EUROPEAN CENTRE FOR DISEASE PREVENTION AND CONTROL

MEETING REPORT

HIV prevention in Europe: Action, needs and challenges Stockholm, 2–3 October 2006

ecdc.europa.eu

TABLE OF CONTENTS

EXECUTIVE SUMMARY

This *Workshop on HIV Prevention in Europe* for designated HIV/AIDS coordinators from all EU Member States, EEA/EFTA and acceding countries was convened by ECDC to review country prevention priorities, share best practices, and identify gaps and areas where ECDC could contribute to European activities that will strengthen HIV prevention within MS.

Coordinators were joined in the meeting by representatives of other relevant EU and UN organisations and key European stakeholder groups representing civil society, people living with HIV, the business community, health professionals, financial donors and the media. Preliminary results of the 2006 ECDC survey on HIV prevention and surveillance in EU, EFTA and acceding countries informed discussions.

Discussions focused around a current situation analysis within the 30 countries of ECDC's geographical area, priority topics (as identified by the ECDC Advisory Forum), partnership and coordination issues. These priority topics included identifying good practice and challenges related to increasing uptake of HIV testing and epidemic control among men having sex with men (MSM), Baltic States and migrants. Summaries of discussions supported by key presentational slides are presented in this report.

Of particular interest was a hot debate regarding 'AIDS exceptionalism' and the new guidelines from CDC, Atlanta, calling for routine screening in health care settings for 13–64 year-olds utilising an 'opt-out' approach.

Group discussions led to a series of recommendations for actions that would best support Member States in addressing the current HIV prevention and surveillance challenges. These recommendations included a call for ECDC to initiate and coordinate activities in the following areas.

1 Improving the basic knowledge on HIV across Europe. Given the complexity of HIV, biological surveillance should be complemented by behavioural surveillance among populations at higher risk (men having sex with men, drug users, migrants, sex workers). Surveillance data should be triangulated with data from other sources (e.g. programme interventions, policies) to allow for meaningful comparison between countries.
2 Stimulating and supporting the search for better, evidence-based interventions to prevent HIV and reduce its impact. The sharing of best practice across Europe, enabling MS to see what has been successful in other countries, and to target their activities more effectively. Some felt this could be accompanied by issuing guidance, offering technical assistance and including a strong training element.
3 Providing practical advice and assistance in translating the data and figures into action, especially in the countries hardest hit and with regards to populations at higher risk, such as men having sex with men, and migrants from high-prevalence regions. Promoting HIV testing and counselling in different settings and amongst different risk groups is also a key strategy to fight the epidemic.
4 Monitoring and evaluating prevention activities, and developing prevention indicators.

It was felt that ECDC could achieve this through the production of guidelines and guidance, country 'audit' visits, and putting political pressure on those in power, to make them take action or to ensure appropriate funding. The need to avoid duplication with existing initiatives was stressed, as was the need for collaboration and cooperation with other agencies (e.g. coordination of data reporting). With regards to prevention indicators, rather than 'reinvent the wheel' it was felt prudent to look at the UNGASS indicators to see what could be modified.

Participants expressed general appreciation of the fact that ECDC was making HIV/AIDS a high priority, and were looking forward to working together.

INTRODUCTION

Background to workshop

Although HIV/AIDS prevention and surveillance has been included in core public health policy in the EU since the 1980s, and has been the focus of extensive internal action and external development cooperation, there has nevertheless been a slump in attention over the last few years. In western Europe this can be partly attributed to the success in curbing the spread of the epidemic, and also to competing pressures for attention and resources from other infectious and chronic disease priorities.

However, the Dublin and Vilnius declarations and Commission communication on HIV/AIDS have led to a recent reaffirmation of commitment at EU level and a call for political commitments to be translated into real action. HIV/AIDS is now 'back on the agenda' and there is now a strong political commitment at the highest level, both globally and within the EU. A lot of work is already being done by the key players, including UNAIDS, WHO, and the European Union. The Commission has established a Think Tank as the main coordination body. Linked to the Think Tank, a Civil Society Forum has been created.

The European Centre for Disease Prevention and Control (ECDC) was established in 2005 to identify, assess and communicate threats to human health from communicable diseases in Europe. ECDC's enabling legislation calls for it to address its mission through surveillance (collection and dissemination of relevant data); technical assistance and training; coordination and networking; the exchange of information, expertise and best practice; and facilitation of the development and implementation of joint action.

HIV/AIDS as an ongoing and increasing threat to health in Europe has been identified as a major focal area of work by the ECDC Advisory Forum. The Advisory Forum, one of ECDC's governing bodies, consisting of country public health representatives, identified HIV/AIDS priorities for ECDC, as follows:

> In coordination with the EC Think Tank on HIV/AIDS, the ECDC should focus on HIV prevention, while at the same time take over the responsibility for surveillance in Europe. The prevention of HIV and STI should be integrated. ECDC should focus on a few key priority projects, including:
>
> - new approaches for prevention among men having sex with men (MSM);
> - HIV/AIDS prevention in the Baltic States;
> - increasing uptake of voluntary HIV testing.

The workshop

This workshop on HIV prevention in Europe for designated HIV/AIDS coordinators from all EU Member States, EEA/EFTA and acceding countries, was convened by ECDC. It forms a central part of a consultative process aimed at developing a workplan for supporting HIV/AIDS surveillance and prevention in Europe. Preliminary results of the 2006 ECDC survey on HIV

prevention and surveillance in EU, EFTA and acceding countries were presented and informed discussions[1].

The objectives of the workshop were to review country prevention priorities, share best practices, and identify gaps and areas where ECDC could contribute to European activities that will strengthen HIV prevention within MS.

Coordinators were joined in the meeting by representatives of the European Commission, EMCDDA, relevant UN organisations and key European stakeholder groups representing civil society, people living with HIV, the business community, health professionals, financial donors and the media.

The organisation of the meeting reflected ECDC's proactive approach to MS and stakeholder consultation, networking and regional programme development. While the central focus of the meeting was to identify core activities that ECDC could usefully undertake to support priority HIV prevention and surveillance needs of MS and at EU level, the meeting was also seen as an opportunity for information exchange, reactivation and strengthening of cross-border HIV/AIDS connections and networks. To this end the meeting was organised so as to provide ample opportunities for countries to reflect upon and provide commentary to plenary presentations, share experience and information through group work, displays, breaks and social events.

Outcomes of the meeting (see section IV below) include a list of possible joint actions for MS, ECDC, and the Commission, which would enhance HIV prevention and surveillance within the EU. Outcomes will feed into the Think Tank process and the conference on HIV prevention under the German Presidency in March 2007.

This report

This report draws on information delivered in all the plenary presentations, country panel commentaries, group discussions and survey findings. Discussions are not reported sequentially nor are most comments attributed. The report focuses on key themes and discussion areas of the workshop and is organised in four sections:

I Current situation analysis.
II Priority areas:
- HIV testing;
- MSM;
- the Baltic States;
- migrants.

III Partnership and coordination.
IV Conclusions.

[1] A copy of the report on the preliminary survey results which were presented at the meeting can be obtained from Françoise Hamers (Francoise.Hamers@ecdc.eu.int).

I CURRENT HIV/AIDS SITUATION IN THE EUROPEAN UNION

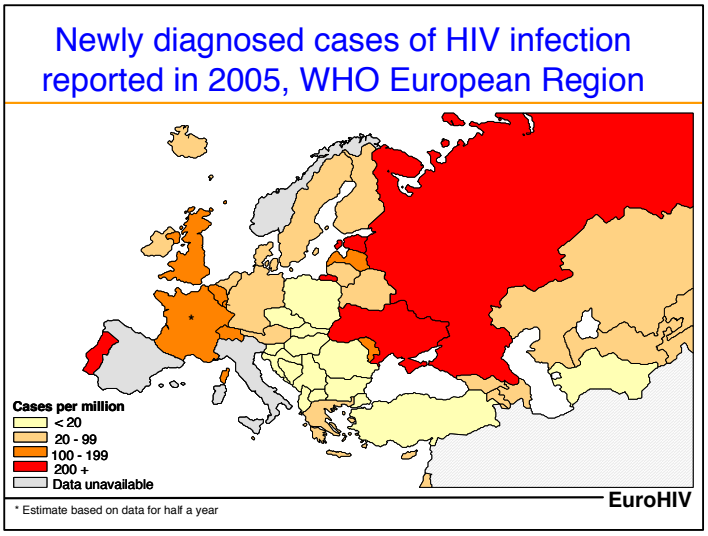
This section focuses on the current HIV/AIDS situation in Europe[2]. There was some discussion over various definitions of 'Europe', as the geopolitical mandate of ECDC focuses on 30 countries (25 EU, 3 EEA/EFTA and 2 acceding countries), whereas the WHO European Region comprises 53 Member States. While the workshop discussions and presentations focused on the 30, ECDC's 'turf' as it were, all agreed that such a focus could only be understood and addressed properly within a broader global context. Most of the material in this section is taken from the presentations of Anthony Nardone, of EuroHIV and Srdan Matic, of WHO EURO.

It was noted that although the epidemic within Europe is globally identified as low-level and concentrated, within the broader WHO European Region it is not under control. Newly reported HIV cases, behavioural data and rising incidence of other sexually transmitted infections (STIs) in the Russian Federation and Ukraine, for example, point to poor epidemic control.

Newly diagnosed cases

There is wide variation in the number of newly reported cases within the 30 countries of ECDC's geographical area (see Figure 1). Two EU countries reported levels of over 200 new cases per million of population: Estonia (nearly 500) and Portugal (nearly 250).

Figure 1

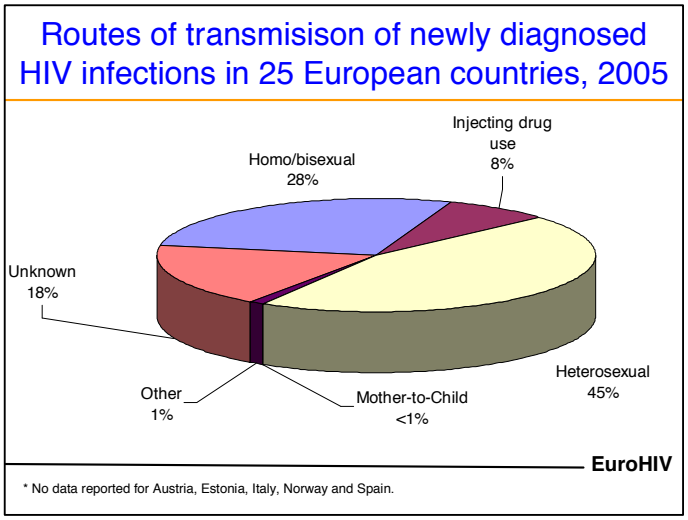


[2] Western Europe: Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, UK.
Central Europe: Albania, Bosnia & Herzogovina, Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, Macedonia FYR, Poland, Romania, Serbia & Montenegro, Slovakia, Slovenia, Turkey.
Eastern Europe: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russian Federation, Tajikistan, Turkmenistan, Ukraine, Uzbekistan.

Mode of transmission

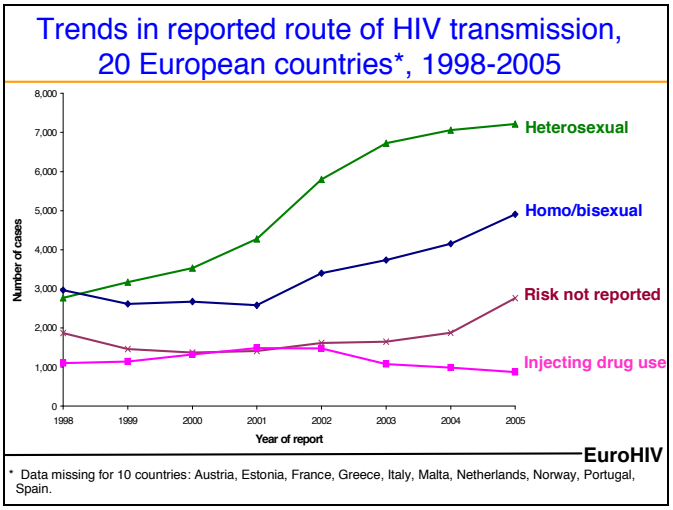
There is also great variation between countries in the mode of transmission, with the majority of cases reported in the EU overall being transmitted through sexual behaviour, as shown in Figure 2.

Figure 2



In Eastern Europe the epidemic is largely intravenous drug user (IDU) driven, with the majority of heterosexual cases being related to IDU contacts (i.e. partners of IDUs). In Western and Central Europe transmission is mainly sexual, with the two main groups being MSM and migrants coming from countries with higher-level epidemics. In Western Europe these migrants come mainly from Sub-Saharan Africa, and in Central Europe they are mainly sex workers from the Russian Federation and Ukraine.

Figure 3



As noted in Figure 3 above, there are upward trends in reporting EU countries, in diagnoses of sexually acquired HIV infections, with a particularly sharp rise in diagnoses of infection acquired heterosexually. A large proportion of these infections are among persons originating from high-prevalence areas, mostly Sub-Saharan Africa. It is worth noting that while the number of HIV diagnoses among IDU is generally slowing down, of those countries not listed as having data available at least three have high levels of HIV among IDU and the relative importance of IDU as a transmission route across Europe, therefore, might be higher.

Participants called for some caution when drawing conclusions on rising incidence from available surveillance data. This data measures new HIV diagnoses, not new HIV infections, and the fact that the number of HIV diagnoses is increasing does not necessarily mean that HIV incidence is increasing. It could well be due to an increasing detection rate. This was identified as an area needing more attention.

Vulnerable groups

There is a disproportionate burden of disease borne by certain vulnerable groups, mainly MSM, IDU, migrants, sex workers (male, female and transgender), and prisoners[3].

Table 1: Burden of disease borne by IDU, MSM and sex workers (WHO EURO STI/HIV/AIDS programme)

	Total prevalence %	*Prevalence among IDU %*	*Prevalence among MSM %*	*Prevalence among sex workers %*
United Kingdom	0.19 – 0.22	0.3 – 4.5	1.0 – 11.0	0.0 – 1.9
Spain	0.29 – 0.92	9.7 – 47.8	3.6 – 17.9	0.3 – 1.8
France	0.20 – 0.68	7.6 – 23.0	3.0 – 18.9	—
Italy	0.24 – 0.77	4.0 – 29.7	26.4	5.9 – 9.9
Netherlands	0.11 – 0.35	0.5 – 25.9	1.9 – 32.1	6.5
Poland	0.04 – 0.12	2.0 – 45.9	4.8 – 10.9	0.0 – 0.5
Latvia	0.32 – 1.03	4.0 – 24.5	2.4 – 5.4	0.0 – 16.3
Belarus	0.23 – 0.67	2.7 – 65.6	0.2 – 0.4	1.0
Russian Fed.	0.55 – 1.73	1.7 – 58.4	0.1 – 4.8	15.1 – 62.3
Ukraine	0.67 – 1.70	8.6 – 64.2	—	8.0 – 18.7

Mother to child transmission

In the Dublin Declaration, EU countries agreed that the goal for mother-to-child transmission rate should be set to <2%, and several countries in western and central Europe have reached this target. In their responses to the ECDC HIV questionnaire, however, some countries raised concerns about low uptake of testing (as low as 23%) and pointed to this as an area needing continued attention. Also noted was a call for improved education of health professionals on the need to offer testing and treatment.

[3] Infected prisoners, or prisoners most at risk of infection, are often IDUs.

The situation is very different in eastern Europe. Participants pointed out that a significant proportion of women in eastern Europe receive no ARV treatment during pregnancy, and that treatment, when it is available, tends to be single-dose nevirapine or short courses of zidovudine therapy. Concerns were also raised regarding high abortion rates for HIV infected mothers, especially in the Russian Federation and other eastern European countries (see Figure 4 below).

Figure 4

PMTCT indicators in 2004

as reported by WHO EURO member states

Subregion	Pregnancies	tested and counselled pregnant women	HIV positive pregnant women	Had an abortion	Had elective Caesarean Section	Had a vaginal delivery	Received PMTCT	Confirmed PMTCT cases (reported in 2004)
West (15)	2.70m	1.36m	1,774	152	1,338	181	1,800	32
Centre (9)	1.23m	0.24m	40	1	19	16	99	28
East (10)	1.19m	0.25m	329	94	37	201	154	39
Russian F.	2.93m	3.52m	11,105	4,724	1,018	6,365	5,601	110*
Total (35)	8.05m	5.36m	13,248	4,971	2,412	6,763	7,654	209*

STI/HIV/AIDS Programme
WHO/Europe

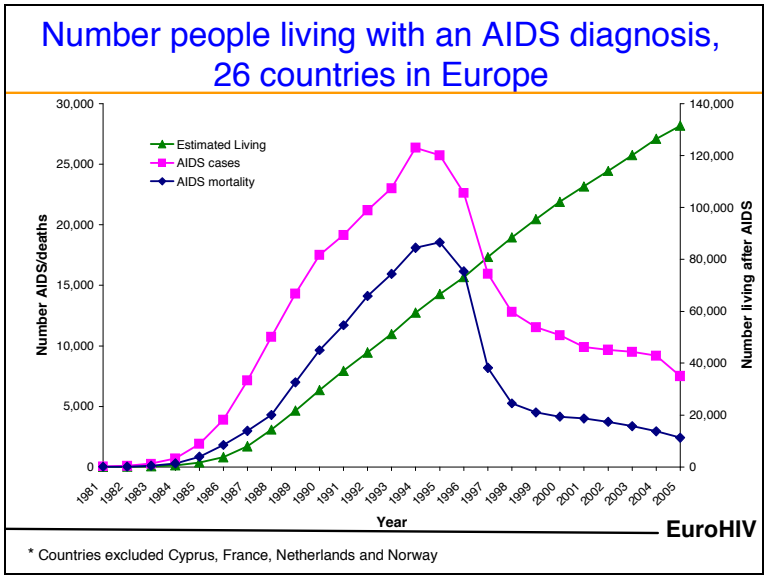
* Russian Federation and Ukraine have very limited testing of children born to HIV positive mothers to confirm HIV diagnosis

17

Impact of treatment

The impact of HAART on the prevalence of people living with HIV was discussed. Because anti-retroviral treatment (ART) significantly delays the onset of AIDS and prolongs the life expectancy of HIV-infected persons, the widespread use of ART in Europe has resulted in a dramatic decrease in both AIDS mortality and AIDS incidence, with a faster decline in AIDS deaths than new AIDS cases. As a result, the number of people living with HIV has increased.

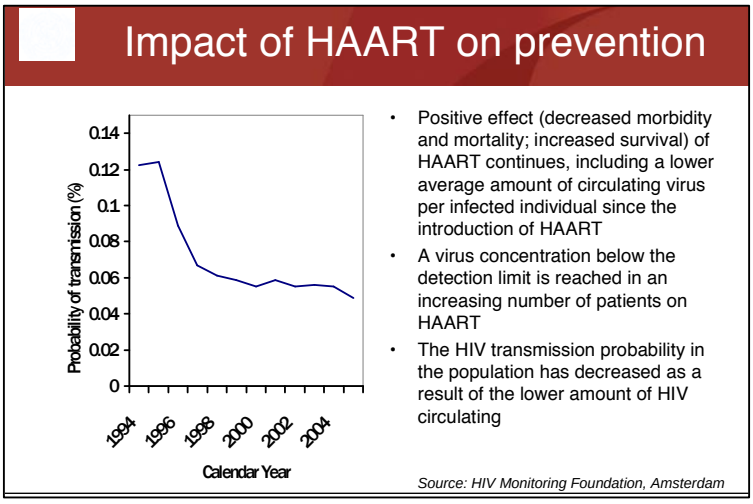
Figure 5



At the individual level, ART has improved the quality of life and the life expectancy of HIV-positive individuals, but at the same time several discussants noted that it may have a disinhibiting effect on HIV risk behaviours because HIV is no longer seen as a fatal illness.

At the general population level, it was noted that the net effect of the wide use of ART on HIV transmission is uncertain. By enabling HIV-infected persons to live longer and feel healthier, ART increases the size of the sexually active HIV-positive population, some of whom may engage in higher risk behaviour. On a more positive note, by lowering the viral load of treated individuals, ART reduces the amount of HIV circulating. While some studies point to an overall positive impact (see Figure 6), this issue was identified as an area for further research.

Figure 6

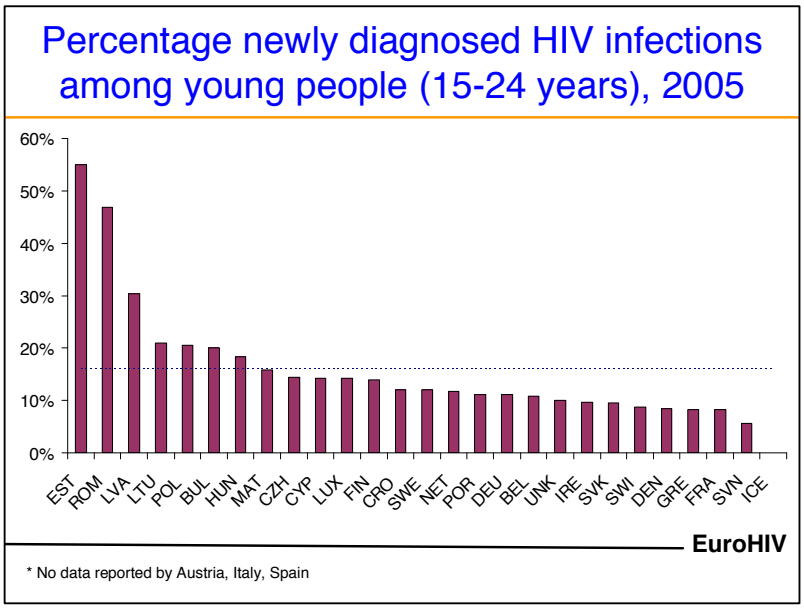


Worrisome trends

Young people

Disproportionately high numbers of young people are being diagnosed with HIV in eastern Europe and the Baltic States (see Figure 7).

Figure 7

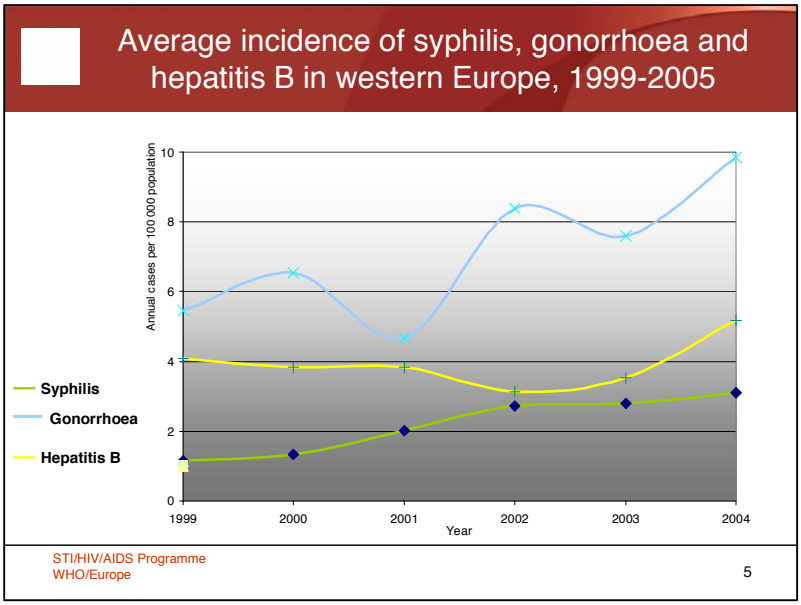


Increasing high-risk sex

Concurrent with the rise in HIV diagnoses, there has been a rise in the incidence of other STIs (see Figure 8), with a disproportionate burden borne by MSM (including HIV-positive MSM). Participants felt that this rise in STIs is indicative of a general increase in high-risk sexual behaviour, including unprotected sex.

Discussants again noted that, although HIV diagnoses and risk behaviours are increasing, there is no clear evidence that HIV incidence is increasing in any group in Europe. Some felt that the effect of treatment in reducing the pool of circulating viruses may well be counteracting other factors. Again, the need was identified for more research into how the different factors were interacting to either reduce or increase the number of new HIV cases.

Figure 8



Implications for prevention activities

Key characteristics of effective and efficient prevention interventions identified by presenters highlighted the need to be:

1 evidence-based and reasonable;
2 ethical and equitable;
3 targeted;
4 comprehensive and integrated with treatment and care;
5 sustained financially and over time;
6 supported with policies and cultural context that reduce vulnerability and enhance prevention;
7 involving people with HIV and those most at risk;
8 innovative.

Additional discussion points

1 HIV is a major problem

The evidence of increasing HIV diagnoses and risk behaviour points to HIV continuing to be a major health problem requiring strengthened prevention activities all across Europe.

2 Approaches need to be customised

The heterogeneity of the epidemic means that to be effective, prevention activities need to be customised to the country needs and targeted at appropriate high-risk groups.

3 Integrate HIV prevention with STI activities

Prevention activities aimed at reducing sexual transmission of HIV need to go hand-in-hand with the prevention, detection and treatment of STIs, especially amongst MSM, sex workers and young people. Ideally, HIV and STI programmes should be integrated.

4 Inequities need addressing

Inequities of access to health care and other services (both on grounds of race/ethnicity or gender, and amongst the vulnerable groups, such as IDU) need to be addressed.

5 Scale up, especially harm reduction initiatives for IDUs

Known effective prevention activities have to be scaled up – there are still great differences, both between and within countries, e.g. in access to needle exchange and substitution therapy for IDUs, which are the best studied and have been shown to be effective prevention methods.

6 Address chronic disease needs of HIV-infected persons

As a large number of HIV-positive people are surviving and living full and active lives, including sex lives, concerns were raised about how to provide for long-term care and offset possible new threats of stigma and discrimination (no country in Europe is below the threshold for stigma and discrimination).

7 Strengthen MTCT control, where needed

Efforts to achieve the targets set for mother-to-child transmission (MTCT), as noted earlier, need to be maintained or, in some countries, strengthened. Whereas Europe overall has achieved the Dublin targets, some countries still have low uptake of HIV testing amongst pregnant women and a low proportion of infected women on ART.

8 Utilise all high-risk settings

Additionally, attention needs to be paid to prevention in other areas, especially prisons, and health-care settings. It was noted that there have been major HIV outbreaks in several health-care settings in the last two years.

9 Develop new tools

While participants identified a wide variety of prevention tools, including pre- and post-exposure prophylaxis, prevention of mother-to-child transmission (PMTCT), female condoms, behavioural interventions, circumcision, and risk-group-specific measures such as substitution treatment and needle exchange, some felt that there was a need to be more 'inventive' and to develop new tools (e.g. vaccines, microbicides, and better pre-exposure prophylaxis).

10 Strengthen coordination

Some felt that while the EU countries have identified and implemented many effective interventions, there needs to be improved surveillance and reporting, with strong coordination between countries, so that no time, money or effort is wasted on prevention measures that have no impact on transmission rates.

II PRIORITY AREAS

1 Unmasking the 'hidden epidemic' – increasing uptake of testing

1.0 Introduction

In the absence of regular, universal testing, it is hard to know precisely the extent of the HIV epidemic as the size of the undiagnosed population is hard to estimate. In the EU, it is estimated that about 30% of people living with HIV have not been diagnosed and are not aware that they are HIV-infected.

When the first HIV test became available in 1985, the primary concern was to safeguard the blood supply. Indeed, systematic screening of blood donations has virtually eliminated the transmission of HIV through transfusion of blood or blood products. Attention was not, therefore, focused on diagnosing HIV infection in individuals. Given the significant stigma and discrimination issues, the protection of human rights was felt to be of paramount concern, especially by the most affected groups; most of whom came from communities already the subject of a great deal of stigma and discrimination, notably MSM. This was compounded in the early days when the shock and fear factors of HIV/AIDS were still very high.

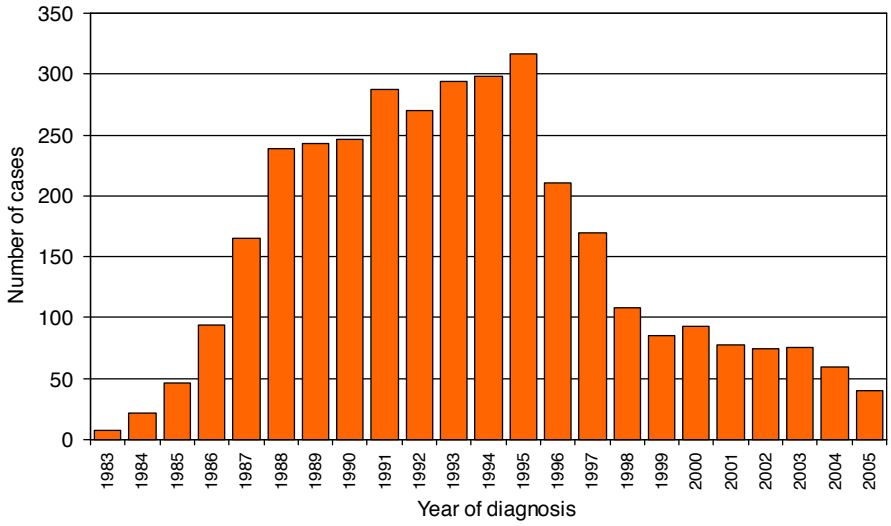
This 'exceptional' situation became the norm, and to a large extent in many countries it is still so today – with little routine screening and much emphasis on the need to safeguard HIV-infected persons' human rights and anonymity. This is the case in spite of significant changes in treatment availability and survival rates and the paradigm shift of AIDS, in most of the developed world, from 'a death sentence' to 'a chronic illness'.

> **'AIDS Exceptionalism' (Bayer, 1991)[4]**
>
> The different way that HIV/AIDS has been addressed by public health compared with other infectious diseases:
>
> - HIV testing restricted, counselling emphasised.
> - HIV case reporting by name limited.
> - Emphasis on confidentiality and privacy.
> - Partner notification and contact tracing limited.

Following the first PMTCT clinical trial in 1993, there came an avalanche of data showing that such transmission could be prevented with appropriate interventions, but that it would require an expansion of testing. Thus, pregnant mothers became the first group to be routinely tested in most countries, with the result that MTCT has been dramatically reduced. In fact, most countries in Europe have already reached, or are within reach of, the target set by the Dublin Declaration of less than 2%. Figure 9 shows the dramatic effect of routine screening on rates of MTCT in Europe.

[4] Bayer, R. 'Public Health Policy and the AIDS Epidemic. An end to HIV exceptionalism?' *N Engl J Med* 1991; **324**:1500-4.

Figure 9: Number of perinatally acquired AIDS cases, by year of diagnosis adjusted for reporting delays, European Union, 1983–2005



Source: EuroHIV

However, routine screening is still not the norm for other groups, and the 'undiagnosed fraction' of the HIV-infected population continues to give rise to the majority of new infections. Methods to quantify and reduce this fraction continue to be the focus of concern in many countries, as shown in the responses to the ECDC HIV survey. Growing evidence suggests that reducing this 'undiagnosed fraction' could reduce HIV infection levels by as much as 30% (see Section 2).

The USA's Centers for Disease Prevention and Control (CDC, Atlanta) had, just the month before, addressed this issue in a way that, for the first time, challenged HIV exceptionalism, with the release of revised recommendations for HIV on 22 September 2006. These new recommendations called for routine screening in health care settings for 13–64 year-olds and changed consent requirements to an 'op-out' approach. Kevin de Cock presented an overview of them which left the meeting buzzing around the question of what should Europe's response be to these new CDC guidelines? And does this mark the end of exceptionalism in Europe too?

This section draws on the content of Kevin de Cock's personal presentation, together with comments made by the country panel responders and other meeting participants in the lively discussion that followed, as well as drawing on relevant material from other presentations and Member State responses to the survey questionnaire.

1.1 The need

In the EU, estimates of the 'undiagnosed HIV fraction' vary by country, ranging from 15% to over 50%, and overall the level of undiagnosed cases is estimated to be about 30%. In Ukraine it is suggested that only 1 in 16 has been tested. In their responses to the ECDC

survey[5], several countries mentioned the need to reduce the number of undiagnosed cases, or reduce late diagnoses, as key public health challenges.

Numerous studies have been carried out and there is now compelling evidence concerning the role of the 'undiagnosed fraction' in new infections: those who are aware of their seropositive status cause 30–46% of new infections, while those who are unaware cause 56–70% of infections (see Figure 13). Knowledge of one's seropositive status often results in behaviour modification and is therefore one of the most effective prevention methods available, with the potential of reducing new infections by up to 30%[6].

The evidence shows that prevention interventions with HIV-positive persons are more effective, and more resource effective (cost, time, etc.), than prevention work focused on HIV-negative persons. Two papers recently published in the *New England Journal of Medicine* indicate that expanded HIV screening in the US is a cost-effective intervention[7].

1.2 Challenges/obstacles

One of the biggest obstacles in some countries is stigma and discrimination, especially as many of the groups involved are already beyond the law and norms of 'acceptable' behaviour. Where the social 'penalties' of being HIV-positive are high, or where an individual attending for testing risks imprisonment (for example for illegal drug use), that is a powerful disincentive to being tested. As a policy to combat the HIV epidemic, it has also been shown to be counterproductive.

- Higher level of legal repression is not correlated to higher rates of injecting, but it is related to higher prevalence of HIV among IDU
- The higher the expenditure on police forces and on incarceration, the higher the prevalence of HIV among IDU, unless similar increases of funding occur for harm reduction and cooperation between law enforcement and public health services

(Friedman et al., AIDS 2006, **20**:93-99)

The point was made that the social environment must be conducive to prevention work. This also raises issues of confidentiality: if this cannot be guaranteed, this will also discourage people from attending for testing.

The meeting also heard that there is a rising trend towards the use of criminal law against HIV-positive people who pass on the infection, and the implications of this for testing were discussed: 'Criminalisation' is another disincentive to being tested.

Implications of criminalisation[8]

- Only those who know their HIV positive status can be criminally liable
- Disincentive to testing?
- Unclear whether condom use will preclude finding of recklessness

[5] Question 4: What are the main public health problems with regards to HIV you are facing in your country?
[6] Marks. *AIDS 2006;* **20**: 1147-50.
[7] Paltiel *et al*, *N Engl J Med* 2005; **352**:586-95; and Sanders *et al*, *N Engl J Med* 2005; **352**:570-85.
[8] Slide presented by Nikos Dedes, European Aids Treatment Group.

- *De facto* requirement to disclose prior to sex provides disincentive to disclose afterwards in the event of condom failure
- PEP implications?
- There may be an adverse impact on the framing of advice (to warn or not to warn about legal implications of disclosure?)
- Prison may result in adverse health outcomes, both for the convicted person and those with whom s/he may be in sexual contact
- Criminalisation of reckless transmission undermines the message of shared responsibility

Dr Matthew Weait, Keele University School of Law

Discussants noted that it is not possible to discuss testing without briefly mentioning mandatory testing, and it is worth relating the experience of Hungary in this regard, who reported that when they moved from mandatory testing to voluntary testing, the numbers of positive results actually increased. This suggests that mandatory testing may in fact be counterproductive and acts rather as an obstacle to increasing the numbers of people tested.

Other obstacles identified included inequality of access to testing for some groups, the implications of screening where treatment cannot be provided, or afforded[9], and fear and denial (study results from Botswana showed that the principal reasons for not undergoing testing were fear (49%) and 'no reason to believe infected' (43%)).

It was also noted that the coverage of testing facilities was inadequate in several countries, and routine testing was not systematically offered to some populations at higher risk (such as IDUs, TB patients or migrants). There were a number of reasons for this insufficient offer, such as time and resource restrictions on the part of providers, and their lack of knowledge and awareness.

Concerns were also raised around the role of other health professionals (i.e. those not directly involved in HIV) in testing, even when a patient presents with symptoms that are strongly indicative of HIV infection. The question was asked why such health professionals do not think about a diagnosis of HIV, often until the patient is already very ill. The representative from the World Health Professions Alliance noted that many professionals, especially the older ones, lack sufficient training and knowledge of HIV. The UK representative remarked that when routine screening was first introduced for pregnant women, involving midwives in the process, there were initially difficulties related to lack of knowledge, although these were subsequently resolved. Other explanations centred on system restraints. For example, the Lithuanian representative explained that in that country, such HIV testing is not covered by professional indemnity insurance.

Given continued high levels of fear, stigma and discrimination in some countries[10], the balance between public health needs (to prevent and treat infections, and avert deaths) and the rights of the individual (autonomy, protection from violence and discrimination, privacy) continues to present a big challenge in increasing uptake of testing.

[9] In Denmark, for example, illegal foreign sex workers have the right to a test, but not to be treated, free of charge.
[10] Participants from some countries, for example Denmark, felt that fear, stigma and discrimination have been addressed in their country and are not the significant factors that they once were.

Testing and counselling: ethical issues

- Individual's privacy, autonomy and integrity
- Individual and public responsibility
- Cost and health benefits
- Human and civil rights, including sexual and reproductive rights of HIV-positive and HIV-negative
- Criminal liability
- Public and private morality

1.3 Interventions that work and obstacles to be overcome

Several participants mentioned the need to 'lower the bar' to make it easier for people to attend for testing and for clinicians to prescribe testing. For IDUs, the inclusion of free and anonymous testing in low-threshold centres is very effective, and also the provision of settings at street level, which are accessible and can reach hard-core drug users (some countries have mobile settings, such as a bus – this is also effective in reaching sex workers on the street). The requirement for pre-test counselling, for example, has been removed in the US (see box below), where it is also possible to undergo testing in different settings, including the possibility of ordering tests online over the internet.

Another effective strategy identified is the 'social network' strategy, where people are asked to refer people in their social network for testing. This is outlined in the next section with reference to MSM, but could be adapted for use amongst other groups.

The provision of confidential, free-of-charge testing options was considered essential by many. Several countries commented on the fact that there are a higher number of positive results from anonymous testing centres, which suggests that some people who are most at risk prefer to be tested anonymously. This point was reinforced by the Norwegian representative's observation that studies showed people were not inclined to be open about their sexual behaviour with their GPs.

The importance of providing facilities at the right scale and in the right places was acknowledged. Several countries reported that such facilities were provided in the big cities, but they lacked country-wide coverage. Ensuring adequate testing and laboratory coverage in isolated and hard-to-reach populations was noted as one way of strengthening testing.

Involvement of sectors other than the health sector – for example, legal, employment, housing, education – in addressing some of the social and legal issues and safeguarding the rights (both human and civil) of the individual was also noted as a way of helping to increase the uptake of testing. Linking treatment and care with social support services after diagnosis of HIV infection was agreed to be critical.

Finally, training health professionals and supporting them in overcoming their discriminatory behaviours and in dealing with issues of confidentiality, can improve their confidence and performance when helping people deal with issues of diagnosis, testing and counselling.

1.4 AIDS 'exceptionalism' – issues to be considered

A key challenge facing Europe now, and ECDC, is how to respond to the latest CDC guidelines. In an effort to increase the number of people tested, and reduce the 'undiagnosed fraction', the CDC has opted for a policy of recommending routine screening for certain groups (see below) in health care settings. These recommendations do not apply to testing in other situations.

Revised CDC recommendations for HIV testing in health care settings, September 2006[11]

- Routine screening for HIV infection for all patients 13–64 years
- Routine screening for HIV infection for all TB and STI patients, and pregnant women
- Informed consent as 'opt-out'
- Annual testing for persons at risk
- Results delivered as other diagnostic tests
- Pre-test prevention counselling not required

The point was emphasised that this new CDC policy did not support coercive (mandatory) testing, nor did it underestimate the potential undesirable outcomes (such as discrimination or violence), but there is evidence from other countries that routine testing is acceptable and effective, and that providing an 'opt-out' is an acceptable approach to 'informed consent'. Nor could fear and denial (common reasons for not being tested: see Section 1.2) be mistaken for an educated, informed choice.

The question was also asked whether, by not offering routine testing where HIV infection was suggested, health care providers were letting patients down.

> Failure to provide HIV testing when symptoms or signs of HIV disease may be present is substandard care and is not acceptable.
>
> (Ministry of Health, Kenya, 2004)[12]

There was some discussion about whether the CDC policy spelled the beginning of the end of HIV/AIDS exceptionalism, and whether it was not time to end it in any case. There are many good reasons for treating HIV like any other communicable disease:

- It is a serious condition that can be diagnosed before complications develop.
- It is detectable by reliable, inexpensive, non-invasive tests.
- It is a condition where early treatment leads to years of increased life expectancy.
- It is cost-effective to screen, prevent and treat.

However, some concerns were raised regarding this new approach:

- The impact on individuals. Many felt that such a policy could not be applied until the barriers to, or potential adverse consequences of, voluntary testing (such as stigma, lack of confidentiality, lack of access to treatment, and obviously where there was a risk of a person being imprisoned) had been removed.

[11] Slide presented by Kevin de Cock.
[12] *Guidelines for HIV Testing in Clinical Settings*.

- Ethical problems with 'opt-out' consents. PLWA, gender and human rights groups have raised concerns regarding opt-out testing.
- Testing scale-up was questioned if ART is unavailable or access limited.
- Pre-conditions. Laws, regulations, policies against discrimination are desirable prior to opt-out testing.
- Testing newborns of untested mothers because a positive HIV test in a newborn means that the mother is infected.
- Diagnostic versus routinely recommended testing of children.
- The availability of prevention counselling for all.

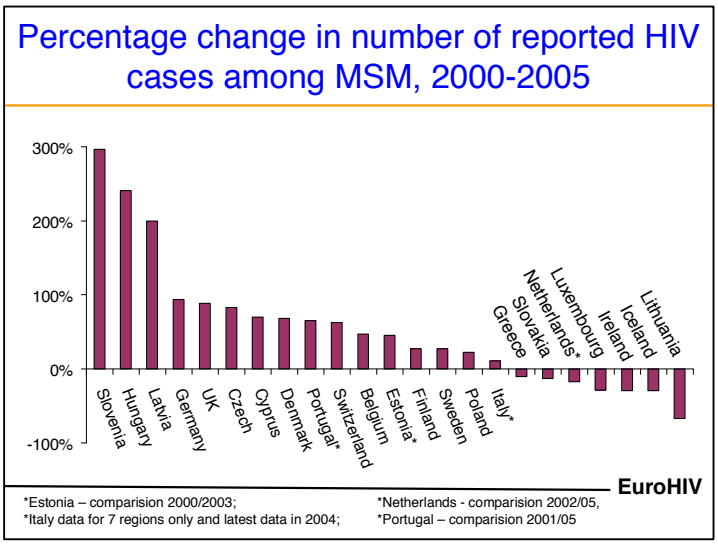
The policy raised various ethical issues around human rights, privacy and autonomy and each country has to make its own decision on whether such a policy would work in its health care system. It was hoped that one role which ECDC might play is to provide a platform for discussion of these issues, in cooperation with WHO and other agencies.

2 MSM

2.0 Introduction

Finding effective ways to identify and address HIV/AIDS in the MSM community has been a driving force in dealing with the epidemic in Western Europe since the 1980s. Recent data indicating rising levels of risk behaviour and HIV diagnoses among MSM point to the need for new and strengthened approaches to this target group. This has been identified as a priority action area by the ECDC Advisory Forum, reinforced by the results of the ECDC HIV questionnaire. That confirmed that this group continues to be a focus of concern in Member States and neighbouring countries in western and central Europe, with some countries citing them as a 'hard-to-reach' target group. Even in countries where the epidemic is concentrated in IDUs, MSM new case rates indicate a need for action. Indeed, the representative from Latvia commented that MSM could well be the next centre of outbreak in the Baltic States.

Figure 10

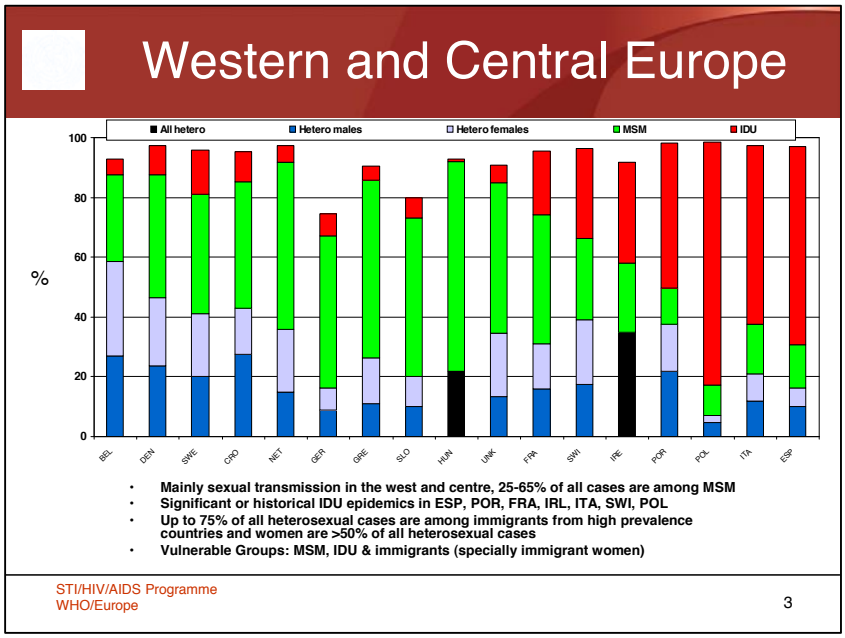


In this section we will look at both quantitative and qualitative evidence related to surveillance data and intervention effectiveness drawn primarily from Kevin Fenton's presentation at the meeting, together with comments of the country panel and other members of the meeting, relevant evidence from other presentations, and the results of the ECDC HIV questionnaire.

2.1 The need

As can be seen from Figure 11, below, the largest proportion of infections in western and central Europe are found amongst MSM (with a few notable exceptions). Given that MSM make up less than 5% of the general population of a country (estimates range from 3–10% of men), but 25–65% of all cases of HIV, it is clear that MSM bear a disproportionate burden of the disease.

Figure 11: HIV cases by category, western and central Europe



The highest rates in HIV diagnoses in MSM are in western Europe. However, discussants noted that it is likely that there is substantial underreporting in eastern Europe. In addition, several countries in their replies to the ECDC HIV survey[13], expressed concern that the numbers of HIV diagnoses amongst MSM are rising in their countries.

Going hand in hand with these high levels of HIV infections, there is also evidence, e.g. in the UK, of a rise in STIs amongst MSM – especially syphilis and LGV. Evidence of this trend was also supported by data from other countries, and the meeting was shown graphs from The Netherlands, Denmark, Sweden and Norway confirming this. Many countries also commented

[13] Question 4: What are the main public health problems with regards to HIV you are facing in your country?

on the rise in STIs amongst MSM, in particular among HIV-infected MSM. There is evidence of a clear link between episodes of STIs and HIV viral load in semen (see figure 12).

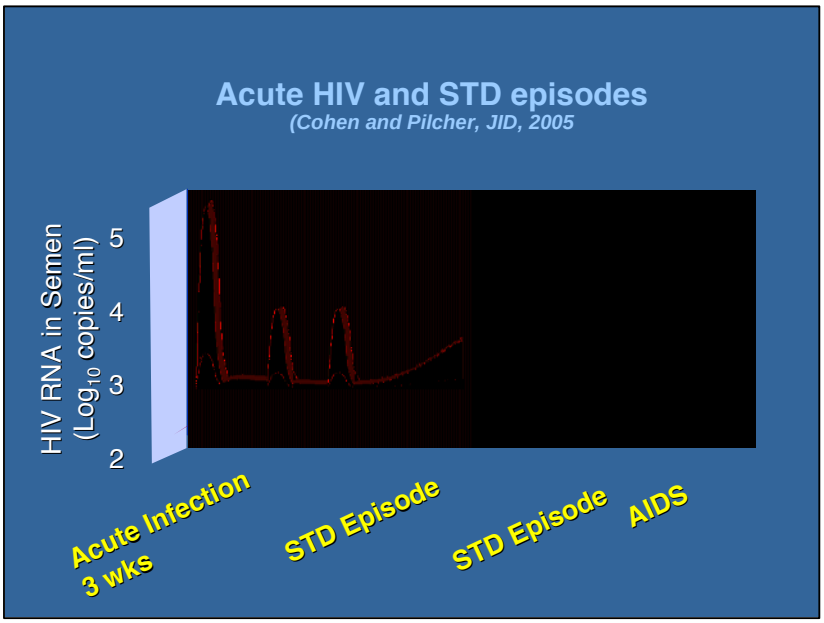
United Kingdom: General trends[14]

The data confirm that MSM bear a disproportionate burden of newly diagnosed STDs. In 2003, MSM accounted for:

- 55% of newly diagnosed HIV infections;
- 19% of gonorrhea diagnoses;
- 58% of syphilis diagnoses.

HIV-positive MSM also bear a disproportionate burden of syphilis (50%); LGV (90%) and gonorrhoea (20%) infections.

Figure 12[15]



The widespread use of HAART has led to an increase in the number of HIV-infected MSM who are living full and active lives, including sex lives, as HIV-positive persons. This requires ongoing chronic disease management strategies, including safe sex and reduction in risk behaviour, on a much larger scale.

There are many factors driving these increases, of which high-risk sexual behaviour is one of the main ones. Other factors include the general trend towards more men having homosexual experiences, and more sexual partners.

[14] Data on STDs among MSM available from a variety of sources including routine and enhanced surveillance systems; behavioural surveillance using convenience and general population surveys. Slide presented by Kevin Fenton.
[15] Slide presented by Nikos Dedes, EATG.

2.2 Challenges/obstacles to addressing the need

2.2.1 Heterogeneity

The tendency to think of MSM as one community was identified as a barrier to effective interventions. Data from the US and Europe show a huge amount of variation in MSM populations, across ethnicity and age groups, with certain ethnic groups bearing a greater burden of disease, and increasing infection rates in young MSM. Additionally, the introduction of HAART (which has, as noted above, led to HIV-positive men living longer) means that there is an 'aging cohort' (aged 55 and over) of HIV-positive men, which goes largely unrecognised. Therefore, when it comes to prevention measures, the message was very clearly that 'one size does not fit all'. Prevention work must be carried out across the full range of ethnic and age groups, tailored accordingly, and if necessary adapted to the specific needs of different MSM communities.

For example, the UK experience with MSM of afro-Caribbean origin is that these men do not tend to identify themselves as MSM, so that prevention measures targeted at the general MSM community do not work with this sub-group. A different approach has therefore been taken to reach this group with prevention initiatives. Outreach work was undertaken in a community setting, with the help of a nightclub where members of this group would mix with other members of the MSM community (music which appealed to this sub-group was used to encourage them to come to the club).

Different communities of MSM will face different issues. For example, there may be issues around poverty, racism, self-esteem, marginalisation, or poor access to health services, and these should be reflected in the intervention strategies used. It was also noted that there are some communities of MSM where there is a lot of overlap with other high-risk HIV groups (for example young MSM (15–24), MSM in sex work (including migration), MSM who are also IDU (many men inject steroids)) which are underestimated in existing prevention programmes and as a result there are very few interventions targeted specifically at these MSM groups.

2.2.2 Evidence

One of the most frequent comments, both in countries' replies to the ECDC HIV questionnaire and comments made during the meeting, was the need for more evidence. Evidence is needed to inform and evaluate national policies and programmes. Discussants noted that if prevention measures are to be targeted effectively, it is necessary to have a full picture of what is actually happening within the target communities in a country. Having reliable data can help to 'change the discourse' around an issue. In the absence of data, too many assumptions are made.

For example, in spite of the rise in prevalence of HIV and STIs amongst MSM, the data shows that prevention approaches continue to beat the same drum, i.e. safe sex, condom use, etc. The dwindling success of these approaches suggests that the situation is more complex than 'use a condom'. It is the availability of behavioural data for MSM that has allowed the identification of some of these other factors (e.g. complacency, alcohol and drug use, the internet, lack of communication) which are driving the epidemic in the USA and Europe. Having identified those factors, it is then possible to find strategies to address them. Reliable data has allowed the UK, for example, to identify and prioritise those groups of MSM who

have the highest risk behaviours: younger men, men with lower levels of education, men with a higher number of sexual partners, men who have been sexually abused or assaulted, some men who are HIV-positive, men who use class A drugs, and black gay and bisexual men.

It was also pointed out that there is ample evaluation evidence that allows us to state that 'behavioural interventions work':

> **Meta-analytic review of HIV interventions for reducing sexual risk behaviour of MSM**[16]
> Data from 33 studies described in 65 reports to July 2003:
> - 22 in United States;
> - 11 in Australia, Brazil, Bulgaria, Canada, Mexico, New Zealand, Russia, and United Kingdom.
>
> Interventions were associated with a:
> - significant decrease in unprotected anal intercourse [OR 0.77];
> - significant decrease in number of sex partners [OR 0.85];
> - significant increase in condom use [OR 1.61].
>
> Authors concluded that behavioural interventions provide an efficacious means of HIV prevention for MSM.

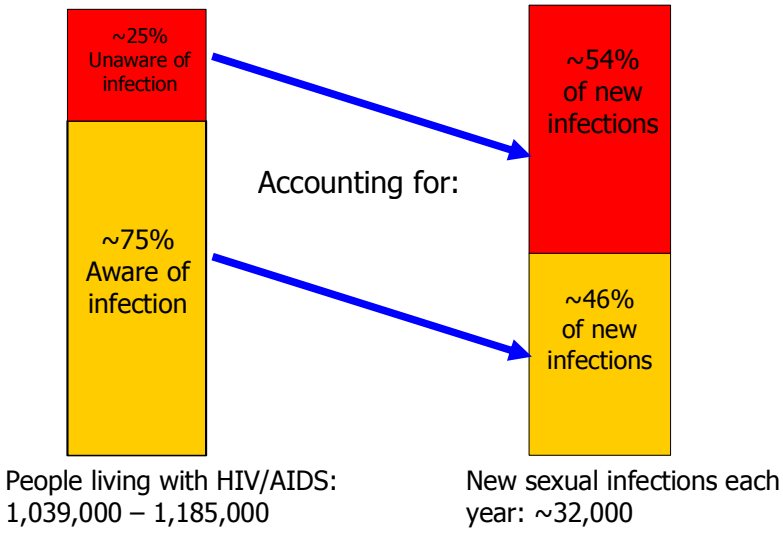
It was noted that there is a need to undertake critical evaluation of our intervention strategies to find out what works, but too many countries have inadequate indicators and rely heavily on disease surveillance, which is too restricted in its scope and does not provide answers to the sort of questions we need to be asking. This is a problem which affects all areas of HIV policy, prevention, care and treatment – it is not just confined to MSM. 'A review of 235 evaluations of guideline dissemination and implementation strategies over 25 years found that few authors gave any rationale for their choice of interventions and presumably used their common sense to choose the interventions.'[17]

2.2.3 Undiagnosed fraction

Great variation in reported knowledge of HIV status across ethnic and age groups was noted by discussants. For example, younger MSM are more likely to have undiagnosed HIV infection than older men, and white men are more likely to know their seropositive status. The meeting heard that in a recent study of young MSM in America, 77% of those who tested HIV-positive mistakenly believed that they were not infected. Young African American MSM in this study were especially likely to be unaware of their infection.

[16] Herbst JH, Sherba RT, Crepaz N, et al. 'A meta-analytic review of HIV behavioral interventions for reducing sexual risk behavior of men who have sex with men'. *J Acquir Immune Defic Syndr.* 2005 Jun 1; **39(2)**:228–41.
[17] Eccles et al. 'Variance and Dissent: response to the OFF theory of research utilization'. *J Clin Epidemiology* 2005; **58**:117–118.)

Figure 13[18]



Those who are unaware of their seropositive status are responsible for more new cases than those who are aware of their status, as shown in Figure 13, above. This is one of the biggest drivers of the epidemic in MSM, as it calls into question the reliability of negotiated safety strategies that are based on knowledge of infection status or seroconcordance.

Shifting people from the 'unaware' to the 'aware' group was identified during the meeting as one of the most effective HIV prevention measures. In the USA it is estimated that this could reduce HIV infection levels in MSM by as much as 30%.

2.2.4 Lack of inclusion of (HIV-positive) MSM in prevention efforts

MSM, particularly HIV-positive men, must be a key component of any prevention efforts, especially as there are now many more HIV-positive men living longer, and being sexually active, as a result of HAART.

The need to include HIV-positive people in prevention efforts is recognised in many countries. Some countries noted extremely active and productive NGO participation; other countries, who noted difficulties in reaching their MSM communities, identified the need to re-establish links with MSM NGOs or set up NGOs for people living with HIV.

Why positive prevention?

'A change in the risky behaviour of an HIV-positive person will, on average, and in almost all affected populations, have a much bigger impact on the spread of the virus than an equivalent change in the behaviour of an HIV-negative person.'[19]

[18] Marks G, Crepaz N, Janssen RS. 'Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA'. *AIDS. 2006* Jun 26;**20(10)**:1447–50.
[19] King-Spooner S. 'HIV prevention and the positive population'. *Int J STD AIDS* **10(3)**:141–50. 1999.

2.2.5 Other barriers/obstacles

Internet

It was reported that the rise of the internet has had a major impact on MSM behaviours. It has played a big role in the 'normalisation' of high-risk behaviour by allowing users to anonymously find partners with similar sexual interests in chat rooms, dating sites, etc. Drug and alcohol abuse were also noted to be associated with increased risk behaviour.

Stigma

Several social and economic barriers to successful prevention efforts were identified in the discussions, including issues such as stigma and discrimination (in the Baltic States, it was noted that little is known about the situation regarding MSM because it is widely stigmatised and thus rarely acknowledged), poverty, inequality of access to services, as well as cultural issues. Lack of communication skills was also noted as a factor (i.e. the inability to discuss issues around, or negotiate, sexual safety strategies) as was poor risk assessment.

Concurrent psychosocial problems

Discussants also noted that evidence suggests a link between 'concurrent psychosocial problems' (e.g. depression, childhood sexual abuse, substance use, and partner violence) and increased practice of risky sexual behaviours.

Treatment optimism

Some participants identified 'complacency' as an obstacle to treatment and care and what one of the countries in its responses to the questionnaire called 'treatment optimism'. After 25 years, and especially since the introduction of HAART, HIV has turned into a chronic, manageable disease, and people fear it less, taking greater risks.

Complexity

It was noted that there is a great deal of complexity in explaining changes in MSM behaviours and risks, and it is quite possible that it is not one factor, but rather several factors combined, that need to be addressed when working towards effective prevention measures in different MSM communities. These factors include the use of the internet for meeting sexual partners; the strategies that have been adopted by MSM to reduce their risk of transmission (e.g. serosorting, strategic positioning); the use of recreational drugs; and the international dimension of the gay identity whereby many MSM meet sexual partners when travelling to foreign countries.

2.3 Interventions that work

There is a lot of good work going on across Europe, as evidenced in the responses to the ECDC HIV survey. The meeting also heard about several effective approaches and interventions in the USA, but the point was emphasised that all the strategies effective with the general population (treating STIs, providing information, providing condoms) are equally effective with MSM, and should continue, although there are still problems with rolling out and scaling up.

Behavioural interventions

As noted above, the evidence shows that behavioural interventions do have an effect: they have been shown to reduce unprotected sex by up to 26%[20]. However, they must be maintained and reinforced and a comprehensive approach is required which includes intervention at several levels. Effective interventions have several characteristics in common.

Figure 14: Summary of intervention characteristics associated with effectiveness[21]

Recommendation	*Examples derived from effective studies*
Theoretic models	Based on diffusion of peer norms or relapse prevention
Interpersonal skills training	Negotiation/communication of safer sex and assertiveness training
> 4 delivery methods	Any of the following methods: counselling, group discussions, lectures, live demonstrations, role play/practice
Exposure complexity	Intensity/dose of intervention More than 1 session More than 4 hours exposure More than 3-week time span

Effective interventions combine a variety of approaches (outreach, social marketing, discussion groups, etc), which are differentiated according to the needs of different target groups. This includes adapting materials, delivery and packaging as necessary. For example, the POL intervention (Popular Opinion Leader – which enlists and trains key opinion leaders, or 'trend-setters') was adapted for african-american MSM by using culturally appropriate materials and including discussions about topics of relevance to the target group (racism, poverty, religion). Most effective interventions can be adapted for use with other target groups in this way.

Settings

The setting in which the interventions take place is important. Most interventions mentioned in the presentation were rolled out in community-based settings. These include gay bars, parties, discos, as well as places like saunas, parks, sex clubs and other sex-on-premises venues.

Sub-group targeting

Another feature associated with effectiveness is the targeting of activities for different groups, including young MSM, MSM with immigrant backgrounds, young men in stable relationships,

[20] Johnson WD, Hedges LV, Ramirez G, et al. 'HIV prevention research for MSM: a systematic review and meta-analysis'. *JAIDS* 2002; **30**(Suppl): S118–S129.
[21] Herbst JH, Sherba RT, Crepaz N, et al. 'A meta-analytic review of HIV behavioral interventions for reducing sexual risk behavior of men who have sex with men'. *J Acquir Immune Defic Syndr.* 2005 Jun 1; **39(2)**:228–41.

young male sex workers. Many of the activities are carried out with the active participation of community members – peer education is a popular feature of the work.

Internet

Just as the internet is one of the biggest threats to prevention efforts, it is also one of the most powerful tools for prevention work. Many countries have web pages or websites aimed at MSM, with games, campaigns, information available about sexual health, self-help, and other relevant issues. Some countries have even more involvement, using chat rooms to discuss issues such as safe sex, mental health, and other related matters (with trained peers), offering tests or tailored interventions online.

Social networks

One highly innovative and successful initiative in the USA is using a 'social networks' strategy. Sex takes place within the context of partnerships, which take place within sexual networks, within communities. The 'social networks' approach encourages individuals to refer people within their network for testing and counselling. In the US initiative, the number of new HIV infections diagnosed this way was five times higher than in publicly funded sites[22]. This network strategy is an effective way of targeting those people who are most likely to be HIV-infected.

Structured services

The suggestion was made that there is a need for more structured services for MSM (as are provided for IDUs), such as low-threshold centres. In its ECDC HIV survey replies, as an example of best practice Norway reported that it has opened a special low-threshold clinic exclusively for MSM, which is free, anonymous and flexible (drop-in or by appointment), and which has been very successful. This was opened in response to survey findings that many patients (especially MSM) were not inclined to be open about their sexual habits when visiting their GP.

Right scale

Perhaps one of the most important points about effective prevention work is that it must be carried out at the right scale to make a difference. Many countries run programmes in the big cities, but have nothing for people in smaller or isolated communities. The successful low-threshold clinic mentioned above, for example, is the only one of its kind and is located in the capital city. The need for more such clinics was recognised in the survey.

2.4 Other issues to consider

Roles for ECDC

The meeting agreed that prevention work with MSM is an area in which ECDC has a role to play, especially in surveillance (both in terms of the actual situation regarding numbers of

[22] Centers for Disease Control and Prevention (CDC). 'Use of social networks to identify persons with undiagnosed HIV infection—seven U.S. cities, October 2003-September 2004'. *MMWR Morb Mortal Wkly Rep.* 2005 Jun 24; **54(24)**:601-5.

infections, and also in behavioural surveys to have some understanding of what is driving the epidemic) and the provision of an evidence base of what works, and why. As noted above, in the absence of data too many assumptions are made, but having good data available can change the discourse around an issue. ECDC could also take the lead in integrating HIV and STI policy and prevention efforts, as well as providing a platform for networking and exchange of information and experiences.

Need to scale up

The need to scale up prevention efforts was heavily underlined. There is a lot of effective work being undertaken, but it is often not reaching the countryside and minority populations. Countries were urged to be more critical, and ask the questions: 'Are we doing the right things? Are we targeting them correctly? Have we got them at the right scale to have an impact?'

'Embrace your gays'

The need to 'embrace your gays' was emphasised. Failure to include HIV-positive MSM in prevention efforts is a barrier to successful interventions. MSM should also be included in all aspects of care, treatment and policy. Some countries have had MSM input to policy at the highest levels for many years.

Fatigue?

It was suggested that 'fatigue' might play a part in the failure of prevention efforts to have any impact. The MSM community has been listening to the same prevention messages for 25 years. However, this was challenged by Kevin Fenton. He explained that a newly infected 17 year-old, who had received no education about HIV, safe sex, and how to protect himself, was not 'fatigued', but 'angry'. It is possible that the prevention workers might be fatigued, and that is why there is a need for more innovative interventions and a more focused approach, with adequate funding and political support.

How far can we go?

Finally, the question was raised as to how far it is possible to reduce HIV in MSM without new technologies (e.g. vaccines, microbicides, pre-exposure prophylaxis); whether there is an acceptable 'minimum' and what that might be. In his response, Kevin Fenton pointed out that the successful reduction of MTCT had not been achieved overnight – new interventions had been added layer upon layer over the years, and that is the approach that has to be taken with MSM (and other groups).

3 HIV in the Baltic States

3.0 Introduction

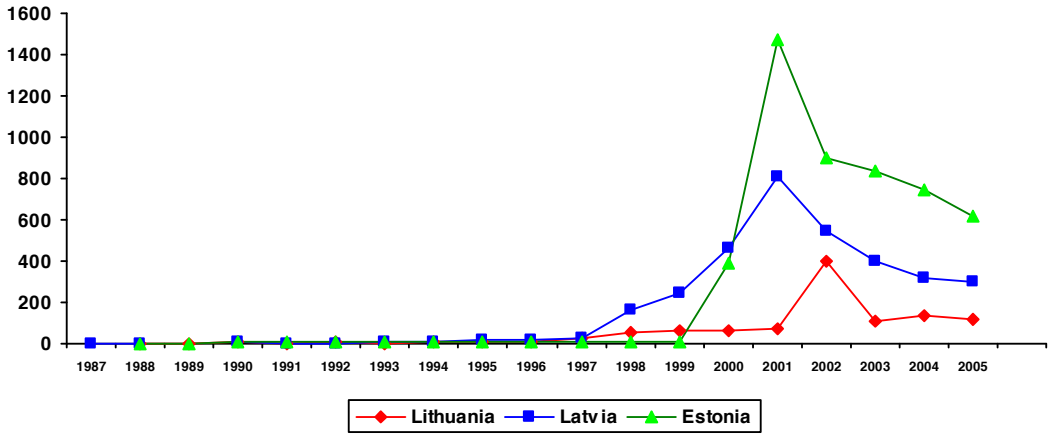
Several of the Baltic States have epidemics concentrated in IDUs, which are now spreading to the general population, and are amongst the highest levels in Europe. The Advisory Forum has suggested that ECDC set the epidemics in these countries as an area for priority action, and the background to these epidemics was given by Zaza Tsereteli. This section draws on his presentation, which focused on Lithuania, Latvia, Estonia and Ukraine, the comments of

country panel members and other country representatives, particularly those from Estonia, Latvia and Lithuania, as well as relevant comments from other presentations and the responses of the relevant countries to the ECDC HIV questionnaire.

3.1 The need

Until the late 1990s, HIV infection rates in the Baltic States of Latvia, Lithuania and Estonia were relatively low. However, over the next 4–5 years the rates of infection grew dramatically, reaching a peak in the early 2000s, as shown in Figure 15.

Figure 15: HIV tendencies in Lithuania, Latvia, Estonia[23]



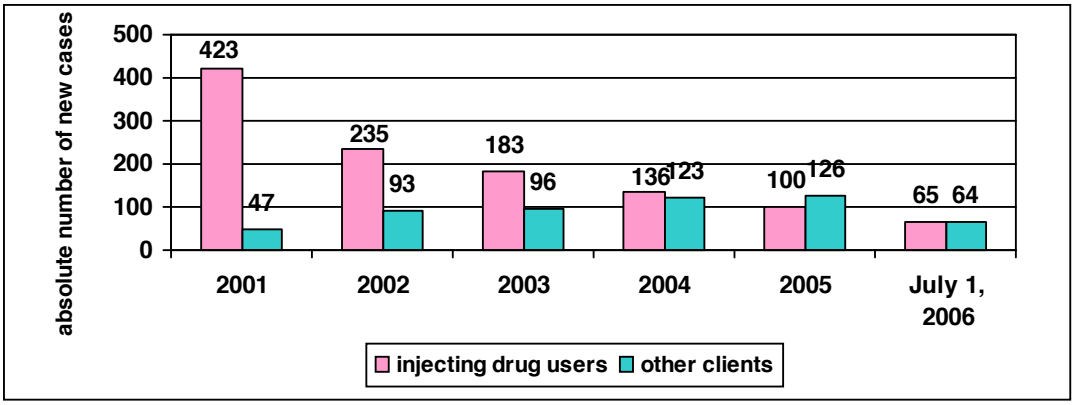
In 2005, Estonia reported the largest number of new HIV diagnoses per population in the EU, at 467 per million, almost twice the number of the second largest (Portugal, with 251 per million).

The epidemics in these countries are mainly concentrated in IDUs (and their sexual partners), who are mostly male but as HIV is spreading heterosexually, there is an increasing number of women. All three countries, in their responses to the ECDC HIV survey[24], mentioned these concentrated epidemics as a major public health problem. They also expressed concern about the number of IDUs amongst the prison population, where there are either limited or no HIV prevention or harm reduction programmes. Lithuania also reported insufficient capacity of drug prevention, treatment and other services, as well as insufficient rehabilitation programmes and the slow expansion of harm reduction programmes.

While the epidemic in drug users is declining, it is rising in heterosexuals – Figure 16 refers to Estonia, but the situation is similar in Latvia and Lithuania.

[23] Slide presented by Dr Zaza Tsereteli, International Technical Adviser for HIV/AIDS, NDPHS.
[24] Question 4: What are the main public health problems with regards to HIV you are facing in your country?

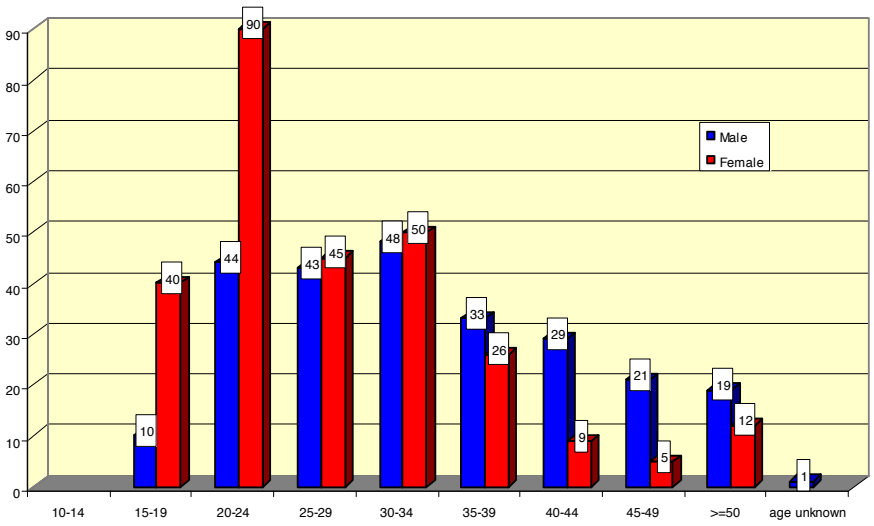
Figure 16: HIV cases detected by AIDS counselling cabinets by modes of transmission in Estonia in 2001–2004



Data source: National Institute for Health Development

Young people (under 30 years of age) are particularly affected in all three countries, especially in the age group 20–24. The following graph shows the situation in Latvia, as far as heterosexual transmission is concerned, where it is clearly women in the 20–24 age group who are most severely affected; the data from Lithuania and Estonia show a similar picture.

Figure 17: Cumulative number of heterosexually transmitted HIV cases by age and sex, 31 August 2006, Latvia



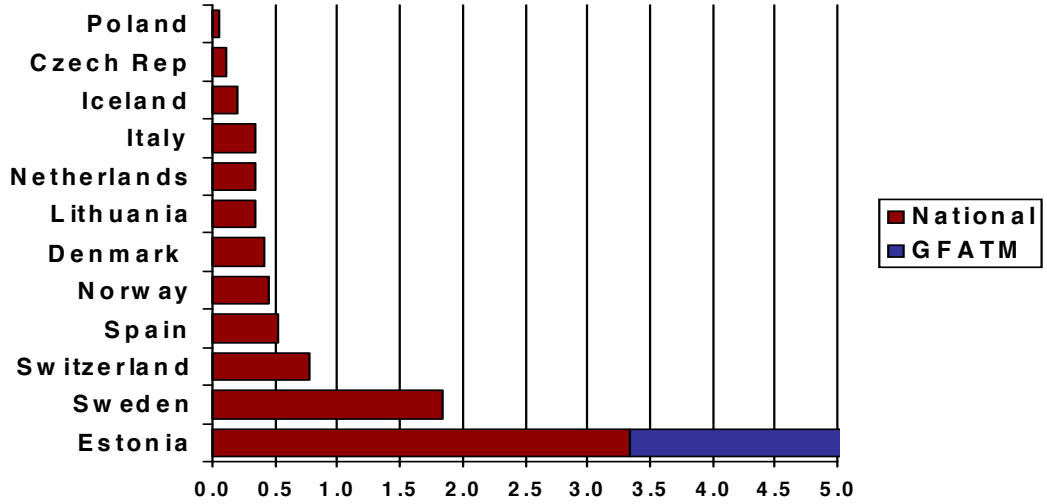
The large numbers involved, and the young age of those affected, have severe implications for these countries in terms of long-term provision of HIV/AIDS care and treatment (e.g. HAART).

3.2 Challenges/obstacles

The biggest challenge is perhaps the sheer scale of the problem. The country comments in response to the ECDC HIV survey consistently pointed to the need to increase the harm reduction capacity of existing programmes, increase the number of low-threshold centres, and especially improve prevention measures in prisons. Zaza Tsereteli said that in addition to strengthening prevention and treatment programmes, there was a 'massive need for scaling up' in these countries. Country survey responses also indicated a need to improve indicators, monitoring and evaluation of their HIV programmes, although there is very little money or infrastructure for systematic surveillance. In his comments following the presentation on MSM, the Latvian representative noted that the reporting in Latvia does not reflect the true situation in his country, and it is likely that MSM are going to be the next big challenge. This was confirmed in the presentation, which stated that very little is known about how the epidemic affects men who have sex with men, since sex between men is widely stigmatised and rarely acknowledged. This gives rise to concerns that HIV may be spreading amongst people and at-risk groups who rarely come into contact with health care and testing services.

The scale of the epidemic has huge resource implications and all countries reported a lack of sufficient resource, both financial and human. Survey data on national budgets showed that Estonia spends more per capita per annum on HIV prevention than any other country in Europe, over 2½ times more than the country which spends the second highest amount.

Figure 18: Per capita annual expenditure on HIV prevention in euro[25]



The Global Fund grant funding accounts for nearly one third of this, but the amount provided by Estonia itself is still more than any other country. During the discussion, the Estonian

[25] The graph is based on figures given in response to the ECDC HIV questionnaire. Where countries gave national and regional expenditure, these were added together to produce the graph. Other countries only cited national expenditure. However, some countries (e.g. Netherlands) have regional expenditure which was not cited in the survey response for HIV/AIDS programmes, in addition to the amounts shown above.

representative raised concerns about Estonia's ability to continue to fund at its present rate once the Global Fund grant funding ceased. Much of the Global Fund's contribution is spent on ARV drugs, which are not available to Estonia at a reduced rate because Estonia is part of the EU.

The lack of resources (financial and human) is also having an adverse effect on the ability of these countries to respond to the needs of at-risk populations. All countries reported insufficient provision of prevention, treatment, harm reduction and rehabilitation services for IDUs (especially in prisons), provision of low-threshold services for vulnerable groups and hard-to-reach populations, provision of youth-friendly services and centres, and difficulties in reacting and expanding existing services fast enough to cope with the growing epidemic. In Estonia there is an ongoing debate around methadone substitution therapy and whether this should be a low-threshold or high-threshold service.

Political will, or rather a lack thereof, was also cited as a potential obstacle. The representative from Estonia mentioned that two previous programmes in Estonia had failed, due to lack of political support: where there was no political commitment, there was no funding. The meeting also heard that there had been 14 ministers of health in the space of 17 years in Lithuania, and while most of them had had some commitment to HIV/AIDS, there was no certainty that this commitment would be shared by future health ministers.

Additionally, multisectoral involvement was noted as being a challenge. Country representatives stated that it was often difficult to get the involvement of ministries other than health (such as education or social affairs), which leads to difficulties in providing health education in schools, for example. Estonia felt that the health professions are not really engaged, noting the lack of training for in HIV (most had received their training abroad). Also highlighted was the fact that civil society in these countries is still relatively 'young', which leads to reported problems with the NGOs. The main problems identified were lack of funding to NGOs, not enough NGOs, weak, underdeveloped capacity of NGOs, and in some cases the absence of any NGO involvement at all.

One country, in its survey responses, cited the 'short history of public health programmes', with the comment that things had been done very differently in the Soviet era and that there is a continuing process of adjustment.

Religious factors were an issue in a couple of countries – with one country citing its 'conservative' religious attitude as a barrier to effective HIV prevention, while another mentioned its lack of moral religious restrictions, and in particular the liberal attitude to sexual relations, as a driver for new infections in young people.

Finally, in drawing an analogy with the situation in Russia, which is seeing a rise of resistant strains coming in from Ukraine, Latvia expressed concern that it might find itself in a similar situation, with resistant strains coming in from Estonia.

3.3 Developing interventions that work

The discussants noted that the situation in the Baltic States is more complex than just looking at effective interventions for IDU. In the light of the country comments, both at the meeting and in their ECDC HIV survey replies, it would seem that the three most urgent needs are for

training for professionals, especially in monitoring and evaluation, greater involvement of NGOs, and resources to cover the increasing cost of ARV drugs.

Effective interventions for IDU are dependent on the availability of harm reduction programmes. Evidence shows that some of the keys to effective IDU prevention work are needle exchange programmes and substitution therapy. The meeting was reminded that these two go together and effective harm reduction requires both. These need to be rolled out at the right scale and quality (e.g. providing correct methadone dosage, sufficient needles provided per client) and include both country-wide coverage and in prisons. A couple of countries have vending machines in certain areas, where clean injecting equipment is dispensed, and Switzerland also provides clean injecting rooms. Recent evidence from Vancouver shows that large-scale injecting rooms can have strong prevention effects[26], while new data from Amsterdam show how the combination of substitution therapy and needle exchange can be synergistic and provide strong protection where the individual measures may be insufficient[27]. Low-threshold and other 'street level' centres have been shown to be effective in reaching IDU – some countries operate a mobile low-threshold centre (such as a bus) to reach 'hard core' IDU on the street.

Regarding the question of resources, especially financial, Valery Chernyavskiy, the Global Fund representative at the meeting, pointed out that there are two criteria on which countries may be eligible to apply for reduced prices for HIV drugs: World Bank economic development classification, and burden of disease. As Estonia has a high burden of disease, it could apply for reduced pricing on those grounds. Additionally, there are several other charitable bodies which provide funding for HIV/AIDS prevention and treatment, and he advised Estonia to 'be proactive' and go in search of such funding. He mentioned, for example, a new charitable body coordinating distribution of development airline taxes, called UNITAID. Its funding is being earmarked, in the first instance, for the purpose of buying HIV drugs.

The representative from Estonia noted that they had found the Global Fund's 'performance-based' approach very useful. It had given them a strict framework within which to work, and provided useful feedback.

In the presentation about the potential contributions that the private sector could make, the meeting heard about Johnson & Johnson's involvement with Project Hope in Lithuania. The Lithuanian representative confirmed that the Project Hope is a good model of intersectoral collaboration and suggested it would be good to expand it to include Estonia and Latvia. The Estonian representative agreed that the role of the private sector is underestimated in Estonia, and they need to pay more attention to cooperation with this sector. Amongst potential areas for cooperation he listed support for community participation, ethical challenges, prevention

[26] Evan Wood, Mark W Tyndall, Julio S Montaner and Thomas Kerr. 'Summary of findings from the evaluation of a pilot medically supervised safer injecting facility.' *CMAJ*, November 21 2006: 175(11). doi:10.1503/cmaj.060863. (http://www.cmaj.ca/cgi/content/full/175/11/1399).

[27] Charlotte van den Berg, Colette Smit, Giel van Brussel, Roel Coutinho, Maria Prins. 'Injecting drug users who fully participate in harm reduction programs are at decreased risk for HIV and HCV, evidence from the Amsterdam Cohort Studies.' Presented by Maria Prins at the 2006 EMCDDA expert meeting on drug-related infectious diseases, 10–11 November 2006, Lisbon, EMCDDA, 2006.

campaigns, the creation of new social norms, reduction of stigma, support for development of educational programmes, and influencing the political environment.

As already noted, the health professionals in Estonia are not currently engaged and there is a need for much greater involvement of the health professions in terms of advocacy, distributing information on their websites, etc. As regards training for professionals, the representative from the World Health Professionals Alliance stated that this is an area where closer alliances with the health profession associations may be of assistance as they have produced guidelines and training materials for their members.

Also emphasised was the importance of networking. It was noted that many countries are experiencing similar problems, and talking to other people who are engaged with the same problems will be one of the best ways of finding out what interventions and approaches work, and what doesn't work. In the context of building up political will, making stronger connections with NGOs, empowering people, and building an environment that is conducive to effective prevention work, networking will be one of the most important tools. It was suggested that this is an area with which ECDC could help.

3.4 Other issues to consider

Priority visit to Estonia

The scale of the epidemic in the Baltic States is such that it was generally agreed to be an important issue for ECDC to work on and it was agreed that this would be done in close collaboration with the EMCDDA. In its plans for country visits, ECDC had already marked Estonia down as one of the first five countries to be visited, and this was welcomed by the Estonian representative.

Strengthening surveillance and prevention efforts

There is a clear role for ECDC and EMCDDA in supporting these countries in the development of their surveillance and prevention efforts, including training in monitoring and evaluation techniques, behavioural studies among IDUs and best practice in harm reduction interventions. In view of the political difficulties experienced by some of the countries, some discussants also noted that ECDC's involvement could help to ensure continuing political will and governmental support for HIV issues. Additionally, ECDC has a role to play in facilitating exchange of knowledge and training, support and networking, in order to supplement the countries' existing pool of expertise.

Possible need for financial assistance?

The problem of the lack of financial resources needs to be monitored and there still remains the strong probability that the EU or other European bodies may need to provide financial assistance to middle-income countries with a high burden of disease, such as Estonia, which fall outside the scope of help available to poorer countries, but do not have the financial resources to afford all the drugs necessary from their national budgets.

4 Migrants

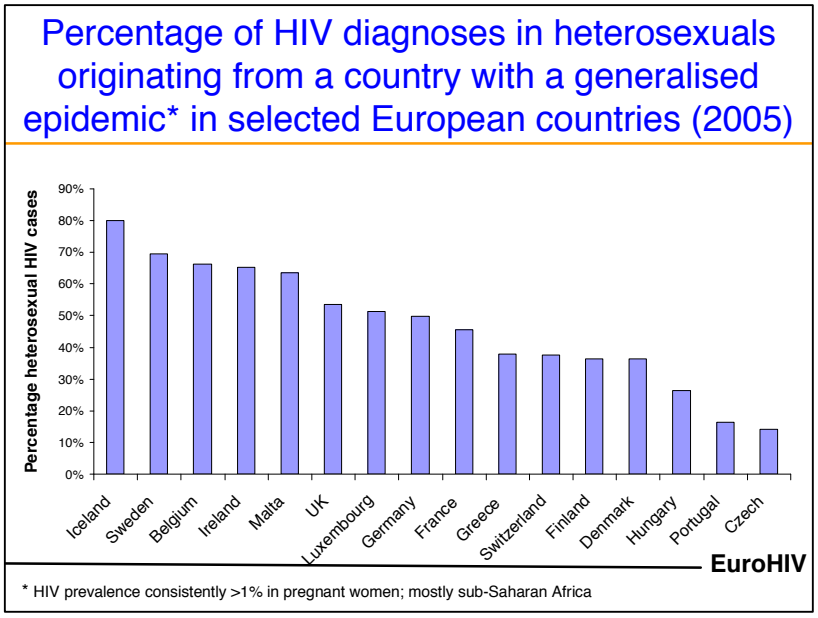
4.0 Introduction

Although HIV among migrants was not an issue initially selected by the Advisory Forum as an area of focus for ECDC, there was a strong sense in the meeting that this was a big problem and an area in which ECDC could play a very useful role. This section draws on relevant material from the presentations, comments from participants at the meeting, and comments made in response to the ECDC HIV questionnaire, in which several countries identified migrants as one of the areas which they felt needed strengthening.

4.1 The need

In their replies to the questionnaire, many countries mentioned HIV among migrants as a cause of concern. Several countries stated that a sizeable percentage of the HIV infections had been brought into their country by migrants from high-epidemic countries (estimates in the range of 30–50%). This situation was confirmed during various presentations, in which it was stated that the majority of heterosexual HIV infection is coming in from outside the EU, brought by people who are already infected, coming from countries with generalised epidemics.

Figure 19



In western Europe, most HIV-infected migrants are coming from Sub-Saharan Africa, while in central and eastern Europe they are mostly from states further east (especially Russia and Ukraine).

As well as people migrating to the EU, there are ethnic populations within the EU countries which are bearing a disproportionate burden of the disease. Several countries mentioned

Roma populations, and the epidemic amongst IDUs in Estonia is largely centred in the Russian community along the eastern border with Russia.

In eastern and central Europe, many of the migrants are sex workers. Hungary, in its survey replies, mentioned the 'presumably massive participation of prostitutes from eastern Europe', and Slovakia referred to 'growing sex work on the borders with Austria and Ukraine'. During the discussion following the presentation on MSM, the meeting heard how there was a lot of MSM sex work across the border with Austria, both men coming from Austria to buy cheaper sex in Slovakia, and men going from Slovakia to work in Austria where they could earn more.

4.2 Challenges/obstacles

One of the main challenges mentioned was inequity of access to health care and prevention services. Also noted were issues of stigma and discrimination, and linked issues such as poverty, poor housing, and socio-economic inequities generally. The need for specific services for migrant communities was also mentioned several times, with prevention activities tailored to their needs.

Some countries reported high-risk behaviour amongst migrants, and the UK mentioned late diagnosis amongst some groups (especially African communities) as a particular cause of concern. Cyprus stated that there was intensive population movement across its borders and the increased migration was having an adverse effect on its social fabric, which was breaking down.

Many countries also mentioned that migrant communities are 'hard to reach'. Concerns were also raised about how to communicate about migrant health issues without adding to existing stigma.

There are also additional challenges noted in the case of illegal immigrants, who will be less likely to seek testing or treatment. Austria, in its survey replies, mentioned problems with illegal prostitution, as the group is hard to reach and highly mobile. At the meeting concerns were raised about health, ethical and economic aspects of providing medical treatment for illegal immigrants. This was identified as an area where guidance from ECDC would be helpful.

Finally, it was noted that there are issues around people who go to work in high-prevalence countries and come back HIV-positive, and 'sex tourism'.

4.3 Interventions that are being taken

The information in this section is mainly a compilation of practices taken from countries' responses to the survey. Many different approaches to migrants were raised. Some countries channel all immigrants through a 'camp' system; some offer an education/socialisation programme to immigrants; some countries offer their immigrants all the rights and privileges of their own citizens, including access to free health care (irrespective of their health status upon arrival); some countries have mandatory testing of immigrants.

Most countries offer voluntary testing and counselling to newly-arrived immigrants, and provide health information leaflets, etc, in foreign languages – as many as 16 different languages were noted in the survey responses – with professional interpreter services provided where necessary.

Many countries work with NGOs and representatives of the relevant communities, as well as offering training to health service workers and social workers to enable them to work in a culturally sensitive manner. Some also train peer educators and cultural mediators. Several countries had adapted their prevention materials for different cultural settings, or to target specific sub-groups (e.g. young people) and the provision of separate services for women was noted in several countries. Discussants noted that in the same way that MSM cannot be regarded as one community, so the heterogeneity of migrants must also be taken on board as a factor. For example, in some countries HIV-infected migrants are predominantly IDUs or sex-workers, and interventions are tailored accordingly.

The need to address this problem was recognised by most countries, and various strategies are being devised to do this. For example expanding the definition of 'migrants' to include persons from ethnic minority groups; funding studies and pilot projects on effective ways to reach migrant populations; legislation and health programmes for migrants, etc. One country talked of the need for community-based development and social inclusion initiatives. Many countries have the benefit of being active members of the EU AIDS and Mobility Network[28].

Finally, with regard to workers who are based in high-prevalence countries, the need to develop workplace programmes to create an 'AIDS-educated workforce' was recognised. The example of Johnson & Johnson was cited, which has introduced a global policy on HIV/AIDS that is applied to its workforce all across the world, and which covers both their employees and the employees' families.

4.4 Other issues to consider

Many countries expressed concern about migrant health issues in their survey responses, and were looking to ECDC for guidance on this matter. With its EU-wide (and beyond) coverage, ECDC is in a better position to address cross-border issues than individual countries. It was also hoped that ECDC's involvement would help to 'legitimise' the issue and reduce stigma and discrimination towards migrants (especially in the press).

With several neighbouring European countries (e.g. Russia, Ukraine) experiencing severe epidemics, which present a great health threat to the EU through increased cross-border traffic (especially of sex workers), many countries expressed worries about the implications for the epidemic in their own countries. However, it was suggested that by setting high standards for surveillance, monitoring, evaluation, care, treatment, prevention, social and other activities, this would have a positive effect on these neighbouring countries, especially those countries which have aspirations to join the EU in the future. It would be sending a clear message that these are the standards to which European countries are expected to aspire.

[28] This is a network for the support of organisations in Europe working in the field of HIV/AIDS and mobile/ migrant populations, with a special focus on young people. It supports governmental, NGO and community-based organisations that develop and provide HIV/AIDS policies and interventions for mobile and migrant populations.

III ENGAGEMENT AND COORDINATION

1.0 Building working partnerships with all key players

In his presentation, Tapani Melkas explained how the Finnish Presidency considered HIV to be an 'intersectoral challenge' and has emphasised the need for better horizontal coordination between health and other sectors to address the 'determinants' based in policies outside the health sector. Health-related targets need to be set in other sectors (such as education, migrants, drug and social policies). This involves working in partnership and collaboration: with other countries (especially Russia), and with other sectors.

Michael Hübel, speaking on behalf of the European Commission, set out the EU approach to HIV/AIDS, as established in the Commission's December 2005 communication on a 'Coordinated and integrated approach to combat HIV/AIDS within the EU and its neighbourhood'. In order to coordinate work between Member States and countries in the neighbourhood, international organisations and civil society, the Commission has established the Think Tank, with a civil society forum. The communication makes numerous references to ECDC, a member of the Think Tank, largely with regard to surveillance. ECDC's growing interest in prevention is welcome, and close coordination with existing work is essential.

It was noted that it is not possible to reduce stigma and discrimination in the health sector alone, which has no control over other factors (e.g. social and economic factors, racism, homophobia, poverty, and lack of access to health care) which act as a barrier to effective prevention work. People's lives do not take place in the health sector, they take place in the community. To be effective and efficient, prevention needs to be supported with policies and in cultural contexts that reduce vulnerability and enhance prevention (including reforming the legal framework).

This approach is recognised by The Northern Dimension Partnership (for Public Health and Social Wellbeing), which operates in the north-eastern part of Europe (covering a slightly larger area than the Baltic States), and whose aims are:

1 reduction of major communicable diseases and prevention of lifestyle-related non-communicable diseases;
2 enhancement and promotion of healthy and socially rewarding lifestyles.

> The new chronic disease perspective changes the needs of infected persons and the focus for prevention to a broader range of responsible sectors, such as the educational, employment and social system as well as local health care systems – multisectoral areas where the National Board of Health has little opportunity to coordinate efforts.
>
> (Comment from Denmark in its ECDC HIV survey responses)

The need for partnership and collaboration was reiterated many times and was one of the key messages to emerge from the meeting. While this is indeed an 'old' message, it was emphasised that it is a never-ending process. It was also felt that new partnerships and new connections was one way to combat HIV 'fatigue'. Bringing on board new perspectives,

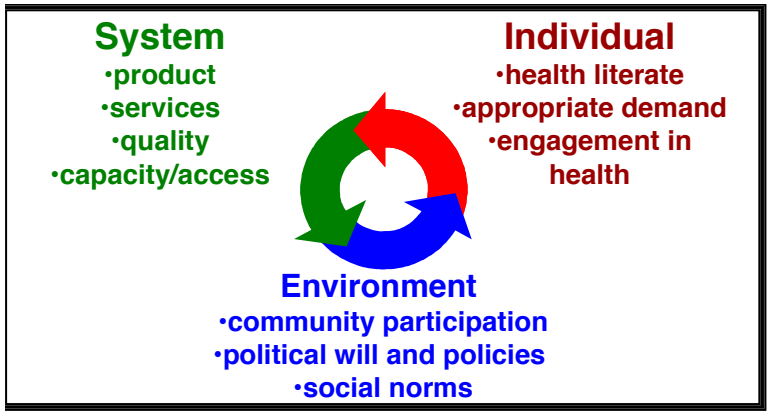
approaches, knowledge and experience was felt to be one key way to keep providers sharp and engaged.

This section will look at some of the issues involved in engaging different stakeholders, how this participation can be achieved, and what part each of the stakeholders can play. The material in this section draws on presentations by Tesfamicael Ghebrehiwet (health professionals), Scott Ratzan (business), Nikos Dedes (people living with HIV), Valery Chernyavskiy (Global Fund), Staffan Hildebrand (artists and film-makers), and Annemarie Hou (media), as well as relevant material from other presentations, country panel comments and other comments made during the meeting, and country replies to the ECDC HIV questionnaire.

It has been noted previously that the lack of involvement of stakeholders and non-health sectors can act as a barrier to effective prevention efforts. Good intersectoral working, with good cooperation between governmental organisations and civil society NGOs, was repeatedly noted in questionnaire responses as one of the 'strengths' of HIV programmes.

The meeting was offered the following 'integrated model for health competence', which underlines the role of all stakeholders in successful health policy.

Figure 20: An integrated model for health competence[29]



Valery Chernyavskiy explained to the meeting how the Global Fund used such an approach in its funding mechanisms (the composition of its governing board and grant portfolio reflects its recognition that governments alone cannot stop the pandemics). Described as a 'public-private partnership', the Global Fund depends on government and non-governmental organisations and the private sector, from its governance to its grants (with roughly half of funds awarded to non-governmental recipients). Grants by the Global Fund are country-driven, not donor-driven, with proposals reflecting the input of public and private partners participating in 'country coordinating mechanisms'. This empowers countries, with 'national ownership' of the programmes supported. It includes government (political will is vital), but also recognises NGO involvement in cooperation with the government. Its 'performance-

[29] Slide presented by Scott Ratzan, Johnson & Johnson.

based' approach to funding, which involves an appraisal of programmes after two years, is an example of how funding can influence country programmes and ensure an integrated approach. It also highlighted that one of the emerging issues is the need for technical assistance, and this is one area where countries can cooperate and share their expertise.

1.1 Private sector

In his country panel comments, the Estonian representative remarked that the potential role of the private sector was underestimated in his country. To some extent, this echoed the opening remarks of Scott Ratzan's presentation, in which he noted that whilst the medicines produced by private industry were regarded as a 'good thing' (the need for new technologies such as microbicides, vaccines and pre-exposure prophylaxis has already been noted), the industry itself was not generally considered in the same light. In his presentation, he discussed some of the ways in which the private sector could work with and support the public sector.

In approaching the question of how the private sector can support public health in HIV interventions, a 'public health' approach was advocated, which looked at possible ways to support in primary, secondary and tertiary prevention.

Three approaches to consider for HIV intervention(s)[30]

1 What can we do to keep people healthy? *Primary Prevention of HIV*

- Universal precaution promotion; support of health competence models (beyond ABC).
- International Partnership for Microbicides support.
- Health Professions and Workers advocacy and capacity building.
- Testing and early treatment.

2 What can we do to help those with HIV? *Secondary Prevention of HIV*

- Appropriate treatment with accurate detection and resistance profiles; track Europe-wide resistance profiles.
- Addressing PMTCT (prevention of mother-to-child transmission).
- Accelerating access.
- Empowerment of PLWHA/NGOs and others for partnering for service provision.

3 What can we do to support effective medical care? *Tertiary Prevention of HIV*

- Supporting health professionals with knowledge, information and practice; diffusion of best practice treatment algorithms.
- Opportunistic infections and palliative care support.
- Innovative scientific/medical breakthroughs in research pipeline.
- Advance policy for HIV/AIDS support and reduction of stigma.

There are many ways in which the private sector can assist in these areas, particularly with regard to evidence-based practice. The need for evidence was another of the key messages that came out of the conference as a whole, as well as being one of the key things mentioned in the survey responses. In particular, the private sector could help the research agenda by looking at 'the dark side of the moon'. In other words, those areas of uncertainty where:

[30] Slide presented by Scott Ratzan, Johnson & Johnson

- questions have not been studied at all;
- issues have been studied, but in small or poor quality trials;
- there are ethical challenges in disease prevention (e.g. diffusion of circumcision; pre-exposure prophylaxis);
- the wrong outcomes were considered, where studies:
  - didn't look at outcomes that matter to patients (e.g. acceptability or quality of life), or
  - didn't look at actual practice in situ;
- studies were too selective (e.g. that didn't include populations of interest or those with co-morbidity);
- studies were not conducted in relevant settings (e.g. done in a tertiary referral centre, not community hospitals).

The meeting heard about a Johnson & Johnson applied research project, in which it commissioned the BMJ to utilise their expertise and research methods to identify best practice in the diagnosis and treatment of HIV/AIDS in resource-poor settings, then to develop applicable guidelines for health professionals, caregivers and the general public. A series of articles has been produced as a result of this project, on different aspects of HIV prevention and treatment, which have been published on the BMJ website.

Another key area in which private sector expertise could make a significant contribution is in campaigning and awareness-raising. The private sector has a wealth of expertise in public relations, social marketing and advertising, as well as a 'can-do' mentality, which could be of great benefit in HIV prevention. This expertise is equally beneficial in influencing political will and key decision-makers and the ability of the private sector to put pressure on politicians has already been mentioned.

The use of 'network analysis' was also advocated. For example in finding the right people and using their networks to disseminate appropriate information. This is another area where the private sector has significant expertise and contacts.

Some key areas of expertise were identified from which public bodies could benefit in a collaboration with the private sector.

- Ability to make an impact on global health **policy**.
- Expertise in **research** & evidence-based products (e.g. drug delivery for pre-exposure prophylaxis).
- Marketing and **communication** expertise (e.g. prevention campaigns; knowledge to practice).
- **Distribution** networks for products and information.
- **Customer focus** (e.g. multiple health stakeholders).
- **Business culture** (e.g. measurable results, 'can-do' attitude.

The 'world of work' had already been mentioned as a key arena for focusing on reduction of stigma and discrimination, and the meeting heard about the Johnson & Johnson global workplace HIV/AIDS policy, which is applied worldwide to every employee, as well as their families. The key components of this policy are:

- non-discrimination and confidentiality protection for employees and their dependants living with HIV;
- voluntary counselling and testing programmes;
- care, support and treatment for employees and their dependants with HIV;
- prevention, education and awareness programmes for all Johnson & Johnson employees and their dependants.

This could serve as a model for other businesses, as well as helping to produce an 'AIDS-educated' workforce.

The example of 'HELP' (HIV/AIDS Education Lithuania Programme) was offered as a model of how the private sector could facilitate multisector cooperation. This is a three-year programme which will build up the capacity of local health and training institutions by:

- training multidisciplinary teams of health and social workers to manage and coordinate care for HIV-positive and at-risk individuals;
- assisting participants with the development and implementation of multidisciplinary programmes and policies;
- building a country-wide case management system to prevent the spread of HIV and provide affordable access to prevention, care and treatment services.

The project will be supported by Johnson & Johnson and mentored by Project HOPE for the three-year period, after which HELP will be self-sustained.

1.2 Health professionals

The health professions have a critical role to play, not only in treatment and care but also in prevention, and in his presentation Tesfa Ghebrehiwet highlighted the unique contribution of health professionals in the fight against HIV.

The World Health Professions Alliance is an alliance of the core health professions and represents the interests of both health professionals (around 20 million) and patients worldwide. They have already made a significant contribution to successful campaigns around human rights, tobacco, patient safety, counterfeit medicines, and other issues, and have set HIV/AIDS prevention, treatment and care as a priority. Both the WHPA and the individual member associations are actively involved in partnerships and activities in the field of HIV, such as:

- knowledge transfer;
- capacity building;
- wellness centres for health professionals and their families;
- policy guidance;
- publications;
- HIV/AIDS networks;
- lobbying/advocacy.

One vital element to their work is the capacity building, i.e. helping to increase the knowledge, skills and confidence of health professionals in a field that is changing all the time. This is done through training programmes, conferences and seminars, dissemination of guidelines and fact sheets, toolkits, skills building, and providing forums for exchange of knowledge and

experience through seminars, journals, websites and other means. In the ECDC HIV survey responses, one country mentioned the need for continuously increasing health professionals' knowledge in HIV, especially physicians.

It was noted that, at the global level, the HIV epidemic was having a serious impact on health professionals, with thousands sick or dying of AIDS, which was weakening health systems (in some countries in Africa, the health systems are on the verge of collapse). The health professional associations are actively involved in the fight to protect and provide for their members, by providing safe working environments and protective equipment, offering appropriate training, engaging in advocacy on their behalf, and the International Council of Nurses (ICN) has also set up Wellness Centres in a few African countries that are most affected, offering comprehensive treatment and health care services to members and their families.

Health professionals have a vital input into:

- prevention;
- care;
- treatment;
- palliation;
- advocacy;
- training/supervision of other health care providers;
- producing evidence to sustain quality care.

It is essential to support the health professionals with training/education, safe practice environments (e.g. to prevent needlestick injuries amongst nurses), protective equipment, access to policy decisions, and active participation in health policy.

It was also noted that unfortunately there is still an issue with stigma amongst health professionals and this is a matter for concern. The ICN has developed training tools targeting health professionals to try to overcome this problem, but in some instances health professionals are still stigmatising people living with HIV and are 'no better than the general public', whereas it was felt that they should be trend-setters, creating stigma-free health care environments. This was one area where it was considered vital for all stakeholders to work together, as the stigma is usually 'worse than the disease itself'. Stigma amongst health professionals regarding ARV for IDU was mentioned as a problem by at least one country in its ECDC HIV survey replies. This can act as a barrier to prevention efforts, when the need to ensure confidentiality, and to ensure that people are treated with respect and sensitivity, are at stake.

In the section on testing, it has already been seen that more general health professionals can often miss out on key opportunities to consider a diagnosis of HIV, and how the involvement and engagement of midwives is key to successful prevention of MTCT. If the uptake of VCT is to be increased, then health professionals in fields outside HIV will have a much bigger role to play.

The comment was also made that not all patients 'have a voice', and health professionals can play a role in advocating for people with HIV.

The discussion in the MSM section around post-test counselling highlighted the role of GPs in continued sexual health educational issues in people living with HIV. In Slovakia, where there are no people living with HIV NGOs, it was noted that 'physicians in clinics solve all problems

of these patients including their personal problems during the counselling for infectious diseases'. This has implications for skills and training of health professionals, especially in the light of Norway's findings that people are not inclined to be open about their sexual behaviour when visiting their GP.

1.3 People living with HIV

The need to involve people living with HIV, not only in care and treatment but also in prevention efforts, was reiterated many times throughout the meeting: it is difficult to preserve people's human rights and dignity without involving them. The involvement of people living with HIV and those most at risk is essential if prevention efforts are to be effective.

Nikos Dedes's presentation showed how the HIV epidemic had given new meaning to the role of patients. People living with HIV have privileged access to the most affected communities (e.g. IDUs do not fear stigma from their peers) and are also actively involved in prevention efforts and policy development. The European AIDS Treatment Group is actively engaged in partnerships in a number of areas (treatment information, training and capacity building, interaction with various stakeholders involved in health care provision and drug development, and policy) and has interactions with EU and other international agencies, the scientific community, industry, and patient groups and other NGOs active on health issues. However, it was also noted that people living with HIV were not included in some of the high-level actions in the EU (e.g. Dublin and Vilnius), and were having difficulty getting themselves involved in the upcoming Bremen conference.

Unfortunately, people living with HIV are not as widely involved as they should be. This situation was also reflected in country responses to the ECDC HIV questionnaire. In the sections on MSM and testing, we have seen how prevention work with and by HIV-positive people can have a greater impact than equivalent work with HIV-negative people, and the meeting heard how people living with HIV could contribute to effective prevention work in other ways.

Figure 21: What could positive prevention include?

3.1 Individually focused health promotion	3.2 Scaling up, targeting and improving service and commodity delivery	3.3 Community mobilisation	3.4 Advocacy, policy change and community awareness
Strategy 1: Promoting voluntary counselling and testing	*Strategy 5: Ensuring availability of voluntary counselling and testing*	*Strategy 9: Facilitating post-test clubs and other peer support groups*	*Strategy 14: Involving people with HIV in decision-making for Positive Prevention*
Strategy 2: Providing post-test and ongoing counselling for positive people	*Strategy 6: Providing antiretroviral treatment for Positive Prevention*	*Strategy 10: Implementing focused communication campaigns*	*Strategy 15: Advocacy for Positive Prevention*
Strategy 3: Encouraging beneficial disclosure and ethical partner notification	*Strategy 7: Reducing stigma and integrating Positive Prevention into treatment centres*	*Strategy 11: Training people with HIV as peer outreach workers*	*Strategy 16: Legal reviews and legislative reform*
Strategy 4: Providing counselling for sero-discordant couples	*Strategy 8: Providing services for preventing mother-to-child transmission*	*Strategy 12: Reinforcing Positive Prevention through home-based care*	*Strategy 17: Advocacy for access to treatment*
		Strategy 13: Addressing HIV-related gender-based violence in Positive Prevention	

International HIV/AIDS Alliance Paper, www.aidsalliance.org

It was noted that in some countries, NGOs and people living with HIV are not organised or ready to be involved in prevention programmes, and this is a significant barrier to effective prevention work. The need to integrate civil society and people living with HIV in prevention work was stressed.

1.4 Media

The media have a key role to play in effective prevention measures and most countries, in their survey responses, stated that they use television, radio, print and other media as vehicles for public awareness-raising campaigns. The 'negative' role of the media was also mentioned by a couple of countries. One mentioned that journalists had grown tired of writing about HIV since it had lost its 'shock effect', and another country noted that its press was more interested in 'tabloid-style' scandal than disseminating truthful information. In some areas the media is contributing to stigma and discrimination, particularly with respect to migrants.

In her presentation, Annemarie Hou looked at ways in which countries could use the media effectively to get their messages across (bad news, or 'doom and gloom' stories, find their own way into the media). Training up staff to give effective interviews; training journalists to help them make sense of technical data and present technical issues effectively; having a 'core group' of journalists who have privileged access to embargoed materials, relevant staff, and 'exclusives'; targeting your messages and choosing the appropriate media; managing your expectations; and good advance preparation, are all essential components of successful press relations. But 'the message' is most important of all. If it has no substance, there is no story. The point was made that everybody at the meeting was an 'expert' and had a lot to offer journalists in this respect.

Several countries reported using the internet to get messages across to target audiences, and we have already seen in the section on MSM how successful this approach can be. This point was underlined in Annemarie Hou's presentation, in which she stated that websites are one of the most important vehicles for getting messages 'out there' today.

To gain increased visibility, two techniques are particularly effective: using a high-profile event as a 'springboard' to launch your own campaign or message, and using 'branding'. The 'Red' campaign was cited as a successful example of branding, in this instance also tied in with celebrity. The white bracelets associated with the 'Make Poverty History' campaign are another good example. Some commercial companies have become involved in HIV and other campaigns, and their brand names have become linked to the topics in question. This is one area where the private sector can make a great contribution as it has a wealth of experience in such 'social marketing' and communication.

Celebrity-led campaigns can also make a big impact. The success of Bono with the 'Red' campaign was again offered as an example. In his presentation, Staffan Hildebrand mentioned the impact that the film *Philadelphia* had had in raising public awareness about HIV and 'mainstreaming' the issue.

Staffan Hildebrand himself has been involved in documenting the changing face of the HIV epidemic for the last twenty years. During that time, many more film-makers and artists had

become involved, and they were helping to fight stigma and discrimination by affecting political and public opinion.

He noted that one of the most exciting developments is the introduction of new digital technology, which allows people to document their own experiences of the epidemic. This 'grass roots' movement could play a big part in informing people and putting 'flesh and blood' on the statistics. The Lithuanian representative told the meeting that they were already running a very successful video competition on HIV for school children, and wondered if this could not be run on an EU-wide, or European-wide, basis.

2.0 Coordination and regional roles

One of the objectives of the meeting (and the ECDC HIV questionnaire) was to identify gaps and areas where ECDC could contribute to European activities that will strengthen HIV prevention within MS. It was hoped that the meeting would generate a list of actions to be taken at European level to enhance HIV prevention in the EU and neighbouring countries. Countries were asked in the surveys to identify possible actions or roles at European level, and in the 'Dragon's Den' exercise at the meeting they were asked to make proposals in three areas:

1 actions (up to three) which the group recommends should be taken on a regional level to strengthen HIV/AIDS prevention and surveillance activities in MS and neighbouring countries;
2 actions (up to three) that could be taken on a regional level to enhance uptake of UNGASS approaches and indicators by MS; and
3 actions (up to three) that could be taken on a regional level to amplify the impact of World Aids Day 2006.

The material in this section is taken from the survey responses and the feedback from the 'Dragon's Den' exercise at the meeting, as well as other relevant material from presentations.

2.1 Suggestions for regional actions

There was remarkable consensus between the groups at the meeting, and also between the suggestions offered at the meeting and those offered in survey responses.

There was a general call for the collection and dissemination of best practice across Europe which would enable countries to find out what was working elsewhere, and target their activities more effectively. Some felt this could be accompanied by issuing guidance, offering technical assistance and including a strong element of training, or be facilitated by providing a forum for discussion. Such 'best practice' would include establishing, monitoring and evaluating prevention activities, as well as looking at specific groups (e.g. migrants, MSM, IDU, sex workers) and considering other areas such as social rehabilitation and support, and terminal treatment. This would help to strengthen and harmonise prevention activities across Europe, as well as building up a strong evidence base to support HIV prevention and policy.

One of the main areas mentioned was surveillance, with a call for increased standardisation and triangulation of biological data with behavioural and other data (e.g. interventions, policy) to allow for a meaningful comparison between countries, as well as eliminating the great disparity in data collection. It was also felt that the existing surveillance networks

should be strengthened, with improved collaboration and networking at regional level. Practical advice and assistance in translating the data and figures into action was also requested.

The need to avoid duplication with existing initiatives was stressed, as was the need for collaboration and cooperation with other agencies (e.g. coordination of data reporting).

It was also suggested that ECDC could issue guidance and guidelines in several areas, especially with regard to migrant health issues (to include a definition of 'migrant'), to promote testing in different settings and amongst different risk groups, to promote collection of good quality data, in respect of diagnostic tools, etc.

In their survey responses, many countries felt that ECDC could provide a platform for exchange of knowledge and discussions, in which countries could learn from each other (especially countries in similar epidemiological situations), share experiences, make comparisons, etc.

There was also some feeling that by becoming engaged in these issues, ECDC could help to put political pressure on those in power, to make them take action or to ensure appropriate funding.

One of the most popular suggestions was that ECDC carry out 'audit' visits to countries. The ECDC team could be joined by a couple of people from other MS, so that countries could learn from each other (rather than being a 'punitive' auditing exercise). Many countries were keen to be involved such visits, both as visitors and hosts.

2.2 UNGASS indicators

The main message regarding indicators was that they need to be specific to the European situation. Many countries had remarked in their survey responses that the UNGASS indicators were not really relevant to Europe, and this concern was evident in feedback from the 'Dragon's Den' exercise. However, the message that 'less is more' was also a strong feature in the feedback. There should not be many new indicators added, as in some countries staff were already overloaded. It was generally felt that the existing indicators should be adapted, rather than the development of a totally new set of indicators. The language used should also be kept simple.

The other main need was for advocacy of the indicators, to let countries know the indicators were available and how useful they could be, with training and technical support in their use.

Questions were raised about ensuring the reliability of the reporting, and several groups and countries suggested greater inclusion of civil society in the reporting process to allow for a more transparent approach.

2.3 World AIDS Day

Various suggestions were made for potential WAD activities, with the most popular being:

1 exert some sort of political pressure (e.g. by issuing a clear statement at the highest level, or by writing to politicians) to shake politicians out of their complacency;
2 hold some sort of high-profile event, or link national events across Europe;

3 support NGOs in their events (there was a strong feeling that this was the special day for NGOs, who could use a budget more effectively, and therefore it would be more useful and better value to support NGOs in their work);
4 present European data, or a report on the European situation;
5 collaborate with existing partners to raise the profile of HIV/AIDS;
6 present a European budget to translate ideas into action;
7 focus on one topic area (e.g. migrant health issues, or promotion/discussion of HIV testing);
8 collect and disseminate best practice;
9 institute an ECDC award for good HIV campaigns.

IV CONCLUSIONS AND NEXT STEPS

In his concluding remarks, Johan Giesecke gave a brief overview of the meeting and then offered his personal reflections on the next steps that ECDC needed to take.

Indicators

There is a clear need for indicators to reflect the European situation, but rather than 'reinvent the wheel' it is better to look at the UNGASS indicators to see what needs to be modified. The next step will be to set up a small working group to begin this process, and participants who are interested in participating were requested to send an email to Françoise Hamers (Francoise.Hamers@ecdc.eu.int). The working group will not produce any indicators, but will start the process of thinking about how the indicators need to be modified.

Visits

ECDC had already decided on country visits as part of its consultation (on all issues) with MS. Some thought will be put into producing a checklist for visits, and the 'peer review' process suggested during the 'Dragon's Den' exercise feedback will be used. A possible format is to have one person from ECDC and two country representatives, and this will not only be useful to ECDC but also help to spread knowledge and experience around the MS. There is already a similar process in use for pandemic flu preparedness, but without much MS input. It was felt that this process for HIV would benefit from more involvement of MS.

Links to other agencies

One of the objectives of the consultation process (through the HIV survey and meeting) was to help in the process of working out how coordination between different partners can be assured. In particular, work needs to feed into the Think Tank and be properly coordinated with the Commission's activities. The feedback and comments of participants had been very valuable in assisting with the process of role clarification.

With regard to the existing surveillance networks, it was noted that the 15–17 similar DG SANCO networks (each focusing on a different disease) will be funded through ECDC in the future, who will audit them for performance. This could mean some changes in the future.

Priority areas

1 MSM

This population was described as a 'travelling' population, and it is one area where many infections are acquired by men while travelling in Europe. There is a lot of cross-border movement connected with the sex industry amongst MSM, and it was felt to be a truly 'European' or international epidemic. ECDC will continue to provide a strong evidence base and involve NGOs.

2 Baltic States

As noted above, ECDC had already decided to use country visits as part of its consultation process and Estonia is one of the five countries selected for the first round (the others being Poland, Cyprus, Netherlands and Austria). ECDC will also continue to collect examples of best practice in IDU prevention, in collaboration with EMCDDA and WHO.

3 The hidden epidemic

ECDC needs to think carefully about whether and how to react to the new CDC policy, and work closely with WHO on this. It is also working on methods to enable the size of the undiagnosed HIV fraction to be estimated. The survey that has already been done by EuroHIV needs to be refined and extended.

4 Migrants

There was a strong call for ECDC to become more involved in identifying and addressing migrant health issues generally, not just HIV.

Take-home messages

Participants were then invited to sum up, in one sentence, what they had got out of the meeting: their 'take-home' message.

There was a lot of appreciation expressed about the inclusion of countries and other key players in the process of consultation and role definition, and many participants were looking forward to collaborating and working with ECDC in the future. Most participants felt the meeting had been very useful and informative, and people were returning home armed with lots of information to share with colleagues and to put into practice in their national programmes.

There was general appreciation of the fact that ECDC was giving HIV a high priority on its agenda, and people were looking forward to working together with other partners, in the EU and beyond, and being part of a 'bigger whole' working on the problem.

Most participants were pleased about the inclusion of migrants, but a few expressed their disappointment that sex workers had not been included as a focal point for action. There is some very good, and effective, work being done with sex workers and there is a lot of knowledge and experience to share. The feeling was expressed that if sex workers are not made a priority, they could well become the next big concentrated population and that it is 'dangerous' to ignore them.

Finally, it was hoped that people would not miss the great opportunity that had been offered by the meeting, to join together and cooperate in tackling the epidemic.

This report was prepared by World Health Communication Associates.

ISBN 978-92-9193-064-7

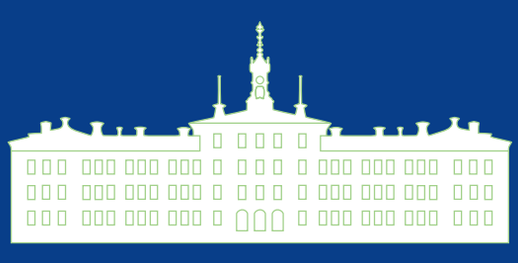
TQ-X1-07-029-EN-C

ABA Kopiering AB 2007

Postal address:
ECDC
171 83 Stockholm, Sweden

ecdc.europa.eu

An agency of the European Union
europa.eu



ISBN 978-92-9193-064-7

9 789291 930647