# Report of Informal Consultation with NGOs on HIV/AIDS Policy

# and

# Results NGO Questionnaire

**Brussels, June 13, 2005**

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


## Content

# I. Pre-consultation questionnaire report

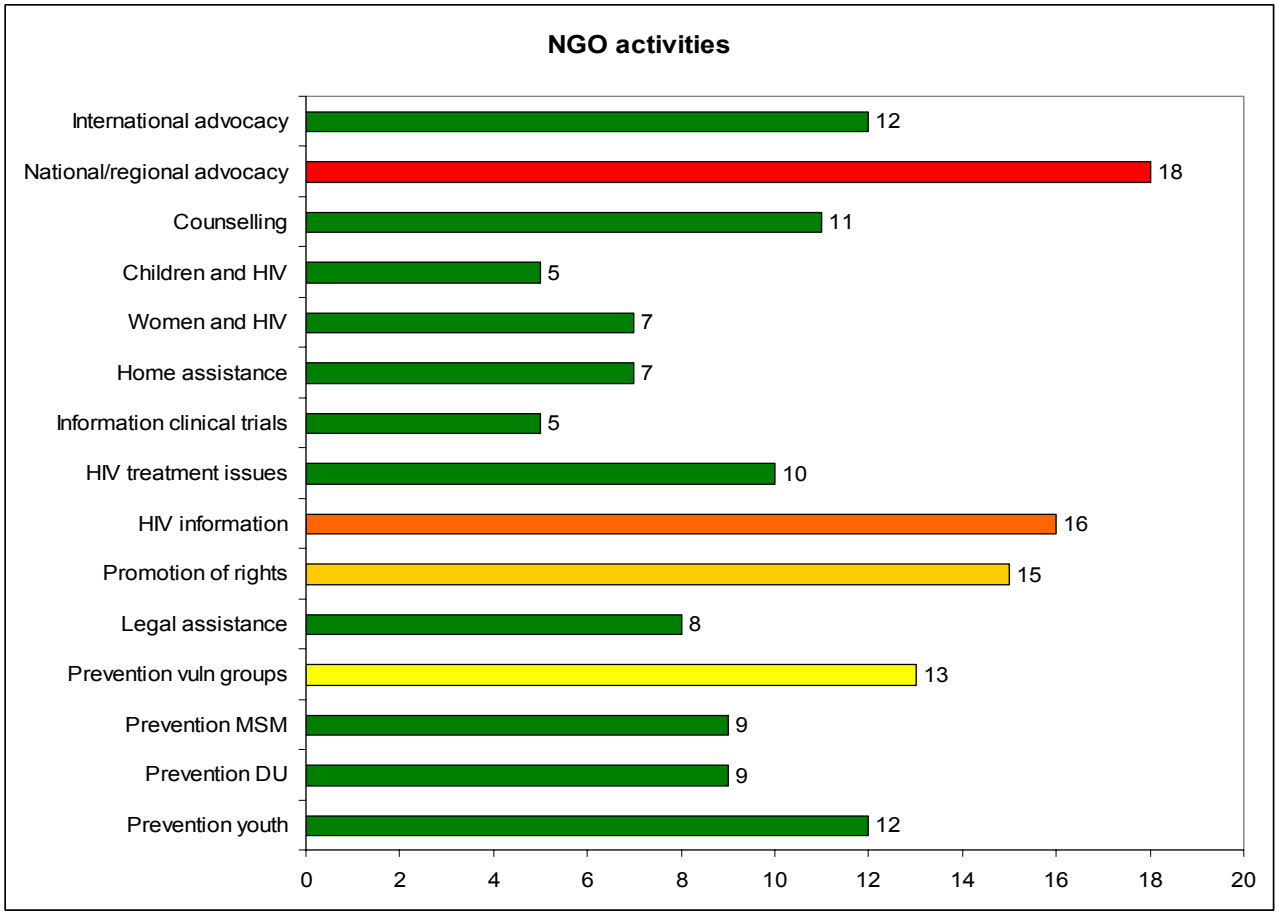
## *Introduction*

This survey was proposed as part of the NGO consultation process to the EU Commission's DG SANCO. Its aim was to illustrate the situation regarding HIV prevention and treatment from the point of view of AIDS service organizations working in the communities. 19 NGOs from 16 European countries completed the survey, of which 9 with focus on the new EU member states and neighbouring countries, and 10 with working focus on EU-15 member states. As these two groups showed high internal coherence, the analysis focused on replies from the two groups in addition to those from the entire sample.

In general, participating NGOs cover an ample range of community services, targeted at numerous high risk or vulnerable populations, with an average of 9 working themes per NGO. The distribution of working priorities of the participating NGOs is shown in graph 1 below. Hence, it is conceivable that the respondents may have offered a representative picture of the state of prevention and care of HIV/AIDS from the point of view of community service providers in Europe.

In consideration of the number of participants in the survey, the analysis used a qualitative-quantitative approach, where the content of single issues was noted side by side to the frequency of certain responses.

**Graph 1: thematic priorities of NGOs participating in the survey**



## *NGO views on the priority areas for EU Commission activities*

Each NGO was requested to spontaneously nominate four priority areas for EU Commission activities in view of the HIV/AIDS epidemic situation in their countries. These priorities are listed in table I.

In particular, five areas of intervention emerged: access to care and treatment, prevention, protection of human rights, involvement of PLWHA and their advocates, and financing.

Across the thematic areas, it is evident how NGOs identify the EU as a source for scientific guidance, information distribution and political leadership. NGOs express their wish that EU institutions be a source for evidence based guidelines (on treatment – 3, prevention – 2, human rights – 3, financing – 2) and that it exerts pressure on governments for the respect of such guidelines.

Another transversal tendency is to look up to the Commission for help in areas where government's intervention is still unsatisfactory. Hence, interventions aimed at vulnerable groups, including drug users, migrants, imprisoned people and sex workers are in high priority on each thematic list, as is the political pressure to win local barriers to evidence-based but neglected practices, such as harm reduction and reproductive health.

Within the thematic area of access to care, the role of EU in promoting universal access to care in Europe is predominant. In many cases (7 replies) this universal access seems to imply a geographic connotation, while in another 5 replies respondents clearly state that universal is meant across population groups to include the more neglected and discriminated such as drug users and illegal migrants.

The concern with vulnerable groups and, again mainly drug users and migrants, is clearly evident also from the thematic area of prevention, where 15 out of 18 requests (83%) focus on provision of prevention interventions to vulnerable populations.

However, the area where the political leadership role of the EU commission is most sought is probably that of defence of human rights. NGOs clearly request the commission to be involved in fostering anti discrimination legislation and guidelines. Within this area, the issue that was most frequently associated with a breach of human rights is that concerning the free movement and rights for residency of people with HIV.

Table I: EU priorities for action according to 19 NGOs

| **Themes** | **Number requests** |
|---|---|
| **Access to care** | |
| Universal access to treatment in Europe | 7 |
| Access to treatment to DU / vulnerable groups | 5 |
| Unified guidelines on HIV treatment and care | 3 |
| Unified care for HIV / DU | 1 |
| Psychosocial support | 1 |
| Promote innovative approaches to treatment | 1 |
| **Sub total access to care** | **18** |
| **Prevention** | |
| Promote prevention in vulnerable groups | 4 |
| Expand harm reduction | 3 |
| Prevention / harm reduction in prisons | 3 |
| Prevention in youth | 3 |
| Promote reproductive health services | 2 |
| Education and information | 2 |
| Prevention to general population | 1 |
| **Subtotal prevention** | **18** |
| **Protection of human rights** | |
| Fight stigma and discrimination | 8 |
| Protection from deportation / abolish travel restrictions | 4 |
| Guidelines on respect of human rights | 3 |
| **Subtotal human rights** | **15** |
| **NGOs / PLWHA** | |
| Involve NGOs / PLWHA | 4 |
| Involve vulnerable groups | 2 |
| Development / financing of NGOs | 2 |
| Develop partnerships between government, civil society, private sector | 2 |
| **Subtotal PLWHA involvement** | **10** |
| **Financing** | |
| Guidelines for financing | 1 |
| Increase funding to global responses | 1 |
| Financial support to HIV care | 1 |
| **Subtotal financing** | **3** |

### *Prevention of sexual transmission*

The views of NGOs on what is missing in sexual prevention are summarized in Graph 2. The trend of more need for activities addressed at the more vulnerable groups is repeated.

It is evident that the two most neglected areas, as far as both EU-15 and new EU member states are concerned include prevention in imprisoned persons and prevention efforts targeted at migrants (84.2% and 68.4%, respectively).

On the contrary, areas where the gap in quality of interventions between the new EU member states and EU-15 states is most pronounced are lack in condom distribution (77.8% vs. 10%), lack in interventions targeted at MSM or at sex workers (77.8% vs. 20%) and lack in prevention efforts targeting women (77.8% vs. 40%).

Additional areas for prevention interventions, not foreseen in the survey questionnaire include:

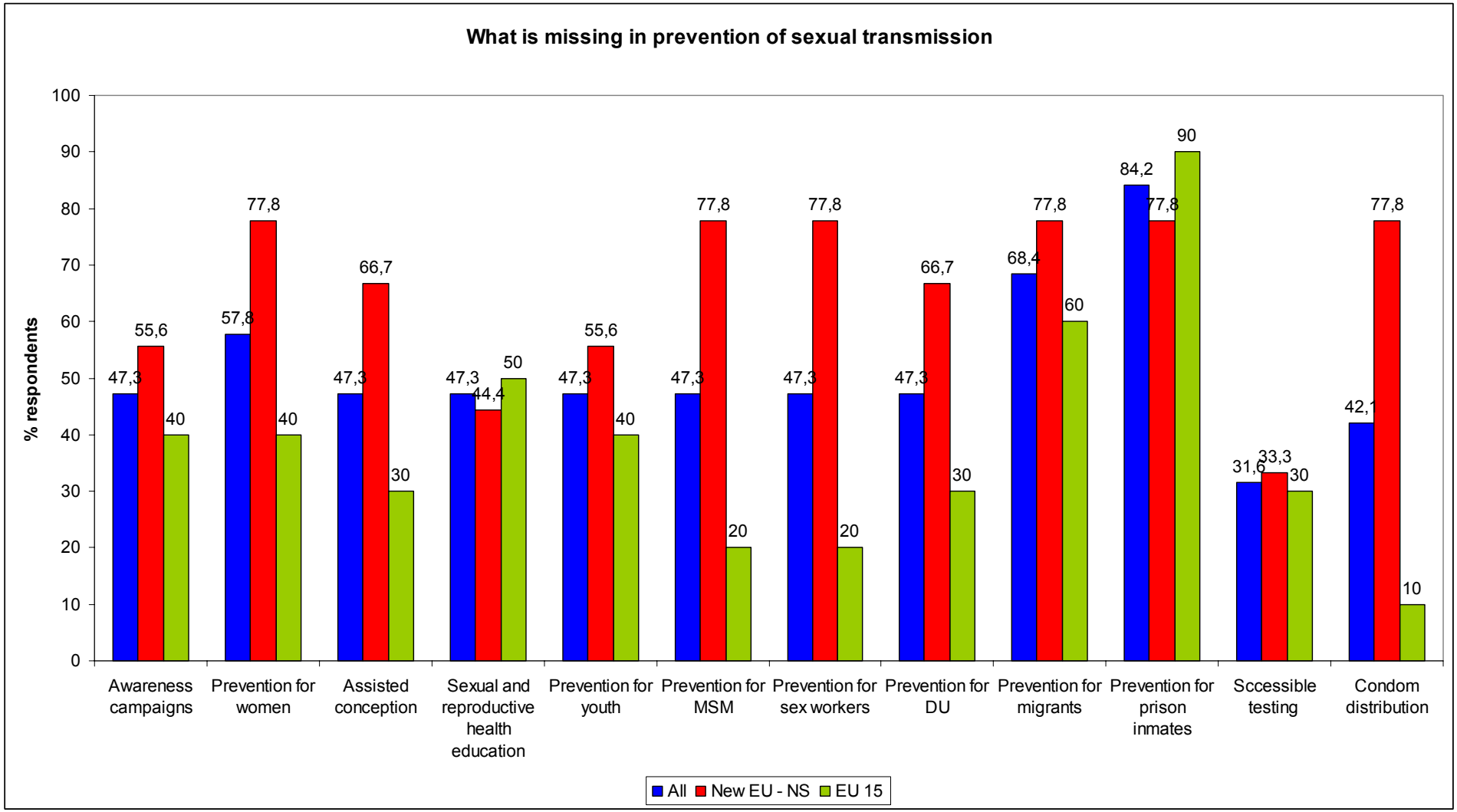
- Increased funding for prevention;
- Prevention interventions targeting heterosexual men;
- Prevention efforts targeting sexual partners of drug users;
- More intercultural approach to prevention.

Expectations from the EU include evidence based guidelines and political pressure to overcome local barriers, and political leadership in targeting vulnerable groups (table II).

Table II: EU interventions for prevention of sexual transmission of HIV

| **Themes** | **Number replies** |
|---|---|
| Evidence based guidelines / programs | 6 |
| Political pressure to overcome local barriers | 3 |
| Wider human rights context | 2 |
| Public health approach | 1 |
| Target vulnerable groups | 3 |
| Education for sex workers | 2 |
| Prevention targeted at women | 2 |
| Foster multicultural approach | 1 |
| Sexual and reproductive health education | 1 |

**Graph 2: what is missing in efforts to prevent the sexual transmission of HIV**



## *Effective control of HIV infection in drug users*

Information on what is missing in the area of HIV control in drug users is provided in graph 3. In this thematic area the difference between the EU 15 and new EU member states is most striking. While acceptable services coverage is reported in EU 15, such services are largely lacking in the countries that joined the EU most recently. The most critical issue is access to HIV medication, which is missing in 66,7% of new EU states that participated in the survey, followed by lacking access to healthcare in general (55.5%), lacking information on harm reduction (55.5%) and insufficient needle exchange and substitution therapy programs (missing in 44.5% of countries).

Other problems in this area, not foreseen by the survey questionnaire include:

- Management of HIV and hepatitis co-infection;
- No connection between HIV and drug use services;
- Discrimination by medical professionals;
- Lack of services in small towns / rural areas;
- No sexual and reproductive health education and prevention of sexual transmission in DU;
- No harm reduction in prisons;
- Stigma and criminalization of drug use as barrier to access to services.

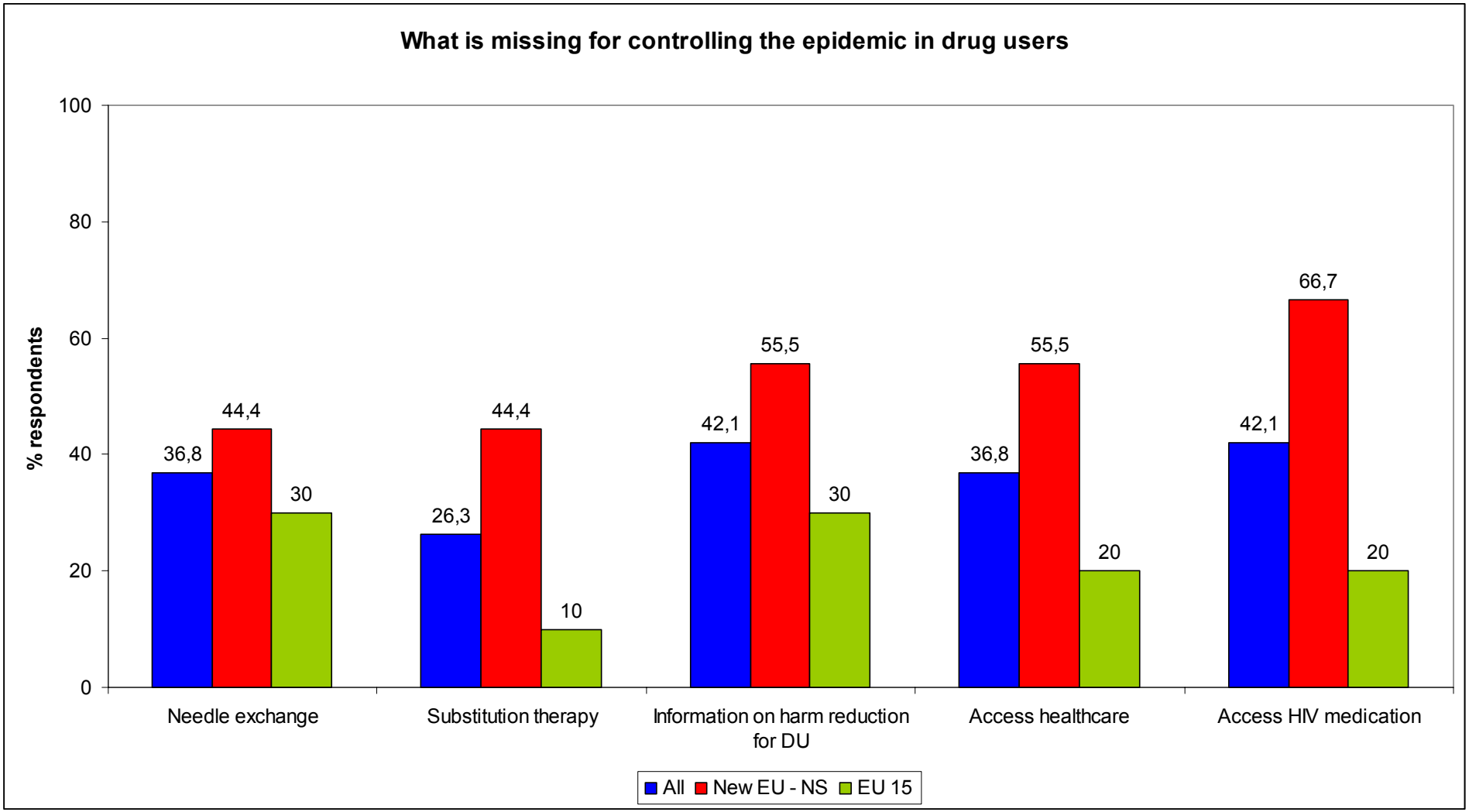
In accordance with the sense of helplessness conveyed by respondents regarding the situation of DU human rights and discrimination and the attitude from local governments and medical professionals, the call for strong political leadership of the EU is more pronounced (table III).

NGOs expect the EU to become the source for evidence based guidelines on harm reduction and on HIV treatment in drug users, and to provide effective political pressure on local governments for the implementation of these European documents.

Table III: NGO expectations from the EU in the field of combating HIV infection in drug users

| **Themes** | **Number replies** |
|---|---|
| Binding evidence based guidelines / share knowledge | 9 |
| Support harm reduction: syringes, condoms, substitution | 7 |
| Support to ARV provision to DU (i.e fixed dose combinations) | 6 |
| Drug law reforms focused on DU health / decriminalisation | 4 |
| DU and HIV services in prison | 4 |
| Promote involvement of PLWHA and DU in policy design | 1 |
| Capacity building of NGOs for advocacy | 1 |
| Support program implementation through NGOs | 1 |
| Interventions for DU who are sex workers | 1 |
| Anonymous testing for all | 1 |
| Projects on DU education for safe behaviour | 1 |
| Information to medical professionals on DU treatment | 1 |

**Graph 3: what is missing in terms of effective control of HIV infection in drug users?**



### *HIV treatment and management*

The level of satisfaction with the standard of care for HIV infection varies largely between new EU member states (average: 2.3 on a scale from one to four) and EU 15 states (average 3.6 on a scale from 0 to four) (graph 4).

The main shortcomings in the management of HIV infection were identified in the new EU states (graph 5) and consisted in difficulty in access to innovative treatments and diagnostic means, and to clinical trials as a vehicle to early access to last generation treatments. Other difficulties in the management of HIV infection included:

- No psychological support to PLWHA on medication;
- Centralized treatment systems;
- Lack of linkage between HIV treatment centres and centres for the treatment of drug use, TB or viral hepatitis;
- Discrimination by medical professional;
- Lack of substitution therapy for DUs in need of HIV medication;
- No reimbursement for advanced diagnostic tools.

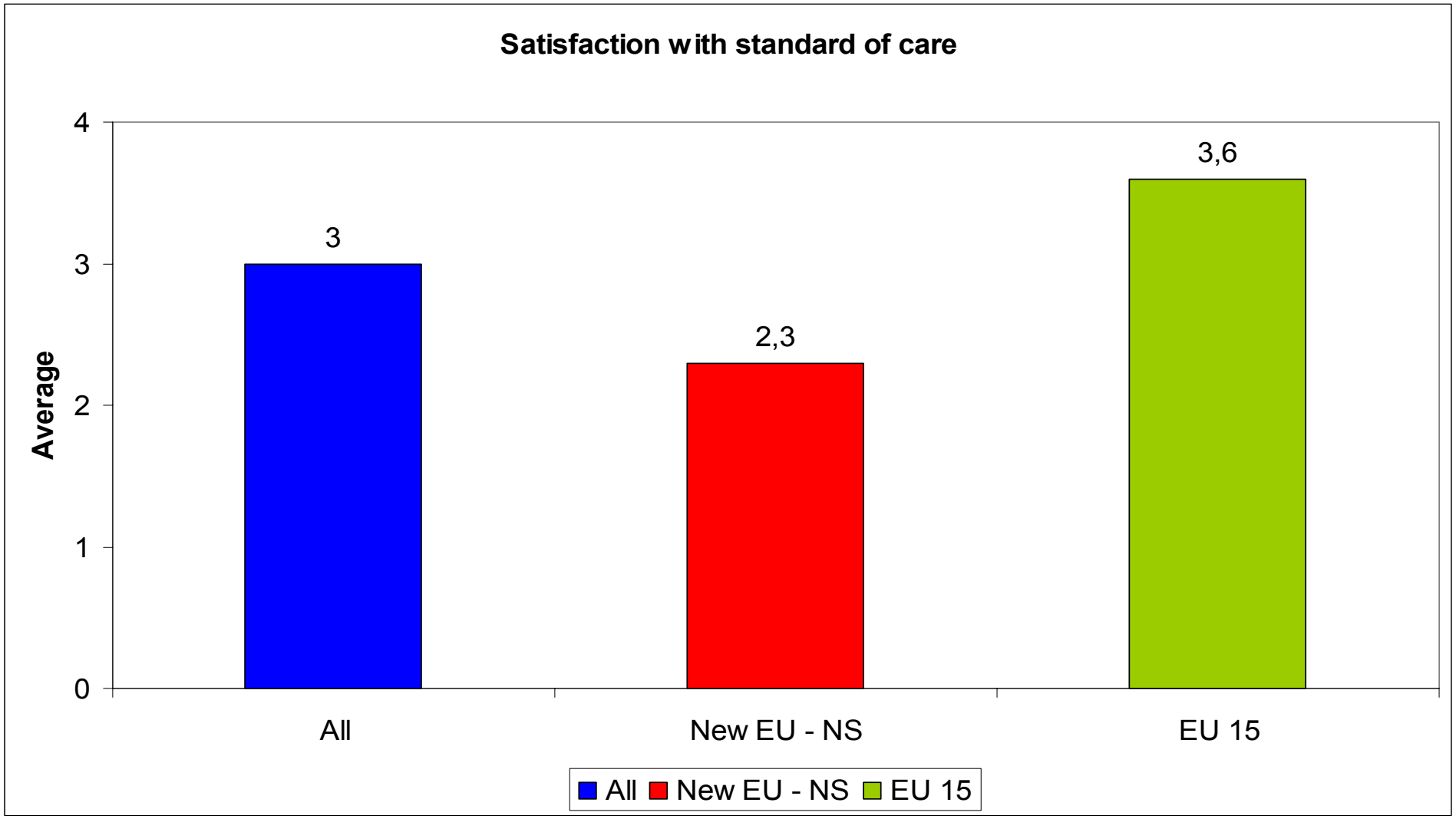
As far as barriers to access to treatment are concerned, the new EU states identified stigma and visibility, geographic barriers (i.e. need to travel to treatment centres) in a centralized treatment system, and lack of psychological support as the main barriers to accessing treatment.

On the contrary, EU 15 states focused the problem in vulnerable groups (100% of respondents) and the ones mainly cited were active drug users (4 respondents) and immigrants without residency status (5 respondents).

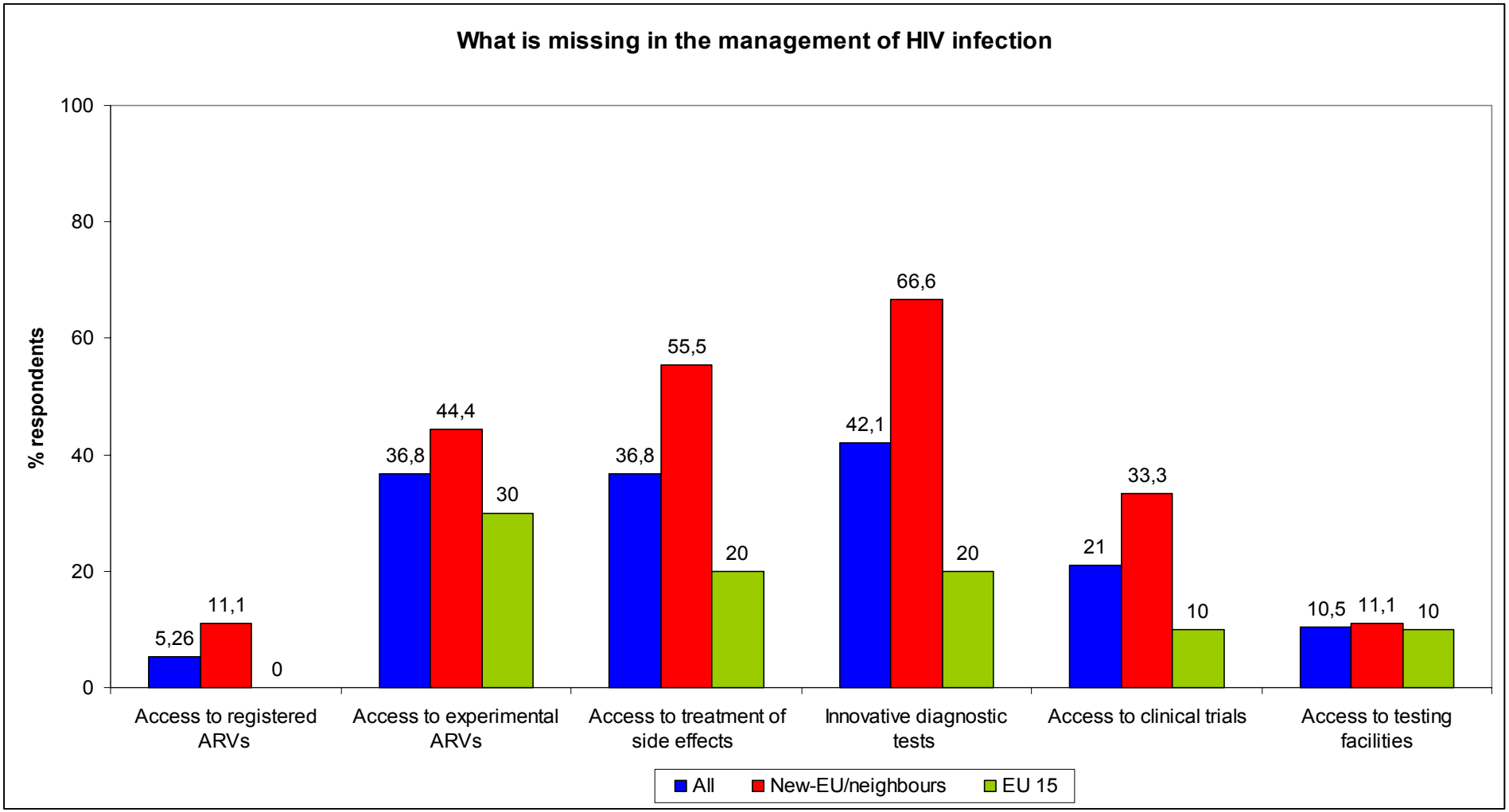
In accordance with the above, the main expectations from the EU include:

- Monitoring and evaluation of treatment provision;
- EU guidelines on treatment and care of HIV infection;
- Advocacy for universal access to all vulnerable groups including active drug users, illegal immigrants, imprisoned people;
- Address stigma and discrimination;
- Pressure for introducing substitution therapy as a mean to scale up HIV treatment;
- Strong recommendation on HIV treatment for drug users;
- Legal measures against discrimination in access to healthcare.

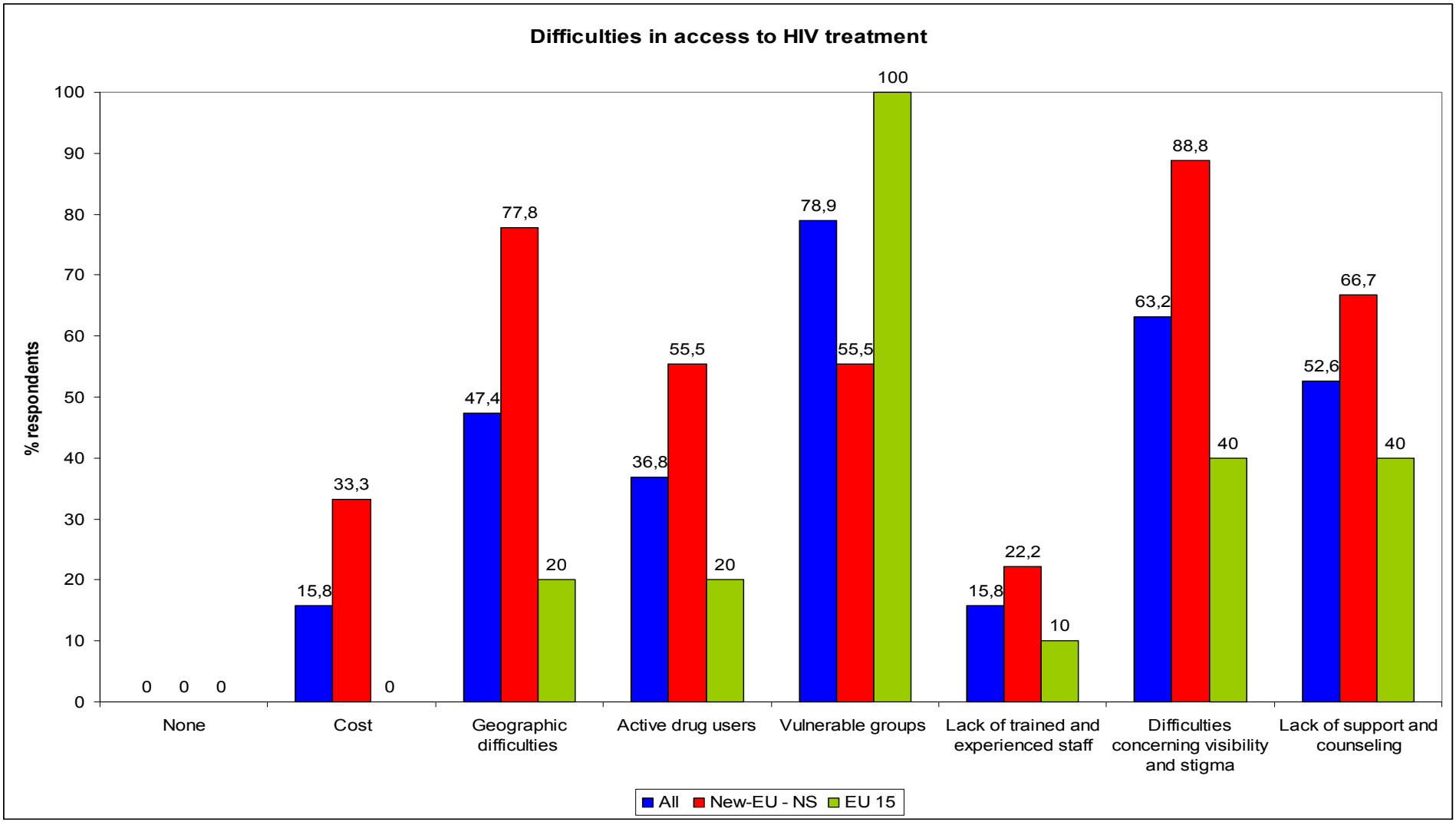
**Graph 4: what is the average satisfaction with standard of care in one's country?**



**Graph 5: What is still missing in the management of HIV infection in your country?**



**Graph 6: what are the main difficulties towards access to treatment of PLWHA in your country?**



## *HIV infection and human rights*

The types of human rights violations denounced by participating NGOs are reported in table IV. The main problems concern the vulnerable groups constituted by immigrants, drug users and imprisoned persons. Other worrying trends are those of breach of confidentiality, compulsory testing in work places, for insurance purposed or of high risk groups, and criminalization of high risk behaviours. Finally discrimination of PLWHA at workplaces or schools and their exclusion from medical care are still frequent problems.

**Table IV human rights violations denounced by NGOs**

| **Themes** | **Number replies** |
|---|---|
| Human right violation of immigrants: no access / expulsion | 10 |
| Human right violations of DU: criminalisation / exclusion from care | 8 |
| Confidentiality / privacy breaches in healthcare and other settings | 6 |
| Workplace / school discriminations | 6 |
| Criminalisation of unsafe behaviour | 5 |
| Human right violation of prisoners: no access to treatment | 4 |
| Exclusion from medical care | 4 |
| Compulsory testing | 4 |
| Discrimination / stigmatization of PLWHA | 2 |
| Exclusion of PLWHA from decisions | 2 |
| Police abuse of vulnerable groups | 2 |
| Travel / residence restrictions for PLWHA | 1 |
| Insurance restrictions | 1 |
| Criminalisation of sex work | 1 |
| Disruption of treatment programs / continuity of care | 1 |

Expectations from the EU in this regard respect the three priorities expressed in other thematic areas and in particular:

- Binding guidelines or legislation, whenever possible;
- Political pressure on local governments;
- Source for evidence based guidelines and experience of best practices.

### *Involvement of NGOs in the work of the Commission*

Suggestions from participants concerning this area were extremely consistent, and allowed to delineate not only their view of the necessity and goals of NGO involvement but also to gather information on the structure and content of such collaboration (table V).

NGOs request to be involved in all phases of policy and programme development. They deem that consultation with NGOs should be continuous through regular meetings and consultations with stable working groups and fora. In addition, NGO representatives ought to be present in all EU meetings and consultations regarding HIV/AIDS. In fact, the interaction of NGOs with various DGs dealing with HIV/AIDS should be streamlined.

NGOs ought to be involved in monitoring of policy as well. On the one hand, EU decisions should be transparent and apparent to NGOs, and on the other NGOs may be used as a monitor for the local application of EU policies.

For this mechanism to be effective representing NGOs should possess good links with the local communities they represent, and EU efforts are expected to build capacity and to raise the profile of NGOs towards local policy makers.

Last but not least, funding is required for NGOs to be able to take up their role as partners in policy development and monitoring.

**Table V: NGO involvement in EU policy making**

| Themes | Number replies |
|---|---|
| Integrated involvement in policy development | 6 |
| Regular meetings | 6 |
| NGO representation in all meetings on HIV | 5 |
| Involve NGOs in monitoring policy | 5 |
| Raise NGO profile towards local policy makers | 3 |
| Form stable working groups | 3 |
| Include a wide range of NGOs, pan European projects / networks | 3 |
| Support for capacity building in NGOs | 2 |
| Transparency on EU decisions | 1 |
| Streamline different DGs on HIV | 1 |
| Technical and financial support for NGO participation | 1 |
| ensure NGOs have contacts with local communities | 1 |

# II. Report of the Informal Consultation with NGOs on HIV/AIDS Policy

## *Introduction*

*Matti Rajala , Head of Unit Health Determinants, European Commission*
Mr. Rajala welcomed the 26 NGO participants on behalf of the European Commission (see annex A for list of participants). The European Commission (EC has) gotten a strong mandate in Vilnius. The implementation of the working paper 'Coordinated and integrated approach to combat HIV/AIDS within the European Union and in its neighbourhoods' is progressing well. Mr. Rajala is also satisfied with the developments in neighbouring countries. HIV/AIDS has increasingly gained attention at high-level EU meetings, like the upcoming meeting of EU Ministers of Foreign Affairs.

The new EU HIV/AIDS policy is due in autumn and the drafting process is coordinated by Maarit Kokki (EC Administrator). The policy will focus only on a certain number of priority issues, and look into the European added value of what the EC is able to do.

*Ton Coenen, member Steering Committee AIDS Action Europe*
AIDS Action Europe and EATG are part of the EU Think Tank on HIV/AIDS. The Think Tank acknowledged that the involvement and support of civil society is crucial in the development of the new HIV/AIDS policy. This meeting is a great start in the process of greater involvement of civil society in Europe.

*David Haerry, ECAP Chair European AIDS Treatment Group (EATG)*
Prior to the meeting, EATG sent out a questionnaire to all invited NGO to learn more about their priorities in relation to each of the 6 workshop themes addressed at the informal consultation. Mr. Haerry presented the outcomes of the questionnaire and invited NGOs that haven't responded yet to do so. The results of the questionnaire were presented in the first part of this report.

Following are reports and recommendations from the six working groups.

## *Working group on prevention of sexual transmission*

The new EU HIV/AIDS policy should:
- Present a European vision on what prevention should entail and what vulnerable groups should be prioritised;
- Embrace a non-coercive and non-moralistic approach, a human rights perspective that combats stigma and discrimination and strives for the greater involvement of people living with HIV and AIDS (PLWHA);
- Contribute to creating a European environment – both socially, politically but also legally- that is supportive, inclusive and empowering. A European vision and mission in sharp contrast with current USA government vision;
- Call for the need to agree upon European standards and guidelines for HIV/AIDS prevention on issues like qualified health professionals Europe-wide (same standards in relation to stigma, level of care, ability to speak openly about sex); Hepatitis B vaccination; availability of PEP (post exposure prophylactics), next to condoms and microbicides; pre- and post test counselling; insurance issues; co-infection with STIs; testing free of charge.

The new HIV/AIDS policy should explicitly pay attention to the needs of the following vulnerable groups:
- Migrants;
- Men having sex with men;
- Prisoners;
- PLWHA;
- Serodiscordant couples;
- Sex workers & human trafficking;
- Young people (negotiation skills of especially girls and young women).

Dadi Einarsson (EC) pointed out what the EC can do in relation to the recommendations and actions mentioned above:

- Bring in specific topics into the European Council;
- Facilitate the transfer of knowledge on specific issues between EU countries through working groups of member states.

### *Working group on drug users issues*

Priority issues for addressing HIV/AIDS among drug users that still need to be addressed are:

- Access to comprehensive and integrated services
  including general health and social care, harm reduction, HIV, Hepatitis B and C, STI treatment, and care, addressing sexual and reproductive health and mental health, simultaneous development of services both in community and in prison settings, better integration of existing services;

- Scaling up and increasing accessibility to services
  including increasing national funds for improving and sustaining existing and opening new low-threshold and other services, increasing their capacities and outreach, increasing geographical access to services;

- Stigma and discrimination
  including stigma and discrimination related to HIV and other associate factors (drug use, sex work etc), related to vulnerability, such as gender and age;

- Drug policies
  promoting enabling environment for HIV prevention and other strategies and services for drug users, including drug legislation and its implementation on the ground;

- NGO and affected communities involvement in decisions and services
  including non-governmental and community based organisations, affected community members, people living with HIV/AIDS, injecting drug users, sex workers etc.

Proposed priority steps on the EU level:

- Initiating recommendation on access to treatment and care of HIV/AIDS, Hepatitis B and C and co-infections;
- Regular evaluation of country progress in implementation of different declarations and recommendations; one of the ways to evaluate policies and existing services is country missions and meetings with different stakeholders (including NGOs and affected communities) to assess the progress;
- Monitoring and evaluation of the above stated fields should be taken as priority;
- More research on substances for drug replacement (substitution) maintenance treatment ;
- Pro-active demonstration of the EU position towards harm reduction at international level, through bilateral mechanisms and within the EU member states;
- Invitation of DG SANCO to countries like Spain and Switzerland to provide the necessary information to closely monitor the design, development, implementation and evaluation of heroin and other controlled substance programs in order to derive lessons learned and eventually elaborate recommendations;
- Elaboration of database of EU national policies, EU/WHO recommendations and best practices (especially with regards to harm reduction and HIV treatment for drug users, linking drug and HIV services);
- Promotion of service integration through sharing good practices;
- Good practice sharing could also take place through country exchanges; it seems essential to continue of good practice sharing not only with neighbourhood countries but also within the EU.
  See Annex B for a detailed descriptive report of this workshop.

### *Working group on access to affordable antiretroviral medication*

The EC should:

- Ensure that no one shall be excluded from getting treatment in countries receiving EC funds or Global Fund means. The EU should ensure in the Global Fund that no one is excluded from treatment (like street kids in Ukraine);
- Ensure treatment preparedness. Treatment is more than tablets. Good treatment management and monitoring is needed. That is difficult when patients have to travel for treatment– there is a need to ensure decentralisation and local capacity. Member states and NGOs could exchange best practises on social standards, laboratory capacity for monitoring, quality of general practitioners who only see few patients with HIV/AIDS, voluntary testing and counselling and means to secure that testing and access to treatment go together;
- Promote guidelines on universal access and standard of care;
- Promote guidelines to promote NGO involvement and collect information on best practises. Should NGOs be part of counselling? In some countries it is obvious, while in other countries controversial. NGOs can however be much more accessible to PLWHA than health professionals. NGOs need education and capacity building to be a relevant source of support for PLWHA. The EC can continue to support NGO management in the field of HIV/AIDS;
- Promote best practices on adherence and motivation. Do doctors ask patients if they need more information? Are they trained to communicate and have a holistic approach? Doctors' time is very limited. Patients can be trained to help patients – there are good examples in countries like France. Polish NGOs invite to information evenings with questions to doctors. Expectations differ. In Sweden three health professionals are assigned to each patient, so the patient always knows who to turn to;
- Regulate or recommend easy access to report side effects, like in pharmacies. Will doctors always take reverse effects of medication seriously? Will they be more interested in cardio vascular problems than in year long diarrhoea? Who to turn to if you have side effects? There may be a role for the EMEA in London;
- Compare or negotiate ARV prices. Even in countries with free ARV, other medication can be a costly affair and not accessible for certain vulnerable groups. Medical costs can be enormous for treating opportunistic effects. In Estonia, Global Fund means stop after Estonian membership of the EU. This year HIV/AIDS medication accounts for 1,4 pct. of the total budget for medication, in 2007 it will be 16 pct;
- Investigate how smoothly 2nd generation medication gets introduced and becomes accessible. Some neighbouring states have none or not universal access to treatment and have only access to 1st generation medication. Is 2nd generation medication without price agreements?
- Pay special attention in its research agenda to HIV/AIDS. Cancer and cardio vascular diseases are always mentioned together with the need for more research and development. HIV/AIDS needs the same long term focus. Research agenda: special attention needs to be paid to social sciences, non industry research and development, quality of life, better prevention and basic science on understanding the virus and the immune system. The EU has an upcoming 7th framework program for research and development and the EC has a directorate general on research. What is their focus?

There is weak or non existent surveillance of the best time to start treatment. There are late presenters (people who only contact health professionals when they have symptoms). Here is a role for the European Centre for Disease Control on Sweden. What is its focus?

## *Working group on improving life conditions (focus on human rights)*

There are several problems concerning human rights, for example:
- Within the EU-region there still are restrictions on travelling for PLWHA (Hungary, Ukraine);
- Data from individual patients are not always protected as they should (Hungary);
- Testing is still mandatory in some countries. This concerns sex workers, health workers, prisoners and migrants. Confidentiality is not always guaranteed;
- In Russia human rights for PLWHA is still a big topic. In all sorts of ways people are discriminated. Confidentiality is not guaranteed. Several groups have no or limited access to treatment;
- In Denmark and the Netherlands there are limitations in access to insurances for PLWHA;
- In Denmark and the Netherlands there is a danger for PLWHA to get criminalised after having unsafe sex.

The EU should:
- Include the human rights for PLWHA in all its anti-discrimination regulations. The EU has a special responsibility in antidiscrimination regulations in general;
- Guarantee free movement of labour and people, including PLWHA. This should exclude travel restrictions and mandatory testing for PLWHA;
- Expand its guidelines for data protection and patient-privacy to PLWHA. The EU should develop guidelines for surveillance which guarantee that no individual information on a patient is needed. The data used can be anonymous;
- Put human rights of PLWHA on the agenda whenever possible in the international arena, specifically in contact with Russia. Human rights should be part of all political declarations;
- Support in very practical ways training on the issue of human rights for new members of the EU and neighbouring countries. These should include the human rights of PLWHA;
- Hold a survey every few years to monitor HIV, health and equality issues. This is important in order to have a clear view on what is going on in the countries and to adjust policy to it.

## *Working group on NGO involvement and HIV/AIDS policies (I)*

The first and foremost concern is the current difficult financial situation faced by many local HIV/AIDS NGOs in the new member states of the EU. Pre-enlargement EC programmes such as PHARE - which use to provide significant support for local civil society - have now ended and many international funders have now left these countries, assuming (wrongly) that entry into the EU would lead to easier access to funding. Action by the European Commission on Health within the member states of the EU is strictly limited by the European Treaties: EC almost cannot, notably, fund the provision of local health services. Overall, the national governments of most of the EU member states still grant minimal acknowledgement (and funding) to their local civil society. There is the very dangerous risk of having many of the most pertinent local actors on HIV prevention and support disappear, as a direct unforeseen consequence of EU enlargement.

There are vast differences between European countries regarding the most democratic practice of involving NGOs in policy-making and programme implementation. In Denmark or in the Netherlands, for instance, consultation with NGOs has been a systematic and standard practice for many years. In France or in Spain this process proved more difficult even if significant progress has been achieved over the years. On the other hand, there are extreme examples such as Belarus where NGO dialogue with governmental authorities remains quasi-impossible. One of the most promising usefulness of a new EU policy o HIV/AIDS therefore will be to demonstrate and make known that the EC fully endorses (and practices itself) involvement of NGOs in policy making. This can be used as a strong incentive to promote a similar approach at the national level, across the European Continent.

Regarding the European level, involving HIV/AIDS NGOs is an essential strategy to ensure that EU policies are as pertinent as they can be (with regards to the needs of PLWHA and other vulnerable communities in Europe, with regards to established best practices). This is especially urgent considering the increasing degree of scepticism among European citizens about the EU institutions themselves.

To be optimal, this process needs to be itself carefully supported:

- Lessons can be learned from successful practices in place in other fields, for instance regarding the role played by environmental NGOs in EU decision making;
- Close attention needs to be paid to the language issue. Non-English speakers need to have ways of being involved and updated. Most Europeans do not speak English!
- NGO delegates who have the honour of being consulted at the European level have a duty to share with and to report back to their local communities;
- Finally, pan-European NGO platforms have a central role to play:
    - by enabling this continuous dialogue and exchanges to take place in a structured way;
    - by actually providing legitimacy and support to its local members (thus facilitating acknowledgement of civil society at the local and national levels);
    - by facilitating exchanges of best practices at the European level – in between NGOs themselves - but also to promote the streamlining across Europe of innovative medical practices which have demonstrated that they work.

NGO involvement and consultation bring therefore a clear added value to European decision making. These processes are costly however (time commitment, translation and communications). The NGOs therefore count on the DG Sanco to provide direct financial support to this important work.

### *Working group on NGO involvement, policy and advocacy (II)*

The EC and the EU policy should:

- Take on a coordinating role in the monitoring and implementation of the Dublin and Vilnius Declarations. In fact, the Vilnius and Dublin Declarations already contain many of the NGO concerns and priorities. There is however a gap between the policy level and what really happens – the implementation at the country and local level. Good monitoring and implementation would enable comparison between countries and their progress at the European level as well as stimulate good reporting at the national level. The Dublin evaluation is already due February 2006. Development of a sound evaluation mechanism is needed urgently;
- Follow-up proactively on monitoring and evaluation outcomes, identifying gaps and problems and encouraging action from member states to address these. The EC needs to monitor funding mechanisms and stimulate national governments to speak out about the need that structural funds from the EC should be applied to HIV/AIDS;
- Assist neighbouring countries to do their monitoring of UNGASS, Dublin and Vilnius. In the end, monitoring and evaluation should include the entire European region, beyond the borders of the current EU;
- Reinforce the need for real partnerships between governments and NGOs since in many countries this process is slowly progressing and experiencing many difficulties;
- Reinforce with member states to have NGOs and PLWHA included in the monitoring and evaluation committees of the implementation of Vilnius and Dublin at the national level;
- Address ARV pricing and trade regulations and advocate for integrated prevention, care and treatment packages;
- Advocate more proactively for the implementation of evidence-based policies, both within Europe and internationally. The EC should take a strong position internationally for example in relation to evidence-based harm reduction approaches. The support by the EC of evidence-based approaches could be especially important in influencing new member states' policies on HIV/AIDS;
- Make the EU Think Tank more visible and communicate more broadly their approaches and activities.

The present NGOs are especially concerned with the current funding gaps that are challenging the sustainability of the NGOs in new member states. In consequence of becoming part of the EU, NGOs have lost their access to previous funders. New funders – EC and others – so far have not come up, abandoning the NGO sector and raising serious survival challenges. The EC is requested to take into consideration this urgency. Without NGOs at the country level, European networks and projects will be unable to survive.

### *Plenary discussions and agreements on follow-up*

Representatives of the project AIDS & Mobility Europe clarified a petition that was presented by one of their members in one of the workshops. The petition calls for action of the EC and the national governments of Central and Eastern Europe to respond to the lack of funding and the lack of civil society participation in national HIV/AIDS programmes. The statement will be presented to the EU Think Tank on HIV/AIDS and to AIDS Action Europe.

Mr. Rajala reacted to the call for action presented by AIDS & Mobility Europe and urged the NGOs to inform the European Parliament about the sustainability concerns of the NGOs in the new member states that have lost their funders due to becoming part of the EU. He also strongly recommended that all NGOs contact their national representatives in the EU Think Tank on HIV/AIDS in order to advocate more effectively.

The EC should be specific on budgetary information. Reading the working paper you get the impression that 1.2 billion can be spent under the heading of HIV/AIDS in the EC and among its neighbours. This is not the case. The public health programme and the specific Global Fund means for EU's neighbours are relevant – not the entire funding of the Global Fund or the budget of the EDCTP.

The EC document should be clear on who the EC considers its neighbours. Present the list in the text, not only in a table.

The EC policy document could reflect the entire undertaking of the EU on HIV/AIDS. As a structural idea, there could be links under some of the paragraphs, like a showing of possible and satisfactory work place policies with a link to the DG for Employment, a link to DG Trade under the chapter on pricing of ARVs and links to DG Research and DG Development etc.

The EC representatives clarified that the new EU policy will consist of a Communication to the European Council and the Parliament. September 5 & 6 the draft policy will be discussed at the first Civil Society Forum that the EC will organise in Brussels. The EC will follow-up with AIDS Action Europe and EATG for the accreditation process of NGOs to become part of the Civil Society Forum. Civil Society Forum participants should be committed previously and posterior to the meetings and share discussion and agenda items with their contacts at the national or local level. There was an appeal to include more PLWHA and migrants among the participants. On September 6&7 the draft policy will be discussed at the EU Think Tank on HIV/AIDS. This process is followed by a formal consultation on the policy within the European Commission. The EC is also exploring possibilities to organise a yearly Open Forum on HIV/AIDS.

Mr. Einarsson informed that on the EC website the implementation status of the working paper can be checked at http://europa.eu.int/comm/health/ph_threats/com/aids/docs/implementation_en.pdf

The NGOs were informed about the plans of the EU Think Tank to develop an EU umbrella public campaign targeting youth and the general population. The possible campaign theme is stigma and discrimination. The World AIDS Campaign is involved. The campaign aims primarily to interest decision-makers at the national level.

In the evaluation of the day the general feeling was that the meeting resulted very informative and fruitful in providing input for developing the new HIV/AIDS policy. NGO representatives also observed that there seems to be a quite homogeneous view among the NGOs and networks about the priorities from civil society.

## *Annex A: Participant list*

| **Participant** | | **Organisation** | **Country** | **Email** |
|---|---|---|---|---|
| **NGOs** | | | | |
| *Familyname* | *Name* | | | |
| Azad | Yusef | National AIDS Trust | United Kingdom | yusef.azad@nat.org.uk |
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| Prochazka | Ivo | Czech AIDS Help Society | Czech Republic | ivo.prochazka@seznam.cz |
| Samoilov | Dmitry | Organization "Community of People Living with HIV/AIDS" | Russian Federation | d_samoilov@positivenet.ru |
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| **European Commission** | | | | |
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## *Annex B: Descriptive report on Drug Users Issues*

General remarks

A number of documents on the European level stress the need and recommend some ways how to address drug use and HIV problems. These include Dublin Declaration (February 2004), European Commission working paper "Coordinated and Integrated Approach to Combat HIV/AIDS within the EU and in its Neighbourhood", Vilnius declaration (September 2004), EU Drug Strategy 2005-2012 and upcoming EU Drug Action Plan 2005-2008, and EU Council Recommendation on the prevention and reduction of health-related harm associated with drug dependence (June 2003).

However a number of documents are vague and/or are not implemented sufficiently. Access to testing, prevention and treatment remains not sufficient for drug users and often lower than for other population groups.

While there are differences between development of epidemics and political and practical responses to HIV and drug use, in general HIV-positive drug users meet additional barriers to access services and enjoy their rights.

Priority issues that still need to be addressed are:

- Access to comprehensive and integrated services;
- Scaling up and increasing accessibility to and sustainability of services;
- Stigma and discrimination;
- Drug policies;
- NGO and affected communities' involvement in decisions and services.

These are reflected below.

Access to comprehensive and integrated services

These should include low threshold access to *health care, social services, care and support*. General healthcare systems usually are based on insurance systems and many drug users and mobile users cannot access even primary care since they do not have insurance. Development of social services, support and care, especially in the AIDS and drug field is embryonic in a number of new EU member states and neighbouring countries.

Access to *voluntary* non-discriminative and confidential *counselling and testing* remains a big issue, especially for vulnerable populations. In Lithuania, a drug user (as well as other representatives of "high risk groups") has to state that he/she is drug user in order to get free of charge HIV testing; pre- and post-test counselling is often not provided.

As a rule, *strategies and services in prison settings* (including detention, and other penitentiary institutions) are even more limited than in the community and vary in different institutions even within the same country. Most countries have two separate healthcare systems in community and in penitentiary institutions. This might lead to interruption of services including HIV and drug treatment. Drug use itself or related activities (e.g. possession of illicit drugs) is often criminalized, therefore inadequate interventions in prisons and low coordination of services in community and inside prisons highly affect drug using population. With regards to HIV prevention among drug users, EU Council's recommendation points that services which are available in the community should be in place in prison settings as well, but this is not implemented in the vast majority of the countries.

Access to *HIV treatment and care for drug users* (both active drug users, those in drug treatment and former drug users) is an increasing issue in the countries with high rates of HIV among drug users, especially in Baltic States, Russia, Ukraine and other neighbouring countries. HIV treatment issue is also in common for other European countries – even in France, which has universal access to HIV treatment and care, active drug users often do not receive treatment. Good practices of delivering treatment to drug users and supporting adherence as well as integrating both drug and HIV treatment is lacking in the East of the European continent. Financial support is coming through the Global Fund to Fight AIDS, Tuberculosis, and Malaria for increasing access in many countries of the Eastern Europe. However, lack of *adherence mechanisms* and illegal status or low scale of such *substitution treatment*, which plays a significant role in improving use of antiretroviral treatment and overall health of drug users, raises concerns whether a substantial part of HIV-positive drug users will benefit from increased access to life-saving antiretroviral treatment.

Drug treatment remains undeveloped in most of the new EU member states and neighbourhood. Substitution treatment still provides little options for drug users and more focus should be given on inventing and *researching new substances for substitution therapy* as well as to address treatment for non-opioid drug users, especially ATS drugs. Piloting of *heroin maintenance* programs should be encouraged in different countries; practice shows that social acceptance is quite high in a number of EU states and promoting good practices could enable quicker introduction of this measure to address HIV and drug use.

The *Hepatitis C* problem (especially among drug users) is not acknowledged and not addressed at a relevant level. Its epidemiological surveillance is lacking. Rates of its caused deaths are high but are underreported. Treatment is lacking even in "old" EU member states.

*Harm reduction*, while established in many EU member states and based on vast evidence, is still debatable and is in low scale in some new EU member states and neighbourhood. In Russia a large anti-harm reduction campaign is experienced in media and general population; support and advocacy for its establishment is lacking. Its implementation in prison settings is even more limited. Pro-active position of the EC would help to strengthen political commitment and state support within EU (especially in new EU member states) and neighbourhood.

*Reproductive* needs are met on a insufficient level. *Sexual health* and education, especially in reaching sexual partners of drug users and other highly affected HIV communities is becoming increasingly important as in some countries (Latvia, Ukraine) HIV epidemics move from injecting drug use-related transmission to sexual transmission to their partners and to the general population.

Existing services need more coordination and integration for people to have comprehensive access to health and social care. Therefore *integrated approach* and good practices should be promoted.

<u>Scaling up and increasing accessibility to and sustainability of services</u>
Often piloted services remain of *low scope and insufficient coverage*, especially with regards to harm reduction. In new EU member states preventive interventions were mainly set up by non-governmental organizations with support of external funds, which now are not available. *Lack of government commitment and government funding* for the field is a major barrier to *sustain* and improve program capacities, their geographical and population coverage as well as quality and range of services provided.

<u>Stigma and discrimination</u>
HIV is accompanied by stigma and discrimination. Drug use is attached by even more stigmatization and prejudice. Stigma and discrimination (especially double one towards drug users or triple ones towards inmates or drug using sex workers) limits effective use of services and implementation of rights of HIV positive people as well as overall prevention of HIV/AIDS.

While *legal basis* is very important for reducing vulnerability and increasing enjoyment of rights of people living with HIV/AIDS and affected communities, even more important is to work with *negative attitudes of health care and other professionals, decision makers and society in general*.

While working towards de-stigmatisation and decreasing discrimination vulnerability related to *gender* and *age* issues needs to be addressed.

<u>Drug policies</u>
Addressing HIV is more effective in an enabling environment which treats people as human beings with rights for the best available services. Drug policies therefore should be based on public health and human right approach above all. Experience of the EU member states shows that incarcerating of drug users and focusing practical drug policy efforts on fighting drug dependent people does not stop HIV/AIDS spread but in contrary might lead to outbreak, as harsh drug policies on the ground might lead to more limited use of services and in prisons drug use is in common, even some people start using drugs there, and services to address drug use are limited if any.

NGO and affected communities' involvement in decisions and services

Different documents reiterate the role of non-governmental organizations and affected communities in response to the HIV/AIDS epidemics. However *funding* of NGOs and community based organization from country budgets, *involving* them and PLWHA, as well as other affected communities by epidemics (including drug users, sex workers) *in decision making and implementation as well as monitoring and evaluation of policies and services* is challenging in new EU member states and neighbouring countries. As it was mentioned above already, NGOs in most of new EU member states are meeting with major funding difficulties.

Other issues discussed

Other issues identified included the need for better surveillance and monitoring, as well as community-based research on risk behaviours, increased access to voluntary testing and counselling. Active and effective involvement and better understanding of the European CDC work is needed.
Awareness raising campaign in some countries are needed to promote testing, build political and society commitment to HIV.
The EU should be even more active in addressing the HIV/AIDS issues in neighbouring countries and activities should be implemented on the European level rather than on 25 country level.
Coordination of activities supported by the EU and EU member states in neighbouring European and Central Asian countries is needed so that funded efforts would be not duplicated.

Recommendations for the EC

Proposed priority steps on the EU level:

- Initiating recommendation on access to treatment and care of HIV/AIDS, Hepatitis B and C and co-infections;
- Regular evaluation of country progress in implementation of different declarations and recommendations; one of the ways to evaluate policies and existing services is country missions and meetings with different stakeholders (including NGOs and affected communities) to assess the progress;
- Monitoring and evaluation of the above stated fields should be taken as priority;
- More research on substances for drug replacement (substitution) maintenance treatment;
- Pro-active demonstration of the EU position towards harm reduction at international level, through bilateral mechanisms and within the EU member states;
- Elaboration of database of EU national policies, EU/WHO recommendations and best practices (especially with regards to harm reduction and HIV treatment for drug users, linking drug and HIV services);
- Promotion of service integration through sharing good practices;
- Good practice sharing could also take place through country exchanges; it seems essential to continue of good practice sharing not only with neighbourhood countries but also within the EU.

*This report was prepared by Lital Hollander from EATG and Martine de Schutter from AIDS Action Europe, based on workshop reports by Ton Coenen, Kirsten Jensen, Raminta Stuikyte and Arnaud W. Simon.*
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