservice group on HIV/AIDS, inform the Interservice group about the CSF.	Wolfgang	No regular meeting held, next one is end November
Welcome letter to new Commissioner	Ton, Nikos	Not done
Table with CSF priorities to new Commissioner	Wolfgang	Commissioner has not been informed yet by Wolfgang.
Information about possibilities to provide input into briefing papers for the Commissioners visit of the Moscow Conference, visit with local NGOs	Wolfgang	Commissioner did not attend EECAAC
Information about the technical meeting between WHO and the German ministry, participation of CSF?	Martine	Done. Peter will send more info on the meeting.
Draft letter to the UNAIDS PCB	Raminta, Vitaly	Final letter was sent
Follow up on the MSM NGO meeting in Slovenia	Arnaud	Ljubljana declaration was issued
Follow up on the MSM meeting prior to the IAC	Ton	Done
Follow up on the ECDC/WHO EUR meeting on 17. April	Jeff	Visit done by Ton/Nikos, MoU will be developed, ECDC is now observer in CSF
Circulate minutes meeting task force travel restrictions	Andreas	Not done
Present outcomes data collection on travel restrictions	Denis	Peter disseminated quick reference booklet
Send reference new regulation asylum seekers	Cinthia (PHEA)	Not done
Working group on community recommendations migrants	Rhon (lead)	Started
Open letter to 3 upcoming Presidencies	Arnaud	Letter to Sarkozy was forwarded to CSF

UNGASS subgroup for follow-up	?	?
Priorities CSF detailed report	Ton	See report CSF
Start working group on vulnerable groups	Rhon	?
Start working group on pricing	Mirjam	Not started
Start working group on GIPA	Andreas	Not started
Start working group on human rights	Yusef	Started - and equality directive campaign begun
Start working group on strengthening NGOs Eastern Europe	Raminta	Not started
Invite Charles Gore to next CSF meeting	Raminta	Not done
Start working group on Hepatitis C	Raminta	Not started
Send letter UNAIDS PCB	Raminta, Andreas, Peter, Wim	Has been sent
Invite new PCB representative Sonia Weinreich to CSF	?	Invite to next CSF
Send letter to Thailand	Raminta, Luis M., Peter	Has been sent
Prepare backgrounder on ethical code	Chris	Done
Support petition Vlatko	All	Done, politicians have now decided to open centre for IDUs
Inform CSF on action related to Egypt	Othoman	Done
Send minutes of CSF on drugs	Raminta	Done
New prevention technologies on agenda	?	Postponed to one of next meetings when it will be on agenda TT

4 Think Tank agenda

The agenda was updated:

- Yusef Azad (NAT) and Kevin Osborne (IPPF) will present to the TT.
- Round table on free circulation of PLHIV
- Overview on HIV/AIDS projects funded under Public Health Program
- HIV/AIDS strategy
- Work place policy
- ECDC update on HIV/AIDS
- Next EU presidencies

CSF members would like to meet with their TT representatives. Wolfgang will investigate a possible meeting between CSF and TT members at the start of the next TT meeting.

5 New Co-chair

The EU has appointed EATG and AAE as the coordinators of the CSF and the representatives of civil society in the Think Tank. Both AAE and EATG have appointed a co-chair. Ton Coenen has decided to step down as co-chair after three years. AAE has decided to elect Yusef Azad as the new co-chair after this meeting in November. To ensure continuity, Ton will stay on as representative in the Think Tank.

Wolfgang thanked Ton for his work and he's confident that Yusef will take over well.

Nikos shared that the close collaboration with Ton and Yusef will continue in the future. EATG is planning a similar succession of the co-chair next year. Many thanks of the CSF to Ton.

6 Human rights

6.1 EU Equality Directive

Update by Yusef Azad on the sign-on campaign by AIDS Action Europe, EATG and NAT. See attached PowerPoint in Annex B. NAT, together with AIDS Action Europe and the EATG, has recently launched a new initiative on the EU Equality Directive which is an opportunity to prohibit discrimination against PLHIV. What can the European Union do to get things changed? The EU has significant power in the area of discrimination. The EU can, by unanimous decision, agree legislation against discrimination. Current legislation only refers to a certain number of grounds - sex, racial or ethnic origin, religion or belief, age, disability and sexual orientation. There have been developed several Council Directives in the past, on equal treatment in employment. There have also been directives prohibiting discrimination in provision of goods and services for the race and gender grounds.

Recently the Commission issued a draft directive on equal treatment which extends antidiscrimination provisions to all areas beyond employment. How can HIV status be protected in the new directive? Our proposal is that it needs to be included within one of the specified 'grounds', that it can be considered a disability.

What needs to change in the current draft directive:

- description of disability needs to be included
- in a petition, already signed by more than 70 NGOs, we call for a description of disability that includes protection for PLHIV.

The campaign update

- Letters from the CSF were sent to Commission, European Parliament rapporteurs, European Disability Forum, among others.
- NGOs in the CSF should contact their relevant minister and national MEP to lobby for the change in Directive.
- Sign-on to the petition at www.nat.org.uk

Discussion

The majority of member states are in favour of the directive, and about half want to have a fuller definition of disability in the directive. So there's a definite chance to influence the directive. We should try and push as much as we can. IPPF has been involved in the directive in relation to sexual orientation. Germany is the country that seems to be most opposed against the directive. Action Against AIDS in Germany will write an open letter to the Ministry of Health.

Concern was expressed that if people living with HIV were defined as disabled this might force disclosure of status in the workplace. Yusef said the Directive simply required protection from discrimination. Anything else in national law around HIV or disability which breached human rights – such as inappropriate disclosure requirements – should be challenged in law.

IPPF will bring these issues to a meeting with ILGA and other platforms.

Yusef explained that it's not about moving backwards in our views on HIV but moving forward in views on disability. HIV infection is a permanent physical impairment of immune system. The impairment may be invisible to others, and people with HIV may function well on treatment, but when stigma or discrimination are experienced, disability protections apply, just as they do for people with diabetes, epilepsy etc.

Agreement on steps forward:

- Members contact their relevant contacts at the country level.
- Yusef will forward list of nationals working in the Council on the directive, when he gets it.
- Yusef will also prepare some draft text that CSF members can use in their advocacy.
- IPPF and ILGA will take the issue on.

Concerning the timelines: it's a long process because it requires an unanimous decision of the Council. We should start ASAP with the member states work. And we should also keep the momentum with the European Parliament. The expectation is that the Swedish EU Presidency will take the decision on the directive.

6.2 People living with HIV Stigma Index

Kevin Osborne from IPPF presented a new tool, the people living with HIV stigma index. See attached PowerPoint in Annex C. There are many different ways in which stigma affects people. We need some kind of measurement of stigma, to collect evidence. A questionnaire index was developed and pilot tested, the instrument is now being rolled out. GNP+, ICW, IPPF and UNAIDS are involved.

4 key messages:

- It's a research tool, qualitative and quantitative.
- Guiding principle: by and for PLHIV, the whole process is owned and conducted by networks of PLHIV
- It's a measure of change over time
- The process is part of the product, it's a tool for GIPA enactment

What do we want to achieve? Amongst other, to improve certain policies, especially laws on criminalisation, it comes out as one of the biggest issues facing PLHIV.

Six things CSF members can do:

- PLHIV networks: get engaged
- CSF GIPA working group: get involved
- Take up policy issues, especially criminalisation and testing and counselling
- On World AIDS Day a "verdict on a virus" booklet will be launched
- Advocacy with the GFATM (Global Fund on AIDS, TB and Malaria) and others
- Next regional workshops are in Eastern Europe and the Arab region

The tool is available in 8 languages. For further information: www.stigmaindex.org

ECUO (Eastern European network of Organizations of People living with HIV) indicated their interest to be involved in the process in Eastern Europe. WHO Europe and the CSAT (Civil Society Action Team) of ICASO should be contacted as well.

7 Testing

Ferran Pujol I Roca presented BCN Checkpoint, which is the implementation of a community based centre of HIV testing for MSM, in Barcelona, Spain. See the PowerPoint in Annex D. In international studies MSM were found to have a 19 times higher risk than the general population to become infected. The community viral load affects the chances of an individual to get infected, as much as the individual risk-taking behaviour. The rapid HIV test was introduced in 2006. The service at BCN Checkpoint is free, anonymous and confidential. Over the last 3 years more HIV cases are being diagnosed. An intervention model like Checkpoint could contribute significantly in the early detection of HIV and lower the community viral load.

From the CSF members only in the UK, Germany, Bulgaria, Serbia, Switzerland, Estonia, France and the Netherlands do the governments offer rapid test services. In Spain there are examples of rapid testing by governmental health services on the street, this is unacceptable, because there is no good counselling and follow-up.

The CSF co-chairs repeated the invitation to members to present in the CSF national or local initiatives that can be of use to others. If organisations have projects that they would like to share with the group, please inform the co-chairs so that they can be planned for future meetings.

8 Travel restrictions

Peter presents the call for a European response to remove HIV-related travel restrictions by 2010. It is in follow-up with the UN task team on travel restrictions. Now it's time to move European governments forward on removing these restrictions. The CSF adopts the document, [see Annex E] with the inclusion of a few lines on the CSF. Peter will come up with concrete proposals on how to work with the call.

9 Recently launched publications

Jeff presented some recent publications. You can send him an email (JLA@euro.who.int) how many copies you would like, especially concerning the Dublin policy brief.

- Full Dublin declaration progress report (English)
- Policy brief on Dublin report (English & Russian)
- Central European Journal on Public Health special on HIV/AIDS
- Supplement of HIV Medicine on the HIV in Europe conference
- Restoring hope: care-giving and faith-based organisations

10 New EU Policy on HIV/AIDS

Civil society was involved in the development of the last Communication on HIV/AIDS. The EC will develop a new Policy (Communication) on HIV/AIDS which has to be ready in 2009. In order to be able to give as much input as possible the CSF had an extensive discussion on:

- the evaluation of the present policy (the EU communication on HIV/AIDS)
- the priorities for the new policy

Wolfgang presented the timelines for the new plan. The communication will be adopted September next year in an oral procedure, which highlights the importance of the document, since it's a discussion between all commissioners. In the next couple of weeks a consultation will take place with key stakeholders such as the CSF and TT, member states and other DGs inside the Commission.

Structure of the new Communication:

- Background: epidemiology, legal and social situation, added value of EU policy
- The response: commitment, political response, empowerment, involvement of civil society, structures of civil society,
- Capacity: prevention, priority regions, priority situations
- The way forward

There will be draft on the table for the next CSF. It is not yet clear what kind of evaluation of the current Communication will be carried out.

10.1 Strengths and weaknesses of the current Communication

The afternoon was spent working in small groups focussing on the evaluation of the present policy.

Strengths

- We have a EU specific policy paper
- Neighbourhood included
- Helped give strength to CSF itself in its interaction with various bodies
- Inclusion of specific language on human rights and harm reduction
- Action plan
- Involvement of civil society: progress at EU level
- Prevention: report Commission on drugs related issues.
- VCT: better in countries where global fund is present.
- Some hard to mention topics at country level are mentioned in this paper: needle exchange, use of condoms. Can be used well for influencing national agendas.
- It makes a benchmark of the rights of PLHIV.
- The action has clear timelines.

Weaknesses

- The paper is comprehensive but embryonic. Perhaps we should attach specific plans as attachments to generic plan.
- Current format is too generic and issues are left out: migrants, gay men, advocacy
- Missing link to other ongoing initiatives such as UNGASS
- Neighbourhood underdeveloped: Central Asia missing
- Action plan is not budgeted, not clear where the money comes from
- No real monitoring and evaluation plan: specific core indicators were supposed to be developed but never done.
- There is the need for an evaluation by the Commission.
- Wording was not so clear in what it means for the member states: what is their role and responsibility
- Inadequate mentioning of specific vulnerable groups
- No mention of special needs of new member states
- Involvement of civil society: at national level there is big problem in some countries, and also concern what will happen for example when Global Fund money phases out

- Education: has anything happened with regard to action plan?
- Research: Commission should report on progress.
- Neighbourhood policy: discrepancy between mention of western Balkans but no corresponding action plan.
- Need for better data on surveillance in vulnerable groups.
- Is the Communication really used and by whom?
- Terminology: define well in new Communication terms like migrants etc.
- Structure of roles of different agencies and stakeholders is very confusing.
- ECDC and DG SANCO relation: who is the lead in some parts of the action plan?
- Imbalance in the implementation of the action plan: surveillance well developed, social field less moved forward.
- Involve more stakeholders
- Focus of EU presidencies did not maintain HIV/AIDS as a continuous line of action

In summary we are happy that the Commission produces the Communication. There is a need for monitoring at the end but also during the implementation. There is a clear complaint about the lack of budget. It is difficult to capture the total budget, but an indication should be available. Whenever there was an EU agency responsible for the activity, there was a clearer roadmap. It is a progressive document and includes the type of things and language we would like the countries to adopt. Perhaps as CSF we could review the action plan and lead some follow-up, reminding the responsible organisations to take action.

Reaction Wolfgang: good to have the feed-back. The formal evaluation is on the agenda, it has to be done, but we need more time to do so. Concerning the budget: there is no direct budget line allocated, but there is indirect budget, from the Commission to the ECDC, Public Health Programme, Global Fund. There are different means and instruments. There should be a clear indication on the Commission website where to get that money. At this stage until 2013 there is no possibility to change the overall budget. Priorities in the Communication are also reflected in the Public Health Programme, 4-5 million euros are spent each year on HIV/AIDS, which is biggest amount for one single disease. It is puzzling who is responsible for what, this will be better defined in next Communication. The new Communication is not going to cover the WHO region, but only EU, accession and candidate and selected number of neighbouring countries.

Feed-back from international observers on how the communication relates to their work:

Denis Haveaux- UNAIDS: will meet with DG SANCO in 2 weeks, will take into account comments CSF.

Teymur Noori - ECDC: plan for next Communication is that ECDC will have big role in monitoring and evaluation, next to surveillance.

Jeff Lazarus- WHO: We welcomed the Communication, but did not pay enough attention to whom the main players are, we need to specify who takes the lead. After the initial excitement at WHO, it was really never mentioned again. It's important CSF keeps it on the agenda.

Follow-up: The CSF will ask the TT members how they used the Communication.

10.2 Priorities for the new Communication

Presentation of the results of the breakout sessions from five subgroups, followed by questions and discussion.

Proposals on structural issues and development process

- There is a need of a National Body developing National Plan for combating HIV/AIDS and coordinating implementation of that plan. The Body has to have allocated budget, and the chairing person needs to be at least on Ministry level, ideally responsible to the Prime Minister in order to be able to negotiate realization of the plan with other Ministers, and also to have influence on the shape of the budget.
- We see the communication as a specific strategic positioning paper/ vision paper. It is a generic document.
- The concept of Universal Access should be the framework for the communication paper.
- We suggest that within the communication three-five priority/focus/niche areas are included in the plan. Those being priority areas of comparative advantage/ issues important to EU (for example travel restrictions)
- Of utmost importance is monitoring, evaluation and reporting with specific timelines indicated, specific key players should be mentioned, indicators and budget should be attached
- Concerning the process: we hope that there would be a better process of engaging member states of ownership of the document

- We want to have a better visibility of the communication. A communication strategy should get developed and followed
- There is a urgent need for a transparent budget (to be added)
- The paper should refer to the Three-ones principles endorsed after April 2004, UNAIDS Conference: a) One agreed HIV/AIDS Action Framework that provides the basis for coordinating the work of all partners; b) One National AIDS Coordinating Authority, with a broad-based multisectoral mandate. c) One agreed country-level Monitoring and Evaluation System. These principles were endorsed to achieve the most effective and efficient use of resources, and to ensure rapid action and results-based management. There is need for the EU Commission to repeat that in the Communication document (Political Leadership).
- The new Communication should be seen first of all as an advocacy tool, so even if its impact is limited because of the non binding nature of the paper is can still empower the actors advocating at national level as well as ensuring a better integration and multi sectoral approach within the European Commission (DG EDU, HEALTH, JUSTICE, EMPL... plus ensure coordination between divisions and agencies)
- Keep a comprehensive approach (although it was felt that the future Action Plan should create a sense of landscapes and priorities)
- Ensure better coordination within the EC
- Get a clear understanding of EC Competencies and EU mandate
- Reference should be made to the UNAIDS policy/statements
- The previous Communication was instrumental in some countries to advocate for 'progressive policies' such as condom use and harm reduction strategies and it would be important to understand how the new Communication could be of use by the government representatives to improve the situation at national level (impact assessment to be proposed to Think Thank members?)

Proposals on content and themes

By themes we refer to issues that should be prioritized in the future communication from the Commission to the Council and European Parliament.

Focus on key populations

- There needs to be a focus on key populations epidemics (key populations should be included in all programs); Universal access should truly be universal, equity should be ensured. That means that the rights and needs of marginalized groups should be reflected and highlighted.
- This applies especially to MSM, mobile populations, (undocumented) migrants and migrants without health insurance, IDUs, sex workers, prisoners.

Universal access

- The new Communication should keep the pressure on the call for universal access to prevention and care and stress that health systems should be supportive to the rights and needs of all (especially the ones most in need).

Human rights, human rights related topics and discrimination

- PLWH and their human rights should be at the heart of the Communication: crucial are: stigma, criminalisation, participation of PLWH, rights in the field of health (transplant, operation), rights in the field of sexuality (positive prevention) and reproduction (access to reproductive health services), data protection, anti discrimination, testing and criminalization of HIV transmissions, travel restrictions, discrimination, MSM.
- Human rights protection, legislative issues and further monitoring of human rights issues in the EU would have added value and is important.
- In general there should be more focus and information on access to rights (PLWH and other stakeholders are not enough aware of the rights of PLWH).
- Under Human Rights we suggest clear reference to universal access to healthcare until 2010 with some reference to marginalized groups.
- Criminalisation is a devastating problem and the Communication should address it showing why is a failure from a public health and a Human Rights point of view
- In addition to the call to respect the Human Rights of PLWH as such we feel that more explicit reference should be made to the double discrimination that affect PLWH because they belong to socially excluded groups or because their behaviour is condemned (Sex workers, drug use...). In particular the abuses and violence that sex workers suffer is a point of great concern and therefore the EC/EU should promote laws which protect the most vulnerable to HIV like sex workers.

- It should also call for more research on Human Rights abuses see Stigma Index to make it operational and produce the evidence to advocate on and measure progress
- Review of all legislation in Member Countries relative to antidiscrimination law, to identify the need of harmonization. That would be with special regard to MSM: MSM antidiscrimination law should be included.
- Travel Restriction is a major problem which need to be addressed in the Communication (this should happen in reference to the findings of the UNAIDS/WHO Task team on travel restrictions)
- Appeal to review and reassess EU legislation on anti discrimination in order to ensure better protection of PLWH and ensure that the AD provisions are implemented (e.g. through the anti discrimination directive in employment, something on the anti discrimination policy and disability).
- HIV Testing and Human rights (ethics and confidentiality crucial principles) , see previous work on this matter, focus on the respect of confidentiality and data protection (EU has a mandate in this field)

Prevention and education

- The Communication should reflect the ("new") epidemic.
- There is a need to scale up, highlight and focus on evidence based prevention, including positive prevention.
- We need linked approaches: HIV and co-infections and other STIs, positive prevention linked to main stream prevention. Plus research linked to social responses as well
- Prevention is key and should target those most in needs (meaning that it would not be bad to have an explicit reference to key populations such as MSM, sex workers drug user's migrants and prisoners. An integrated prevention strategy should be developed with the focus to prevent new infections - not only in the sense of primary prevention but also secondary prevention. The new Communication should also refer to the new definition of prevention (combined integrated prevention) promoted in Mexico (Lancet).
- Under education we suggest the development and monitoring of sexual education programs (rational: some countries still haven't got it)

Neighbourhood policy

- Neighbourhood policy needs to be strong (we suggest expansion of neighbourhood -> East and South).

Civil Society

- Strengthening and involvement of civil society in Europe especially in new EU countries
- Every action in the new Communication should have a civil society component
- There is a strong need to involve PLWH directly (the research project like Stigma index might deliver opportunities.

Surveillance and monitoring

- There is a need to monitor especially the Dublin Declaration since it highlights the strengths and weaknesses in the work of the countries
- More emphasis should be put on 'better surveillance of HIV and Co-Infection especially on Hepatitis C (in new member states).

Harm Reduction

- Harm Reduction: The EC should advocate for the legalisation of substitute treatment and should take HIV and harm reduction in consideration when developing its policies on drugs
- Implementing substitution therapy throughout the region; this would have enormous added value if this would be implemented throughout the region

Research

- Under research and treatment we suggest that the paper clearly expresses the expectation of substantial increase of government support for both Clinical Trials on the area of HIV/AIDS and Social Science research, to develop efficient intervention program, and evidence based policies
- Further research is needed and anti discrimination training services providers at all levels (legal aid, social and community, health) should be promoted and supported by national anti discrimination bodies.

Discussion

The discussion that took place after the presentation of the results from the break-out sessions highlighted on further recommendations to be integrated into the document:

- Integrate the key recommendations of the Dublin Declaration and the non-discrimination clause of the European convention
- Integrate the recommendations of the AAE report on HIV and law and human rights
- Highlight public health as a human rights issue

- Integrate positive prevention at the European level (controversial term) but don't follow the CDC definition of positive prevention
- The document should always reference to and reiterate what already has been achieved (conference outcomes, meetings, declarations, etc.)
- Human rights and discrimination should as well focus on violations at work places, transmissions at work places; Sex work and human rights should be integrated
- We encourage the commission to come up with tools to evaluate the achievements and outcomes
- The communication should sets benchmarks and standards that should be followed by all member states

Questions and answers

Q: What role can the EU communication play in terms of monitoring and reporting on member states (political leadership on national level?)

A: Wolfgang clarifies that it's up to the member states to use the document (and up to the civil society to push and move the content)

Q: To which extent do you want to use universal access as a framework for the paper? Is it a top priority?

A: Wolfgang: it surely will be one of the priorities. It is not established all across Europe but how it is weighted ... This is still open. But there are as well other important topics, like prevention and access to treatment and care.

Q: When will the first draft be available? What is the timeframe?

A: Wolfgang: Next step is to consult with other international organizations, other bodies in the commission. A first draft should be ready by mid January 2009. The next CSF and TT should therefore take place soon afterwards, likely in mid March 2009.

Question to Martine de Schutter on logistics to organize a much wider consultation of Civil Society.

Martine: an early draft would be appreciated. How to integrate civil society in a broader consultation is still open, maybe as email forum. The process needs to be well prepared and thought through. It can be a nightmare because everybody wants to push for his own agenda. We will get back to the CSF with a proposal for the consultation process.

There was a discussion whether a task team should be created to work on the draft. However, it was felt that it's the co-chairs responsibility to reflect on drafts and to organize the procedure. There was no decision in favour for a task group: the process will therefore be guided by the whole group.

Action: co-chairs organize feedback on the first draft of the Communication.

11 Ethical code

Chris Lambrechts explains the reasons for bringing this topic to the floor: There is a general concern, when NGOs rely financially on companies and other sponsors, we should be aware of it. Chris participates in the European Health Policy Forum, another Forum for umbrella organizations. Many of those Organizations do have more than 75% funding by companies, sometimes more than 50% from one company. For that forum, there was a need of a code of conduct to reach transparency. Some months ago there was a huge discussion of the impact of pharmaceutical companies, who fought for a better "communication" (advertisement) to patients. There is a general fear of increase of pharmaceutical company's wish to influence the agenda of NGOs. Therefore, every NGO that receives funding from pharmaceutical industry should have a code of conduct. We should make clear as the CSF that this is of concern for us. This is basically a plea for any member of the CSF.

There was a lengthy discussion on whether the CSF needs such a code of conduct or not, how to introduce it and who would have to control it. Some requested that it would be the Commissions duty to ask for it if this is of importance; most of the NGOs present at CSF seem to have already signed code of conducts.

Ton argued that we should refrain requesting a code of conduct, since we don't get any money from anyone.

Martine informed the CSF about the existing NGO code of good practice for NGOs responding to HIV/AIDS and recommended to check it at www.hivcode.org. She informed the CSF on new developments, such as new plans by the EAHC that will limit NGO Public Health Programme funding for operating grants in case they receive more than 50% coverage from industry.

Wolfgang stated that he considers this as an internal discussion. The obligation of the CSF is to advise the Think Thank on HIV/AIDS and the Commission. He reminds us on the email that was sent to publish the names of the members of the CSF on the webpage.

Conclusion

Katarina Jiresova will present the Code of Good Practice mentioned above, since she was involved in its creation. It was generally felt that we should refrain from implementing a mandatory code of conduct for the members of the CSF, since the EU decides on the membership – it would be for the Commission to determine the criteria for selection.

The following questions will be dealt with during the next meeting:

- Presentation of a code of good practice for the next CSF
- What are the EU parliament requirements?

Action: Code of conduct: Co-Chairs prepare the topic for the next meeting of the CSF (invite speakers etc)

12 Updates on the EU Presidencies

France

HIV was not on the priority of the French presidency, we should complain about that at the TT meeting.

On 21 November 2008: meeting on late diagnosis and undiagnosed infections, co-organized with AIDES, organized by the French Ministry of Health. Topics relate to HIV testing, new paradigm on HIV testing, rapid test, which is not as yet allowed in France. The meeting is a follow up from the meeting that took place in Brussels, November 2007.

Given the lack of substantial agenda on HIV/AIDS during the French presidency it was proposed to raise the issue during the Think Tank meeting

Next presidencies

- Czech Republic (first half 2009)
- Sweden (second half of 2009)
- Spain (first half of 2010),
- Belgium (second half 2010)

Agenda Belgium presidency

Chris: the agenda is already under discussion. It should be covered in the discussions at the Think Tank. Wolfgang confirms this, but, at the end of the day, the member states decide what they want to do.

Agenda Sweden presidency

A meeting with minister of health will take place in spring; representatives will be participating a technical meeting on MSM, next week, a meeting with interparliamentary advisory group. So far, there is no information on content, there is little information on possible agenda items to be covered during the presidency. Andreas received an assignment to write about HIV/AIDS for the presidency. HIV is still on the agenda, the door is not closed.

Agenda Spanish presidency

Peter suggests using the Spanish presidency to bring topic of prison health on the agenda. This is an area where Spain looks pretty good in comparison to many other European countries. It might provide the chance to promote harm reduction in prison at EU level, other countries could learn from the Spanish example, which gets quite some coverage at prison health conferences. Ferran says that Spain has nothing to be proud of in its practices in prisons. There are many problems with harm reduction in prisons on the ground. The Spanish Government knows how to make the situation look as good as possible. Peter suggests that NGOs should come up with a shadow report, if this is the case.

13 Vienna – World AIDS Conference

The first preparations for the IAC in Vienna are taking place. There are several chair positions available for community members for certain committees (International chairs community program; scientific committee, global village, regional chairs; community chairs and the Conference coordination committee [CCC]). Some members of the CSF applied or were nominated. ECUO will participate at the global village and in the scientific committee. Decisions will be made in November during the first CCC meeting; the Commission (DG development) has one seat and will participate.

It was proposed to invite a community person involved in the preparations to the next meeting of the CSF, most likely Frank Amort from AIDS-Hilfe Vienna.

Action: invitation of a community person involved in the preparations to the next CSF

14 Any other business

14.1 UNAIDS

Vitaly Duma talked about the NGO delegation for the program coordination board. Each of the meetings of the coordination boards has thematic sessions. Topic of the next session is interaction with the Global Fund. Topic for the meeting in April 2009 will be "people on the move" where migrants and mobile populations will be reflected and the conclusions and recommendations of the International Task Team on HIV related travel restrictions will be discussed. Gracia Violeta Ross Quiroga from Peru will give a presentation as a member of the task team. The NGO delegation to the Program Coordination Board prepares an NGO report. The work on the report will begin in January 2008. The term of the European NGO representative (Vitaly) will end next year. The search for a new delegate from Europe will begin in April 2009.

117 nominations were sent in for the new executive director for UNAIDS. Due to his commitment towards the GIPA principles the NGO delegation to the Program Coordination Board decided to recommend Michel Sidibe, who is now deputy director.

Recommendations are confidential, the NGO delegation hopes that the executive director respects the voice of the PCB.

Action: forward the call for new NGO delegates to the program coordination board to the members of the CSF (Vitaly Duma)

14.2 European Agency for Health and Consumers

The CSF members that have been main beneficiaries of Sanco projects are of the opinion that the new agency EAHC so far has not improved the administrative burden very much. Lack of clarity and inflexibility in financial rules and regulations are of main concern. For small NGOs it is very often not possible to live up to rules and regulations; regulations constantly change; it takes a lot of time to make even small changes (a change in a contract can take for example up to a year as a CSF member experienced).

Procedures sometimes paralyze everything. There is also concern at policy level: it looks like the new agency sets the priorities and not the Commission. There are questions about the competence and the mandate of the agency: What are the priorities of DG Sanco? There is the fear that the agency influences the implementation of the communication.

Running a EU project is sometimes a financial loss, NGOs get into financial risks, the issue of overhead costs needs to get raised, because 7% overhead does not cover real expenses. So on top of the co-funding, other funding is needed to cover for these expenses not eligible by EC funding.

Another co-funding problem is that the amount of co-funding NGOs have to look for is too high. Mobilization is difficult in certain cases; overhead costs are a major problem.

Co-funding received from the pharmaceutical industry should not be an exclusion criteria. It is difficult for European NGOs to receive money since there are few foundations and other sources that cover the expenses for work that focuses on Europe.

Ton will present these concerns to EAHC at the TT meeting.

14.3 Cook case in Portugal

Wim presented the Supreme Court decision of the "cook case" in Portugal (Information had been distributed on the CSF members list). Yusef volunteered to participate to work on that together with Luis Mendao and the Portuguese participants of the CSF. UNAIDS will as well react. It was suggested to get in contact with Anand Grover.

14.4 Working groups

Rhon initiated a discussion on the terms of reference and the mandate of working groups. Some working groups had been implemented at the last CSF meeting but little had been achieved. It looks like that the working group on migration was the only working group that organized itself and delivered something. The "driver" of the working groups output were the Lisbon recommendations (lobbying during UNGASS took place) other main topics are currently the EU return directive and the work on travel restrictions (the call for a European response to remove HIV related travel restrictions by 2010). Human and financial resources are needed to write position papers, to create background materials etc. At the moment such resources are not available. AAE will receive Commission funding for an operating grant which includes primarily support for Martine's work in follow-up between CSF meetings and to undertake the civil society inventory on the new policy. But the work of the working groups is not included in this proposal. This could be something to include in next year's proposal.

It was discussed whether inactive working groups should be abolished.

Peter says that we need a term of reference for working group members. It is not acceptable that we create working groups that don't deliver anything. This relates to our own seriousness and accountability as members of the civil society.

It was felt that we should keep the structure as simple as possible. Working groups can be very effective and useful. If people in a working group come up with a certain problem, they should get in contact with working group chairs and work on that. We therefore should keep the groups and link it to the work that is on the agenda and happens during the meetings of the CSF. The work on travel restrictions is one example on how this can be organized.

Nikos pointed out that the working groups can at the minimum play a consultative role, working groups can arise, work can arise or not, we should be as flexible as possible on that. The problem is that we don't have money at this time.

Raminta says that working groups are important for the functioning of the CSF. There should be time during the CSF for discussion. To have efficient work we should encourage people not to join more than one working group. There should be a discussion and decision about the mandate at the beginning of the working groups work. Time during the CSF should be better used, maybe in smaller groups. There is some clarity needed on what is needed.

Action:

- Working group topic will be put on the agenda of the next meeting;
- Co-Chairs of the CSF facilitate a process on the existence of working groups and its members participating (list of working groups to be sent for sign-on to the CSF members)

15 Action list

What	Who	When
Send info of a satellite on the Swiss Guidelines during the Glasgow Conference	Wim	ASAP
Send info on the quality assurance conference	Peter	ASAP
Forward list of nationals working in the Council on the equity directive	Yusef	ASAP
Prepare some draft text that CSF members can use in their advocacy on equity directive	Yusef	ASAP
Contact relevant contacts at the country level to push for Equity Directive	All CSF members	ASAP
Present national/local initiative to Chairs to include on agenda CSF	All CSF members	Before next meeting
Send final version call against travel restrictions and inform CSF how to use this tool	Peter	ASAP
Inform CSF about procedure for consultation process on development of new Communication	Martine & Co-chairs	January
Presentation code of good practice	Katarina	Next CSF
Send list of working groups to CSF members and ask to make selection for one (or no) working group	Co-chairs	ASAP
Working group: put topic on the agenda of the next CSF meeting	Co-Chairs	Next CSF
Vienna Conference: invitation of a community person involved in the preparations to the next CSF	Co-Chairs	Before next CSF
Forward the call for new NGO delegates to the members of the CSF	Vitaly	ASAP

16 Annexes

16.1 Annex A – List of participants

SURNAME	FIRST NAME	ORGANISATION
ANDREO	Christian	AIDES
ARILDSEN	Henrik	HIV Europe / NordPol

AZAD	Yusef	National AIDS Trust
BERGLOF	Andreas	RFHP Swedish Association for HIV-Positive People
BJÖRKENHEIM	Corine	Finnish AIDS Council
BRUSSA	Licia	TAMPEP
BRUTTIN	Daniel	Swiss AIDS Federation
CLARKE	Heather	IAVI
COENEN	Ton	AAE
DE SCHUTTER	Martine	AIDS Action Europe
DEDES	Nikos	EATG
DEKOV	Vlatko	HOPS
DONADIO	Irene	IPPFEN
GHERMAN	Liliana	Soros Foundation Moldova
GRIMALSCHI	Sergiu	Deutsche AIDS Hilfe
HAFF	Jakob	STOP AIDS
HAVEAUX	Denis	UNAIDS
ILIC	Dragan	JAZAS
JIRESOVA	Katharina	OZ Odysseus
KHODAS	Hanna	All-Ukrainian Network of PLWHA
KLAVINS	Sandris	AGIHAS
LAMBRECHTS	Chris	SENSOA
LAZARUS	Jeffrey	WHO Europe
LIMA E SILVA	Jose Rojas	LILA
MALKUSZEWSKI	Tomasz	Social AIDS Committee
MELLOUK	Othman	ALCS
NOORI	Teymur	European Centre for Disease Prevention and Control (ECDC)
OSBORNE	Kevin	IPPF European Network
PEJKOVIC	Miso	CAZAS
PHILIPP	Wolfgang	DG SANCO
PROCHAZKA	Ivo	Czech AIDS Help Society
PUJOL I ROCA	Ferran	Projecte dels NOMS-Hispanosida
RAMME-FÜLLE	Beate	Action Against AIDS
RHON	Reynolds	African Hiv Policy Network
SHONNING	Shona	EATG
SOLINC	Miran	SKUC-Magnus
STUIKYTE	Raminta	Central and Eastern European Harm Reduction Network
TOMCZYNSKI	Wojciech	EUCO
VAN DE VELDE	Wim	EATG
VASILEVA	Silvia	HESED
WIESSNER	Peter	EATG
ZHUMAGALIEV	Vitaly	Russian Harm Reduction Network

16.2 Annex B – presentation Yusef Azad (NAT)

SHAPING ATTITUDES
CHALLENGING INJUSTICE
CHANGING LIVES

November 2008

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

The proposed EU equality directive:

An opportunity to prohibit discrimination against people with HIV

Yusef Azad, Director of Policy and Campaigns, NAT

EU powers to prohibit discrimination

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

- Under Article 13 EC the EU by unanimous decision of the Council can legislate to combat discrimination
- BUT such legislation can only address discrimination in relation to the grounds specified in the Treaty – sex, racial or ethnic origin, religion or belief, disability, age, sexual orientation

Current EU discrimination law

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

- Council Directive 2000/43/EC – equal treatment irrespective of racial or ethnic origin: scope covers employment, trade union membership, social benefits, education, provision of goods and services
- Council Directive 2000/78/EC – general framework for equal treatment in employment and occupation: scope covers religion or belief, disability, age or sexual orientation
- Council Directive 2004/113/EC – equal treatment between men and women in access to goods and services

The proposed EU equality directive

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

- Proposed directive on equal treatment irrespective of religion or belief, disability, age or sexual orientation – extends anti-discrimination provisions to all areas beyond employment
- Opinions requested from European Parliament and from the European Economic and Social Committee
- Detailed discussions began October 2008 in Council working group

Why is EU-level protection important?

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

- EU-level protections ensure consistency of legal protection across all member states of the EU
- EU-level protections allow appeal to the European Court of Justice from the member state
- EU-level protections are informed by strong human rights principles: as found in the EU Charter of Fundamental Rights, the European Convention on Human Rights and other human rights instruments

But how can HIV status be protected?

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

- For HIV positive status to be protected, it must come under one of the specified 'grounds' in Article 13 of the EC Treaty
- HIV positive status can be considered a disability, irrespective of symptoms or stage of infection
- HIV positive status is already protected from discrimination as a disability in some EU member states, for example Ireland, Sweden and the UK, but not (or not clearly) in others

Why is HIV positive status a disability?

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

- The concept of disability has changed significantly in recent decades – from a 'medical model' to a 'social model' of disability
- The most current statement on disability in international law is the UN Convention on the Rights of Persons with Disabilities 2006
- Disability can result simply from prejudice against someone with an impairment even when there is no functional problem or environmental barrier

The proposed directive – what needs to change?

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

- The current text of the proposed directive contains no definition or description of disability
- The CSF and nearly 70 NGOs from across Europe are calling in a Petition for the Directive to contain a description of disability which will clearly include all people living with HIV
- Go to www.nat.org.uk for the campaign, the Petition and Q&A looking at the issue in detail with proposed amendments to the directive text

Postscript – access to insurance

TRANSFORMING THE UK'S RESPONSE TO HIV NAT

- People living with HIV find it impossible to access life insurance and many other financial products in most EU countries
- The proposed equality directive would require statistical or actuarial data to justify any proportionate differences in financial services provision
- Current campaign to go even further and require compiling, publication and regular updating of relevant data – as in the gender directive

The campaign – what needs to be done?

TRANSFORMING THE UK'S RESPONSE TO HIV NAT

- Letters have been sent to the Commission, to European Parliament Rapporteurs and to the European Economic and Social Committee
- But the key decision-makers are the member-state Ministers in the Council
- Representations should be made within member states to the relevant Minister and to national MEPs on the two relevant EP Committees
- Two proposed amendments to the Preamble to the Directive to ensure an EU definition of disability which includes asymptomatic HIV infection

www.nat.org.uk

TRANSFORMING THE UK'S RESPONSE TO HIV NAT

**SHAPING ATTITUDES
CHALLENGING INJUSTICE
CHANGING LIVES**

National AIDS Trust is a registered charity, number 2472977 and a company limited by guarantee (registered in England and Wales) number 2175935. Registered office: Target Works Ltd, 29 Longle Hill, London EC4M 7JF.
© National AIDS Trust 2008. All rights reserved. No part of this publication may be copied or transmitted in any form or by any means without the National AIDS Trust's permission.

16.3 Annex C – presentation Kevin Osborne (IPPF)

THE PEOPLE LIVING WITH HIV STIGMA INDEX

**'Gathering the Evidence':
The People Living with HIV Stigma Index**

Kevin Osborne
HIV Advisor
IPPF: London
3 November 2008

IPPF UNAIDS

THE PEOPLE LIVING WITH HIV STIGMA INDEX

What we know.....

- Pervasive power of stigma & discrimination
- Affects uptake of all services
- Different forms (enacted, internal)
- Programmatic interventions
- Subtly of stigma & discrimination has changed
- 'Evidence' of stigma is often viewed as 'soft' research

IPPF

THE PEOPLE LIVING WITH HIV STIGMA INDEX

What we don't know.....

- How does stigma have an impact on the work you do?
- Why and how should we measure stigma?
- How do we ensure that we keep pace with the changing face and realities of stigma as it affects PLHIV?
- How do current policies exacerbate HIV related stigma and discrimination?

How can the evidence generate change in
 policies such as criminalisation and the GIPA (Greater Involvement of PLHIV) Principle?
 programme responses such as testing?
 the lives of people living with HIV?

IPPF

THE PEOPLE LIVING WITH HIV STIGMA INDEX

Evidence Informed: Filling that Missing Gap

- March 2004: IPPF and UNAIDS and PLHIV networks Consultative Meeting at IPPF offices, London
- Jan – Dec 2006: Pilot the questionnaire Kenya; Lesotho; India; South Africa and Trinidad and Tobago Supported by UNAIDS Regional Office
- 2007: Finalisation of Questionnaire and User's Guide Sampling; reliability; weighting; Epi- info; collation of information
- 2008: Regional Roll Out Training of PLHIV networks and country roll out Supported by DFID and GTZ

IPPF



The People Living with HIV Stigma Index

- Research Tool: Quantitative and Qualitative**
Questionnaire and User's Guide
Quantitative questionnaire and in-depth case study research
- 3 main sections; referral; quality check
- Guiding Principle: By and for people living with HIV**
- Measure:**
Change over time of experiences of stigma
What is and isn't working; unintended outcomes
Experiences of different communities most vulnerable to infection (MSM; IDU; Sex workers; migrants, women and young girls) and where and how HIV stigma 'attaches'
Stigma in different settings e.g. workplace, home, community, church, self
Links with other measurements of stigma: health care providers; household/community
- Process = Product**
Tool for GIPA enactment : product of a partnership between IPPF, UNAIDS, GIPA and ICW
Referral, follow-up, 'side by side' interviewing
Capacity building of PLHIV capacities and networks



5



Ten sections of the Index:

- Experience of Stigma & discrimination from others
- Access to work and services
- Internal stigma and fears
- Rights, laws and policies
- Effecting change
- Testing & diagnosis
- Disclosure & confidentiality
- Treatment
- Having children
- Self-assessment of stigma & discrimination



6



A Sample of the Index:

Section 3.4: Having children

8. Has a health care professional ever advised you not to have a child since you were diagnosed as HIV-infected? Yes (%) No (%) Not applicable (%)

9. Has a health care professional ever advised you not to have a child since you were diagnosed as HIV-infected? Yes (%) No (%) Not applicable (%)

10. Is your ability to obtain antiretroviral treatment conditional on the use of condoms or other forms of contraception? Yes (%) No (%) Not applicable (%)

11. If interviewed as a woman, go to Section 3.5

12. Has your community been advised or are you pregnant? Yes (%) No (%)

13. If the answer to both questions 8 and 9 is NO, go to Section 3.5

14. Have you been advised by a health care professional in relation to any of the following since you were diagnosed as HIV-infected? (Tick one or more boxes as appropriate)

Formulation of pregnancy intentions	Do this first, 12 completed	Refused to do this
Intention of getting pregnant	(%)	(%)
Intention of getting pregnant	(%)	(%)
Intention of getting pregnant	(%)	(%)
None of the above mentioned to me (%)	(%)	(%)

15.1 Have you ever been given antiretroviral treatment to prevent mother-to-child transmission of HIV? Yes (%) No (%)

15.2 If yes, were you also given training about healthy pregnancy and breastfeeding? Yes (%) No (%)



7



Using evidence to generate change

Evidence to improve policies and ensure that policies are grounded in the realities of living with HIV. The findings from the index will be used to promote the human rights of people living with HIV and advocate for policy change on key issues including the criminalization of HIV transmission

Improved programs influenced by the perspectives of people living with HIV to better meet the needs of people living with HIV and increase access to, and uptake of, services. It will also provide better evidence-informed action to support key vulnerable populations (MSM; SW and people who use drugs)

Models of best practice for the greater involvement of people living with HIV (GIPA) by putting people living with HIV at the centre of the process and ensuring that it remains by, and for, people living with HIV throughout all stages of implementation



8



To date: Capacity Development and Country Roll out

- Regional workshops
 - 5 of 7 done so far
 - 66 organisations; 50 countries
- Seed grants
 - GNP= administered
 - 30 proposals so far, 8 sent, 20 review
- Countries underway in 2008
 - DR
 - Thailand, Bangladesh
 - Zambia, Nigeria, Kenya
- Strengthening regional partnerships
- Resource mobilisation




9



"THE STIGMA INDEX WILL HELP US DOCUMENT OUR OWN EXPERIENCES AND STRENGTHEN OUR ADVOCACY WORK. THIS IS A WAY THAT WE CAN START TO CHANGE THE CONVERSATION - WE WILL HAVE EVIDENCE TO BACK US UP."




"IT'S ABOUT CREATING SPACE FOR PEOPLE TO SPEAK OPENLY. IT'S AN EMPOWERING TOOL."




Six things you can do....

- PLHIV Networks
- GIPA Working Group
- Policy : Criminalisation; PITC
- WAD: 'Verdict on a Virus': 13 Nov
- Advocacy: GFATM
- Next regional workshops:
 - Eastern Europe
 - Arab World



12



16.4 Annex D – presentation Ferran Pujol I Roca (BCN Checkpoint)

bcn checkpoint

HIV-AIDS • STD • SEXUALITY • MEN • HEALTH

Implementation of a Community Based Centre of HIV detection for MSM in Barcelona, Spain

Ferran Pujol
Projecte dels NOMS-Hispanosida

Civil Society Forum
Brussels, 3 November 2008

Impact of HIV in MSM

- The HIV epidemic is not homogeneously distributed among society
- MSM living in low- to middle-income countries have a greater risk of HIV infection than the general population of these countries
- MSM were found to have a 19.3-times greater chance of being infected with HIV than the general population
- In some countries MSM had a 100-times greater chance of being infected (Republic of Georgia: 24-times greater chance; Republic of Senegal: 27-times; China: 45-times; México: 109-times more chance)

Stefan Baral et al.
Elevated Risk for HIV Infection among Men Who Have Sex with Men in Low- and Middle-Income Countries 2000–2006: A Systematic Review
PLoS Medicine, Vol. 4, No. 12, (1 December 2007), e339

Why a Community Based Centre of HIV detection for MSM?

- Significant MSM community in Barcelona
- High HIV prevalence and incidence in MSM
- Vulnerable group (ECDC: "Most-at-risk group" = prevalence > 5%)
- Early detection of HIV (individual and collective impact)
- Peer counseling for MSM for an effective risk reduction

The Community Viral Load R. Stall / CROI 2008

20 different studies reviewed

Average incidence rate of HIV infection in MSM in US and Europe = 2,5%; and in Australia = 1,1%
General population incidence rate = 0,6%

What does a 2,5% incidence rate mean?

If we follow a group of young gay men at the age of 18, none of whom is infected:

- At the age of 18: 100% HIV-
- At the age of 25: 15% HIV+
- At the age of 35: 33% HIV+
- At the age of 40: 41% HIV+

Ronald Stall, PhD, Abstract 53, CROI, Boston 2008

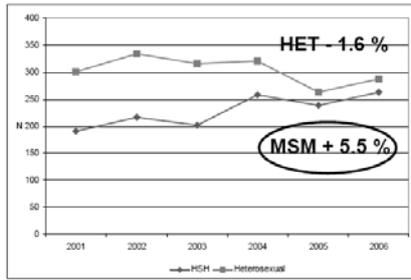
Difference between Europe and Australia

Age	Europe (2,5%)	Australia (1,1%)
18 years	0%	0%
25 years	15%	8%
35 years	33%	16%
40 years	41%	20%

Does the incidence depends on individual behavior?

- No, it also depends on the Community Viral Load
- Within this context, even modest levels of sexual risk- taking can result in very high transmission rates
- It is the context that matters, not the individual risk-taking behavior

New HIV diagnoses and change of annual percentage, by sexual transmission and year of diagnosis. Catalonia, 2001-2006
Source: CEEISCAT. Departament de Salut – Generalitat de Catalunya

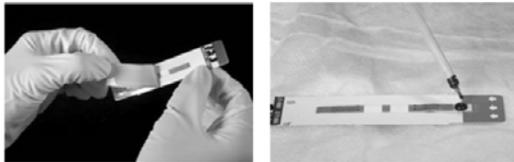


2004

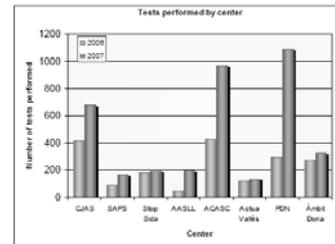
Projecte dels NOMS-Hispanosida established in Spain the 20th October as the "National HIV Test Day"



Projecte dels NOMS-Hispanosida introduced the rapid HIV test (implementation in October 2006)



Impact of rapid HIV test in Catalan NGO
Source: CEEISCAT. Departament de Salut – Generalitat de Catalunya



HIV testing has been performed in Catalan NGO since 1995. With the introduction of the rapid HIV test in October 2006, the number of tests performed during the compared periods showed an overall increase of 118%, and in some NGO reaching more than 400% increase.

Services

- Rapid and conventional HIV test
- Rapid and conventional Syphilis test
- Information about hepatitis (A, B y C)
- Information about other STI
- Information about PEP
- Derivation to Public Health Centres (HIV hospital unit or STI Clinic)

Characteristics and Methodology (1)

- Service is free, anonymous and confidential
- Situated in the middle of Barcelona's gay area
- Peer counselors: all are gay and most are HIV+
- VTC takes up around 1 hour: clients will be able to talk openly about their sexuality, risk perceptions and sexual safety
- Determine™ HIV-1/2 and Determine™ Syphilis TP
- Specific outreach to our community through campaigns and presence of our volunteers in clubs, discos and other gay venues (HIV Task Force)

Characteristics and Methodology (2)

- Men with an HIV positive result, confirmed by Western Blot test, will receive emotional support, and will be offered an appointment in one of Barcelona's HIV units
- They also will be given the possibility to join another program of our organization, called INFOTRAT. This peer-led program, exclusively for and by people living with HIV and AIDS, has two goals: to meet other people in the same situation, and to learn more about HIV/AIDS and their treatment and management
- Men with an HIV negative result will receive counseling in order to maintain sexual safety, and will be invited to repeat the test every 6 or 12 months. Counseling offered includes education to avoid discriminatory attitudes towards HIV positive men within the MSM community

Introduction campaigns of BCN Checkpoint (2006-2007)



Specific campaigns towards youth and non-nationals
(2007-2008)



HIV Task Force of BCN Checkpoint



Results BCN Checkpoint 2007

Number of tests performed	
Total of persons attended	951
Total of HIV tests	1098
Total of Syphilis tests	904

Results BCN Checkpoint 2007

	Number of persons		
	Total	Positive	%
That received an HIV test	938	37	3,94%
That received a Syphilis test	770	25	3,25%

Results BCN Checkpoint 2007

HIV-Syphilis coinfection			
	Total	Coinfected	%
HIV+ tested for Syphilis	28	8	28,57%
Syphilis+ tested for HIV	22	8	36,36%

Results BCN Checkpoint 2007

Distribution of HIV cases by age groups			
	Total	HIV+	%
< 25 years	144	4	2,78%
25 - 35 years	464	16	3,45%
35 - 45 years	261	12	4,60%
> 45 years	69	5	7,25%
Total	938	37	

Results BCN Checkpoint 2007

Distribution of HIV cases by origin			
	Total	HIV+	%
Spain	574	15	2,61%
Other parts of Europe	140	4	2,86%
North-America	7	0	0%
Latin-America	202	17	8,42%
Africa	8	1	12,50%
Asia	2	0	0%
Australia & New Zealand	5	0	0%
Total	938	37	

Results BCN Checkpoint 2007

Data from Public Health Agency of Barcelona (2007)		
	Total	%
Total of HIV cases reported	349	100%
HIV cases reported in MSM	158	45,30%

The 37 HIV cases detected in BCN Checkpoint would be comparable to 23,74% of all HIV cases reported in MSM in Barcelona

Results BCN Checkpoint 2008*

(*until 30 September)

Number of tests performed	
Total of persons attended	752
Total of HIV tests	799
Total of Syphilis tests	716

Results BCN Checkpoint 2008*

(*until 30 September)

Number of persons			
	Total	Positive	%
That received an HIV test	745	45	6,04%
That received a Syphilis test	673	29	4,31%

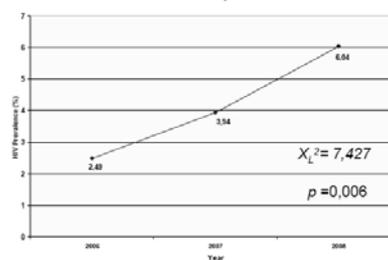
Results BCN Checkpoint 2006-2008*

Results 2006-2008			
Year	Persons	HIV+	Prevalence
2006	281	7	2,49%
2007	938	37	3,94%
2008*	745	45**	6,04%
Total		89	

* until 30 September

** At least 12 out of 45 positive results (26,7%) in 2008 correspond to recent infections (< 1 year)

Results BCN Checkpoint 2006-2008*



The trend for prevalence rate increase is statistically significant, possibly due to an increase of HIV infections and/or to the outreach of the campaigns to the most-at-risk group

Conclusions

- The MSM community has well accepted the concept of BCN Checkpoint, as demonstrated by the satisfactory results from a survey conducted among the clients and the increasing demand (± 40 calls per day)
- Gay NGOs, patient-based organizations, as well as clubs, bars, magazines and other gay business have shown interest in providing support and collaboration to maintain the project
- An intervention model like BCN Checkpoint could contribute significantly in early detection of HIV in MSM and lower the Community Viral Load
- The BCN Checkpoint experience could be used in other urban areas with an important MSM community
- Health Authorities should provide adequate funding for community based centres, and MSM communities should get involved actively in its development
- A community VTC approach for the most-at-risk groups gives better results and is more cost/effective than an approach to the general public
- A strong need for more community evidence based research for MSM

Next steps

- Consolidation of our project
- Extension of our services
- BCN Checkpoint has started a prospective cohort study among HIV negative MSM

Acknowledgments

- CEEISCAT
- LGBT publications and enterprises
- BCN Checkpoint team
- M. Meulbroek, J.Saz, H.Taboada, C. Manzardo
- Volunteers of BCN Checkpoint (HIV Task Force)
- Models of the campaigns

EU HIV/AIDS Civil Society Forum

Call for a European response to remove HIV specific travel restrictions in Europe by 2010

In 2010, the International AIDS Conference will take place in Austria/Vienna. The fact that a European country is chosen as the host for this important meeting should be a great honour for us.

As the EU HIV/AIDS Civil Society Forum representatives, we see this event as a great challenge for a reinforced European commitment in the fight against stigma and the discrimination people with HIV and AIDS in Europe nowadays still face. There are 21 countries in the WHO Europe region that still have discriminating HIV specific entry and residence regulations in place. We want to see these restrictions removed by 2010 and call the EU institutions and the EU member states to work closely together, to demonstrate leadership by translating the key findings and recommendations of the International Task Team on HIV related travel restrictions into action.

The HIV/AIDS Civil Society Forum 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. The Forum acts as an informal advisory body to the European Think Tank on HIV/AIDS.

We want to see all HIV specific entry and residence restrictions in Europe be removed by 2010 when the global HIV community will meet in Vienna. This can only happen if the European institutions and Member States act immediately by working closely together with intergovernmental organisations like WHO, UNAIDS and IOM and civil society organisations in Europe.

Rationale:

For people living with HIV and Aids, travel can be connected with uncertainties since many countries have enacted discriminating entry and residence regulations. 66 of the 186 countries included in a survey by the German Aids Federation DAH have specific entry regulations for PLWHA in place. In another 22 countries, restrictions cannot be ruled out due to contradictory or imprecise information. 30 (!) countries do not stand back from deporting people living with HIV or asking them to leave the country once they are detected to be HIV-positive. The majority of countries with entry restrictions require mandatory HIV tests. Findings are published at the global database on HIV specific travel restrictions at ww.hivtravel.org.

There are currently 21 countries in the WHO Europe region with HIV specific restrictions in their legislation. These restrictions range from the denial of work and residency applications and study permits due to HIV status, (treat of) deportations, mandatory HIV tests for certain groups and

populations, like house maids, construction workers, sex workers and people working in the tourism industry, people arriving from endemic regions and returning citizens. There are European countries that consider HIV as a disease that is threatening public health and that refer to restrictions imposed on people living with HIV and AIDS as good public health standard.

Entry prohibitions generally affect persons who want to stay in a country for longer than three months. It depends on the duration of the stay whether an HIV test must be presented for approval of the stay, or not. HIV-positive test results generally lead to refusal of entry or to being forced to leave if one is already in the country. Such regulations limit people with HIV in the selection of educational opportunities and places of work. This discrimination cannot be accepted in the face of the change of HIV to a treatable chronic disease, since people with HIV – just like any other citizens today – need to plan their education and pursue a profession.

People with HIV are at constant risk of losing what they have built: their workplace and income, access to the health care system, their home, their friends and family, and sometimes their life!

The fact that these restrictions are still in place in so many European countries is shameful. Europe can do much better. European institutions should give a proof and do whatever possible to convince governments and ministries to remove these restrictions. It is up to us to demonstrate that Europe is a dignified host for the participants of the International AIDS Conference.

After 25 years experience with HIV we, as representatives from Civil Society Organisations throughout Europe, know that:

- Restrictions on entry, residence and stay based on HIV don't have a public health justification, since HIV is not very contagious. Transmissions are caused by specific behaviours that are a target for prevention efforts. Safer sex and safer use behaviours should be observed by everyone (independent of nationality, residence and HIV status). Screening at borders sends the wrong message and undermines public health efforts on HIV prevention and care.
- Restrictions on entry, residence and stay based on HIV infection are discriminatory and fuel negative perceptions of people with HIV as a burden to the health care budget, as virus carriers and as a threat to public health.
- Restrictions on entry, residence and stay based on HIV are contradictory to the GIPA principles (greater involvement of people living with HIV and AIDS); they deny the great contribution people with HIV make to society.
- Restrictions on entry, residence and stay based on HIV and forced HIV disclosure drives people away from health care services, it threatens the health of HIV positive individuals, leads to self stigmatisation, imperils self empowerment and increases the vulnerability of people with HIV.
- Restrictions on entry, residence and stay based on HIV imperil some of the most important public health principles and commitments taken by States to ensure access to treatment and care are in contradiction to political commitments.

Recalling the Declaration of Commitment and HIV/AIDS (2001) adopted by the special session of the General Assembly of the United Nations in June 2001 *"By 2005, develop and begin to implement national, regional and international strategies that facilitate access to HIV/AIDS prevention programmes for migrants and mobile workers, including the provision of information on health and social services."*

Recognizing the Political Declaration on HIV/AIDS (2006) where Governments called for the scaling up of *“comprehensive responses to achieve broad multisectoral coverage for prevention, treatment, care and support with full and active participation of people living with HIV, vulnerable groups, most affected communities, civil society and the private sector towards the goal of universal access to comprehensive prevention programmes, treatment care and support by 2010.”*

Recalling your commitment as States in Europe to scale up the response to HIV/AIDS in the European Region of WHO to end travel restrictions, as declared in the WHO Regional Committee Resolution 9: *“(f) to develop a supportive social and legal environment for groups at risk, especially sex workers, and for people living with HIV/AIDS and to fight social and legal exclusion, including travel restrictions.”*

Taking into account the International Guidelines on HIV and Human Rights (1996/2006), stating that *“There is no public health rationale for restricting liberty of movement or choice of residence on the grounds of HIV status. [...] Therefore, any restriction on these rights based on suspected or real HIV status alone, including HIV screening of international travellers, are discriminatory and cannot be justified by public health concerns.”*

Recognizing the UNAIDS Practical Guidelines for Intensifying HIV Prevention: Towards Universal Access (2007) underlined the importance of including programmes for migrant workers and mobile populations within national HIV responses.

In light of these commitments and the negative impact of the restrictions we, the EU HIV/AIDS Civil Society Forum, urge the European institutions and Member States to work closely together towards the removal of HIV specific entry and residence restrictions:

1. The EU HIV/AIDS Civil Society Forum urges all States in Europe with HIV-specific restrictions on entry, stay and residence, in the form of laws, regulations, and practices, to review and then eliminate them, and ensure that all people living with HIV are no longer excluded, detained or deported on the basis of HIV status.
2. The EU HIV/AIDS Civil Society Forum urges all States in Europe to ensure the full protection of the human rights of people living with HIV in the context of mobility, under the international human rights framework.
3. The EU HIV/AIDS Civil Society Forum urges all States in Europe to stop exclusionary policies and include all mobile and hard-to-reach populations like migrant workers, undocumented migrants or migrants without health insurance into health care programmes, to ensure universal access to treatment, care and support.
4. The EU HIV/AIDS Civil Society Forum urges all States in Europe to stop any expulsion of undocumented persons with serious illnesses, or detention measures before expulsion, as stipulated by the Committee on Civil Liberties, Justice and Home Affairs of the European Parliament (20.9.2007, REPORT on the proposal for a directive of the European Parliament and of the Council on common standards and procedures in Member States for returning illegally staying third-country nationals (COM(2005)0391 – C6-0266/2005 – 2005/0167(COD)).
5. The EU HIV/AIDS Civil Society Forum encourages the European Commission to improve our knowledge about the situation in different States in Europe and to monitor the impact of HIV-

specific restrictions on entry, stay and residence in Europe, especially to report on HIV related deportation and access to treatment and care services for mobile populations.

6. The EU HIV/AIDS Civil Society Forum encourages the intergovernmental institutions in Europe, especially WHO Europe, IOM, UNAIDS to work closely with European States with HIV specific travel restrictions towards their removal.
7. The EU HIV/AIDS Civil Society Forum encourages intergovernmental bodies like WHO Europe and UNAIDS to get in contact with countries in Europe that consider HIV as a disease threatening public health and that promote HIV specific restrictions as good public health principles to convince them on the contrary.
8. The EU HIV/AIDS Civil Society Forum encourages the European States, as part of UNGASS reporting, on whether they have HIV-specific restrictions on entry, stay and residence or have removed them during the reporting period.
9. The EU HIV/AIDS Civil Society Forum encourages the European Commission to support leadership through the development of advocacy tools and a communications strategy; engagement of the broadest possible range of partners; and strategic support to civil society to take up the issue of HIV-specific restrictions on entry, stay and residence, including facilitation of dialogue between government and civil society.
10. The EU HIV/AIDS Civil Society Forum encourages the European Commission to support the continued collection of information and evidence through strategic support to civil society efforts to develop and maintain a comprehensive, sustainable and publicly available global database on HIV-specific restrictions on entry, stay and residence with references to available laws, policies and practices, and the commissioning of necessary research on relevant economic, public health and human rights issues related to such restrictions.
11. The EU HIV/AIDS Civil Society Forum encourages the European Commission to promote and support the leadership of communities most affected by HIV specific travel restrictions and encourages further documentation of how such restrictions affect diverse groups of people and to build up and strengthens coalitions through the active engagement of a wide range of partners, including migrant organisations, law and human rights groups, and trade unions.
12. The EU HIV/AIDS Civil Society Forum encourages intergovernmental bodies, especially WHO-Europe, UNAIDS and IOM to work closely together with civil society to develop a policy brief on HIV testing among people crossing borders, migrants and mobile populations, to break the WHO guidance on provider initiated HIV testing and counselling (2007) down to the reality migrants face in European States and to initiate a dialogue between civil society, migrant organisations and European States to ensure that minimal standards on HIV testing and counselling are respected.
13. The EU HIV/AIDS Civil Society Forum encourages the European Commission to promote and support balanced and non-discriminatory and non-stigmatizing media coverage on HIV positive migrants and people crossing borders. Media in Europe does have a great responsibility to develop a sensitized understanding of the vulnerability of mobile populations. Further research should be supported to measure the counter productive impact on discriminative media coverage on public health.
14. The EU HIV/AIDS Civil Society Forum encourages the European Commission together with intergovernmental bodies, like WHO Europe, ECDC and UNAIDS to improve our knowledge about costs-effectiveness of access to HIV treatment and care for all (without exclusion of certain groups like mobile populations and undocumented migrants).

Adopted by the members of the EU Civil Society Forum, 03 November 2008