Annual Meeting of the European Network for HIV/AIDS Surveillance

Copenhagen, Denmark, 11–12 November 2008
ABSTRACT

The annual meeting of the European Network for HIV/AIDS surveillance was held in Copenhagen, Denmark, from 11 to 12 November 2008. The transition of the European HIV/AIDS surveillance, the establishment of the joint ECDC/WHO database for HIV/AIDS surveillance and collection of the 2007 HIV/AIDS data were considered a success: 49 out of 53 countries submitted data, among which five submitted only partial data. General and specific surveillance objectives to optimize the collection and use of 2008/9 data were reviewed and discussed. Although significant progress has been made in standardizing HIV/AIDS surveillance in Europe, further discussions are required to fully establish agreed standards for reporting, including the use of appropriate dates, risk status, and more detailed information on modes of sexual transmission. Member States are invited to submit and validate their 2008 data as soon as they become available.

Keywords

HIV INFECTIONS – epidemiology
ACQUIRED IMMUNODEFICIENCY SYNDROME – epidemiology
EPIDEMIOLOGICAL SURVEILLANCE
WHO Regional Office for Europe
European Centre for Disease Prevention and Control
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### Abbreviations

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<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>AIDS</td>
<td>acquired immunodeficiency syndrome</td>
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<td>ART</td>
<td>antiretroviral therapy</td>
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<td>ECDC</td>
<td>European Centre for Disease Prevention and Control</td>
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<td>EFTA</td>
<td>European Free Trade Association</td>
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<td>EEA</td>
<td>European Economic Area</td>
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<td>EMCDDA</td>
<td>European Monitoring Centre for Drugs and Drug Addiction</td>
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<td>EU</td>
<td>European Union</td>
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<td>EuroHIV</td>
<td>European Centre for the Epidemiological Monitoring of HIV and AIDS</td>
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<td>HAART</td>
<td>highly active antiretroviral therapy</td>
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<td>HIV</td>
<td>human immunodeficiency virus</td>
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<td>IDU</td>
<td>injecting drug use</td>
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<td>MSM</td>
<td>men having sex with men</td>
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<td>MTCT</td>
<td>mother-to-child transmission (of HIV)</td>
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<td>STI</td>
<td>sexually transmitted infection</td>
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<td>SSA</td>
<td>sub-Saharan Africa</td>
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<td>TESSy</td>
<td>the European Surveillance System</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>WHO/Europe</td>
<td>WHO Regional Office for Europe</td>
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<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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Executive summary

The 2008 annual meeting of the European network for HIV/AIDS surveillance was held in the Regional Office for Europe of the World Health Organization (WHO/Europe), Copenhagen, Denmark on 11 and 12 November 2008. The meeting was hosted jointly by WHO/Europe and the European Centre for Disease Prevention and Control (ECDC). Participants included nominated contact points for HIV/AIDS surveillance from 47 of the 53 Member States of the WHO European Region, including 25 of the 27 countries of the European Union and the four countries of the European Free Trade Association (EFTA), as well as experts from the WHO Regional Office for Europe, WHO headquarters, ECDC and representatives from the European Commission, Joint United Nations Programme on HIV/AIDS (UNAIDS), European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), and civil society.

Since January 2008, the WHO Regional Office for Europe and ECDC have been jointly responsible for coordinating enhanced HIV/AIDS surveillance in Europe. Both strive to ensure a high quality of standardized HIV/AIDS surveillance data from all Member States of the WHO European Region. A joint database for HIV/AIDS surveillance has been established using The European Surveillance System (TESSy) platform for collection of national HIV/AIDS data. Data collection was carried out from June to October 2008, and the draft report *HIV/AIDS Surveillance in Europe 2007* was compiled from submitted data. The objectives of this meeting were to review the transition of HIV/AIDS surveillance from EuroHIV to ECDC and WHO/Europe; review the new data collection process and; review the 2007 HIV/AIDS surveillance data; identify key issues for the 2008/9 data collection process; and, review the state of the art of selected topics in the surveillance of HIV/AIDS.

Transition of the European HIV/AIDS surveillance system from EuroHIV to ECDC and WHO/Europe was considered to have been successful. Important lessons have been learned and experience gained. This will be reflected in the collection, analysis and reporting of the 2008 data. Collection of 2008 data will begin earlier in the year, and will not be restricted to a short collection period. Countries are invited to submit and validate their data as soon as they become available at national level. The deadline for data submission will be the final cut-off date, after which all submitted data will be analysed for the 2008 report. During the next data collection, efforts will be made to ensure completeness of reporting and to ensure full geographical coverage of the WHO European Region.

Despite high coverage of HIV/AIDS reporting, not all Member States submitted their 2007 HIV/AIDS data. No national data were received from 4 countries and five countries submitted only partial data. Based on information available through a variety of other sources it is estimated that this missing data more than doubles the approximately 49,000 HIV cases reported in 2007, increasing the regional total to approximately 102,000 cases. Caution should therefore be exercised in the interpretation of the 2007 data.

The 2007 data suggest that the main mode of transmission for new HIV infections in the western part of Europe was sexual transmission, mostly due to sexual contact between men who have sex with men (MSM). In the eastern part the main mode of transmission is though injecting drug use (IDU). Throughout Europe, however, the proportion of reported HIV infections associated with heterosexual transmission appears to be increasing. Cases reported in individuals from countries with generalized epidemics play an important role in the HIV epidemic in the western part of Europe. Available data do not allow accurate assessment of the relative proportion of infections acquired through heterosexual contact between injecting drug users (IDUs) and their partners.
The quality and completeness of the data needs to be improved before conclusions can be drawn on the nature of heterosexual transmission in Europe.

A series of general and specific surveillance objectives to optimize data collection and the use of these data for HIV/AIDS surveillance were reviewed and discussed during the meeting. There was broad agreement with the stated surveillance objectives, although concern was raised that the integration of HIV/AIDS surveillance into broader surveillance for sexually transmitted infections (STIs) was not yet feasible in Europe. Similarly, several of the specific surveillance objectives represented long-term goals.

Although significant progress has recently been made in promoting and standardizing HIV surveillance in Europe, further discussions are required to establish agreed standards for reporting, including the use of appropriate dates, risk status, and more detailed information on modes of sexual transmission. Establishment of the new surveillance framework presents an opportunity for these technical discussions to take place, and for appropriate standards and methods to be further developed and implemented.

Feedback and comments from this meeting will be used to modify the current surveillance objectives, and the redrafted document will be presented at the next annual meeting. Technical groups for the revision of reporting variables will be formed and will propose changes to the variables to be collected from the 2008 data. Further discussions are needed on the use of AIDS surveillance and the possibility of moving towards surveillance of outcome of HIV infection. This will require input from the network and experts are needed to advise ECDC and WHO/Europe on appropriate strategies.
Introduction

This annual meeting of the European network for HIV/AIDS surveillance was held jointly by the WHO Regional Office for Europe (WHO/Europe) and the European Centre for Disease Prevention and Control (ECDC). Srdan Matic opened the meeting on behalf of the WHO Regional Office and Andrew Amato-Gauci welcomed the participants on behalf of the ECDC.

Participants included nominated contact points for HIV/AIDS surveillance from 47 of the 53 Member States of the WHO European Region, including 25 of the 27 countries of the European Union and the four countries of the European Free Trade Association (EFTA), and experts from the WHO Regional Office for Europe, WHO headquarters and ECDC, and representatives from the European Commission, Joint United Nations Programme on HIV/AIDS (UNAIDS), European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) and civil society.

Since January 2008, the WHO Regional Office for Europe and ECDC have been jointly responsible for coordinating enhanced HIV/AIDS surveillance in Europe and agreed to share the data submitted by all 53 countries of the WHO European Region. Both organizations strive to ensure a high quality of standardized HIV/AIDS surveillance data from all Member States of the WHO European Region, including the 27 EU and the four EFTA countries. The first round of joint HIV/AIDS surveillance data collection for 2007 and historical data was conducted from June to October 2008 using the joint ECDC/WHO online database for HIV/AIDS surveillance. Collected data has been collated, analysed and compiled into the annual report HIV/AIDS Surveillance in Europe 2007 that was presented during the meeting for validation and comments.

Objectives of the meeting were to:

1) review the transition of HIV and AIDS surveillance in Europe from EuroHIV to ECDC
2) review the new data collection process and identify problems and constraints;
3) present and critically review the 2007 HIV and AIDS surveillance data from Europe;
4) identify key issues for the 2008/9 data collection process;
5) review the state of the art of selected topics in the surveillance of HIV/AIDS.


Session I. Current status of HIV/ AIDS surveillance in Europe

The transition of HIV/AIDS surveillance from EuroHIV to ECDC, and the WHO Regional Office for Europe, was first presented in September 2007, and has now been successfully completed. A single database structure for collection of data from the whole of the WHO European Region has been established.

National data have been uploaded directly to the joint database using The European Surveillance System (TESSy) platform. Data variables have been formatted to match the new format and permit direct uploading of national data directly from countries, together with verification of data through automated validation protocols. Anticipating that the new requirements could present problems for some countries, a converter tool was developed to transfer data from the old (EuroHIV) data format to the new format. Hands-on training in accessing the database,
uploading and viewing data was held for national contact points and their data managers. Helpdesk assistance was provided throughout the data upload period.

The data collection period for 2007 data was originally set as June 1 to August 31, 2008. However, only eight countries had submitted full datasets by August 31. A series of reminders were sent in September and October, and support was provided to selected countries to upload their data. Data collection was closed on October 15. Data collection for 2008 data will not be restricted to a specific time period, but countries will be free to upload data as and when it becomes available. The only restriction will be the date for final submission, after which the database will be closed to further uploading.

Variables used for reporting to the joint database were based on the variables used for EuroHIV reporting, with a number of modifications made to improve comparability across case reporting systems but limitations to comparability remain. For HIV/AIDS many different dates are collected, including date of onset of infection, date of HIV diagnosis, date of notification, date of AIDS diagnosis, date of death and date of report of death. The “date used for statistics” is a compulsory variable that must be reported, and should match the date used in national reports. For HIV/AIDS reporting, however, some countries use “date of diagnosis” and some use “date of notification”. Choice of date makes a substantial difference to interpretation of the status of the HIV epidemic due to the delay in reporting. There is a need for standardization of the date used and agreement on the preferred date to be used is required. For the 2007 data presentation, date of notification was chosen for the HIV reports while date of diagnosis was chosen for the AIDS data, in an attempt to minimize loss of data from national data collection systems.

The 2007 data presented in the draft report were incomplete as not all countries provided full datasets, and several countries did not submit the requested historical data or did not update information in the historical datasets previously reported to EuroHIV. Missing data makes interpretation difficult and great caution is required in the use of summary information on the status of HIV/AIDS in Europe.

For the purposes of the analysis of HIV/AIDS surveillance data, the WHO European Region is sub-divided into three geographical areas: west, centre and east. The 2007 data were presented and discussed in two presentations: the first covered the WHO European Region and its three geographical areas while the second focused on the EU/EFTA countries.

Preliminary findings of the 2007 report suggest the following:

• Despite incomplete reporting, the number of reported newly diagnosed cases of HIV infection in 2007 has increased. The rate of newly diagnosed HIV infections in the east is more than double that in the west while the number of reported AIDS diagnoses continued to decline in the WHO European Region. In the east the number of AIDS cases has continued to increase.

• In the EU/EFTA, the predominant modes of transmission for HIV infection appear to be sex between men followed by heterosexual contact. Around 40 per cent of the cases reported to be heterosexually acquired were diagnosed in individuals originating from countries with generalized HIV/AIDS epidemics.

• In the three geographical areas, injecting drug use is still the main mode of transmission in the east, while in the centre, the predominant mode of transmission is heterosexual contact, although the number of HIV cases reported among men having sex with men has also increased. In the west, the predominant mode is sex between men, followed by heterosexual contact, when cases in persons originating from countries with generalized
epidemics are excluded. An apparent increase in heterosexual transmission in the east is difficult to interpret from the existing data, as it is not possible to distinguish independent sexual transmission from secondary IDU related transmission (from male IDUs to their female sexual partners).


It was discussed that the data reported to the joint database for HIV/AIDS surveillance are incomplete as certain countries did not provide data. Approximately 49,000 cases were reported through the joint database for 2007. Other available data sources included, this figure could increase the regional total to approximately 102,000 cases. Efforts will be made to ensure the completeness of future reporting and to ensure full geographical coverage of the WHO European Region. It was debated how future reports should address the issue of missing data and underreporting and that it may be advantageous to make use of data obtained from other publicly available sources in future reports, so that a more comprehensive assessment of the HIV epidemic in Europe can be made.

Session II. Plenary lectures and country presentations on HIV/AIDS

A series of presentations were made on a range of HIV/AIDS related topics.

Serological testing is currently the most widely used method for estimating the incidence of HIV infection. Several groups have developed specialized serological assays that attempt to distinguish recent (< 6 months) from long-standing infections to estimate HIV incidence at the population level. These assays are often referred to as STARHS (serological testing algorithms for recent HIV seroconversion); however this refers to the mathematical algorithm to measure incidence, not the assays themselves. The currently available assays are recommended by WHO/UNAIDS for use only after careful consideration and local validation. Use of HAART and the existence of elite or viremia controllers result in false positive results. There is a clear need for a standard and comprehensive framework for the development of incidence assays. There is an International Working Group on HIV incidence assays that is developing the protocol and pathway to validate the different HIV incidence assays.

Multi-parameter evidence synthesis (MPES) is a generalized meta-analysis approach to estimate HIV prevalence that has been successfully used in the United Kingdom since 2005. MPES allows full utilization of all data sources and provides an indication of the uncertainty in the prevalence estimates derived. The method also provides a flexible framework for modelling biases and accounting for them systematically rather than through ad-hoc adjustments. Initial work in the Netherlands, conducted in collaboration between the Health Protection Agency (HPA) of the United Kingdom, the National Institute for Public Health and the Environment (RIVM) and the WHO Regional Office for Europe, suggest that the method can be used in countries other than the United Kingdom, although more work is required to determine the range of conditions required for successful implementation.
Several countries in Europe have reported an increasing proportion of AIDS cases and HIV infections acquired through heterosexual intercourse. Some of this heterosexual transmission is associated with migrants from high prevalence countries; some is associated with secondary transmission from high-risk partners, particularly IDUs. Conclusive data is limited, but migrant populations, particularly from sub-Saharan Africa (SSA), appear to represent a considerable and growing proportion of both HIV infections and AIDS cases reported in the EU in 1999 to 2006. The proportion of migrants from SSA among heterosexual and mother-to-child transmission (MTCT) reports is very high, and their contribution to the HIV/AIDS epidemic in Europe, particularly among females, appears to be increasing rapidly. Limited evidence suggests that in countries in the east, a large proportion of the reported heterosexual transmission is associated with secondary transmission from male IDUs to their female sexual partners. Due to lack of data it is not possible to document the extent of heterosexual HIV transmission occurring independently of transmission through IDU.

In the 2007 annual meeting it was agreed to start collecting information on CD4-cell counts as a proxy for late diagnosis of HIV infection. 13 of 53 countries provided information on CD4 cell counts. More work is needed, however, to determine the optimal cut-off level for a significant CD4 cell count. Some studies have used 350 as the cut-off, others have reduced it to as low as 200 to describe late diagnosis. A systematic review of available data is required to determine the optimal level.

**Session III. HIV/AIDS surveillance**

ECDC has developed a long-term strategy for the surveillance of communicable diseases in the European Union. One element in the further development of surveillance will be to continue working on strengthening and developing the European framework for surveillance, to better harmonize the reporting methods, systems and practices in use. This long term surveillance strategy includes two parts: one on general surveillance objectives, the other on disease specific surveillance objectives. During this meeting, working group sessions were held to discuss the HIV/AIDS specific surveillance objectives in relation to the proposed enhanced set of reporting variables. Specific questions to be addressed are listed in the background paper for Session III: working groups on improving HIV/AIDS surveillance (Annex 2).

In working group session 1, meeting participants were allocated to one of four parallel working groups for discussion of the specific disease surveillance objectives. Specific questions addressed to the working groups included:

1. Which HIV/AIDS general and specific objectives are relevant and have an added value for future HIV/AIDS surveillance in EU and WHO European Region?
2. Which HIV/AIDS specific objectives should be changed or formulated in other way?
3. Which HIV/AIDS specific objectives are missing and should be included?

A substantial and increasing proportion of HIV and AIDS cases in Europe are reported to have been acquired through heterosexual contact. Some of the heterosexual transmission is associated with other high risk behaviours, particularly IDU, and some is associated with migrants from high prevalence areas. To gain understanding of the changing HIV transmission patterns more information is needed on the spread of HIV through heterosexual transmission that is unrelated to high risk partners and the role of migrants from high prevalence areas in heterosexual transmission.
In working group session 2, participants were requested to join one of four Working Groups discussing the following issues:

1a. Heterosexual transmission and migrants  
1b. Heterosexual transmission and high risk partners  
2. Late diagnosis (CD4 cells) and HIV/AIDS mortality surveillance  
3. HIV incidence – next steps

Details of the background papers provided to the working groups are provided in Annex 2.

**Session IV. Feedback from the working group sessions**

The feedback from the working group sessions is presented in annex 1.

**Session V. Final discussion and summary of next steps**

The transition process for the European HIV/AIDS surveillance system is considered to have been a success. Important lessons have been learned and experience gained. This will be reflected in the collection, analysis and reporting of the 2008 data. Care needs to be taken, however, to ensure that available resources are not over over-extended in attempting to make modifications to the current system.

All feedback from the Working Groups and the meeting participants will be carefully considered. Feedback on the surveillance objectives document will be incorporated into a revised draft of the document, which will be discussed in the Coordination Group and subsequently during the next annual meeting.

Most of the surveillance standards have already been established, although better definitions and guidelines for use may be required. ECDC and WHO/Europe will attempt to structure the data collection process to better incorporate these standards for the collection of the 2008 data.

Discussions on heterosexual transmission were very helpful. The variable needs careful revision to generate more information on route of transmission. It should be possible to specify a new sub-variable within the existing variable to determine the HIV status of partners of heterosexual cases.

There was an argument to move away from AIDS surveillance and move towards surveillance for outcome of HIV infection. This will require input from the network, and experts are needed to prepare a paper on the options available.

Standard methods and a standard protocol are required for establishing HIV incidence estimates. Again, experts from the network are needed to support the drafting of a methodological framework to achieve this. ECDC will launch a call for tender to develop this methodological framework in 2009.
Conclusions and recommendations

The following general conclusions and recommendations were drawn from the meeting:

- ECDC and WHO/Europe should be acknowledged for the successful implementation of the EuroHIV transition plan and establishment of HIV/AIDS data reporting through the joint database. The new system is not yet perfect, but it is functioning well and the planned improvements will make reporting of 2008 data easier.
- It was agreed that future reports on HIV/AIDS should attempt at presenting a more comprehensive overview of the current status of the HIV/AIDS epidemic in Europe, potentially drawing on other available sources of information and not necessarily be limited to case reports of HIV and AIDS.
- The reported data should be interpreted with caution because of incomplete reporting and conclusions drawn should fully acknowledge the limitations present in the dataset.
- Further technical discussions are required to establish agreed standards for reporting, for example regarding the use of appropriate dates, risk status and more detailed information on modes of transmission for sexual transmission.
- Available data show that migration, particularly from SSA, is contributing to the number of new cases of HIV infection reported in European countries, notably heterosexually acquired cases. However, although there appears to be a rise in reported heterosexual transmission, the predominant modes of transmission continue to be IDU in the eastern part of Europe and MSM in the western and central parts.
- Despite incomplete reporting, available data show that HIV transmission in Europe is increasing. Comments on the draft report as presented in the annual meeting are welcomed until the 18th November to allow for adjustments and subsequent analyses to be included in the final report on HIV/AIDS surveillance in Europe (to be published on 1 December 2008).
Annex 1. Feedback from the working group sessions (Session IV)

Working group Session 1

General feedback:
- Several participants expressed the opinion that there was insufficient information on how surveillance data will be analysed and modelled at the regional level. It was considered that if Member States were more aware of how surveillance data would be used, there would be a more proactive response to collecting and reporting the data.

1a. Feedback on general objectives for HIV/AIDS surveillance:
- The ordering of the objectives is not logical. Objective 3 “Develop behavioural surveillance for HIV and STI related to sexual activity and drug use and develop behavioural indicators to be used at the EU level” should be the first objective. The other two objectives then follow naturally from this;
- Some aspect of blood-borne diseases, particularly hepatitis C, should be added to the list of specific infections;
- STI and HIV surveillance systems may not be integrated at this point since many countries have vertical surveillance systems and the nature and extent of STI surveillance varies widely in the Region. Integration may be a future goal;
- Clarification is needed on the details of risky behaviours which will be included in routine data collection;
- Objectives should focus on improving outcome monitoring by looking at morbidity and mortality data and treatment coverage among HIV-infections rather than looking at AIDS cases;
- An additional objective on the evaluation of surveillance systems at regional and national level should be developed to focus attention on the requirement for complete and accurate routine surveillance.

Improve the quality of available data for HIV/AIDS case reporting.
- Standardization of data (improving definitions of the variables) and data quality assessment could be added as additional objectives;
- Data collection and data submission needs to be better standardized with clear definitions of the variables, for example, date of report appears to mean different things to different people. This area requires further discussion.

Assess the current epidemiological situation in Europe.
- MSM and IDU populations should be included together with the heterosexual population in the first bullet point;
- It is not clear why migrants are being singled out. Not all migrants have high HIV risk, and the objectives should be should be specific about “highly endemic areas”. There may also be problems in collecting this type of data in some countries;
- Monitoring HIV testing it is beyond the current routine data collection capacities of many countries, but should be retained as a goal for the future;
- The nature of HIV testing is diverse across countries, and clear standards and definitions are required;
- MTCT treatment of both mother and child should be included in treatment monitoring.
Promote the development of laboratory network on HIV serological incidence assays.
- This is very difficult to implement at present and led to discussion on how the objectives could be prioritized. Other data needs should be met first.

Monitor HIV prevalence in vulnerable populations, e.g. MSM, IDU, TB patients, migrants (and others).
- Obtaining realistic population denominator data is a significant problem in many countries. How should population sizes be estimated?
- There are legal constraints on making these estimates in some countries;
- More standardization is required, with clear definitions and recommended methodologies.

Monitor mortality and causes of death in HIV cases (feasibility study).
- This was generally seen as useful, but the feasibility of implementing the objective was questioned.

Assess trends of AIDS to monitor disease outcome and impact of treatment.
- A longer-term goal of the surveillance system should be to move away from monitoring AIDS-related deaths and AIDS cases, as they are becoming fewer and more difficult to define in many European countries.

Detect and monitor the emergence and spread of resistance to antiretroviral treatment for HIV infection.
- This is important but needs to be guided correctly due to past problems in sampling, and cost implications must be considered.

1b. Feedback on the data reporting process:
- When changes to existing surveillance variables or data collection methods are implemented at the regional level, Member States should be given ample warning of any changes and additional support they may require to modify their systems;
- Some participants were of the opinion that the online training materials for using TESSy were very good but time consuming and requested that a paper-based manual could also be provided. Support for the data validation and uploading of 2007 data was very good, particularly the direct communication via e-mail. There was a request that this be continued and strengthened.
- For future reports, there should be more time to check the final reports before publishing;
- Validation rules and definitions of variables should be published online;
- The data conversion tool (from EuroHIV to TESSy format) should remain available for countries to use in the future;
- A follow-up meeting is necessary for exchange of experiences with using TESSy (for example it is difficult to have e-mail contact between Russian and non-Russian speakers);
- A Russian language translation of TESSy is needed as soon as possible; it was discussed that this could be feasible along the multi-language development of TESSy covering all EU languages in future;
- TESSy should provide greater possibility for reporting and descriptive data analysis than it currently does;
- Support measures provided for the 2007 data collection were greatly appreciated. The e-mail and phone support was effective, but in future could be supplemented by an interactive technical web forum;
- There should be increased standardization of the case definitions used across countries of the WHO European Region;
• Some countries require more support in the transfer of data;
• Comment fields should be featured in the database. These should be visible in reporting and may provide an explanation of certain historical anomalies;
• Machine-to-machine automated data transfer and upload (parallel to human assisted manual upload only) remains a requirement for an effective system.

Working group Session 2

2a. Heterosexual transmission and migrants

• Many countries in Europe have over 20 years of experience in attempting to collect data on migrant populations affected by HIV. Experience has demonstrated this to be a difficult and complicated task;
• Data on country of origin of migrants is increasingly missing, and there is an obvious need to collect more geographical information. Those responsible for reporting cases must be made more aware of the importance of this information;
• The questions to be asked at national level include:
  - How many HIV cases are imported (through migration and/or travel)?
  - How many are the result of spread within the country of report?
  - How many are related to high risk groups (IDU, migrants)
  - How many are related to independent spread through heterosexual transmission?
• The indicator that may be feasible and kept in the dataset for enhanced surveillance is “probable country/region of infection”, but this could be reduced to “imported/not imported” it that would be easier to implement. However, there was no overall agreement within the group over these variables.
• The variable ‘probable country of infection’ could be included as a pilot variable in the 2008 data collection as some countries could already provide this information.
• A clear and common definition of migration (migrant populations) is needed. There are large and significant differences between different migrant populations (labour migrants, immigrants, asylum seekers). Any definition should encompass these differences;
• It may be more effective to use the term “mobile populations” rather than “migrants”;
• Questions of ethnicity are very complicated. It may be possible to collect information on second (and first) generation migrants, but there is huge heterogeneity in the Region, complicated by legal issues. There is also the danger of (further) stigmatization of some groups if this data is sought. Some countries attempt to collect information on the country of birth of the mother and/or father, but data is often incomplete or judged to be inaccurate;
• Why are data on country of origin increasingly missing? This requires some investigation. Some of the missing data may be associated with reporting delay;
• Different countries are at different stages of developing and implementing HIV surveillance. Not all countries are yet in a position to deliver data on the basic variables, let alone attempt adding variable to the dataset. Progress in implementing existing surveillance requirements should be monitored carefully before attempting to increase the number of variables being monitored.

2b. Heterosexual transmission and high risk partners

• To improve the understanding of heterosexual transmission of HIV in Europe we need to:
  - Improve education and awareness of HIV at the patient/doctor level;
- Improve national data collection;
- Provide better teaching materials for doctors so they can give more appropriate information and guidance to their patients;
- Improve the confidentiality of patients;

- Indicators for patient risk should be added to the HIV/AIDS dataset, these should describe the sexual partner’s risk status. Variables for patient risk group could include:
  - MSM
  - IDU
  - heterosexual
  - originates from a high prevalence country
  - MTC
  - Unknown

Variables for partner risk could be the same as for patient risk, but include the variables “HIV positive” and “HIV negative”. If the patient is recorded as heterosexual, then the partner’s HIV status would need to be recorded. However, it must be noted that in many cases the patient may not know the HIV status of the partner.

2c. Late diagnosis (CD4 count) and HIV/AIDS mortality surveillance

- It is useful to collect data related to CD4 count to monitor late presenters, and this information should be part of the enhanced surveillance of HIV/AIDS;
- Clear definitions and guidelines for the data to be collected and the time frame for collecting (e.g. within 3 months of diagnosis) are required;
- CD4 counts are routinely conducted in many countries, but the information is not systematically collected or reported. Countries should be encouraged to increase the completeness of reporting for this variable;
- Caution should be applied to interpretation of data on late presenters in the migrant population as oversimplification may lead to misinterpretation, stigmatization and a disincentive to report;
- A thorough feasibility study should be conducted before introducing surveillance variables for the cause of death among HIV infected persons;
- Clear definitions and guidelines are required on the data requirements related to anti-retrovirus therapy (ART) history (e.g. the minimum time frame, type of ART, etc);
- Further investigation is required to assess the quality of HIV-related mortality data collected from death certificates. The majority of deaths of HIV-infected persons are now not directly related to HIV/AIDS;
- There is a need to establish better linkages between surveillance units and hospital records departments. A considerable amount of important hospital data is not being used for surveillance;
- In Europe many more people are living with HIV/AIDS and an objective of surveillance should be the monitoring of outcome of HIV-infected persons rather than the outcome of AIDS cases. Case reporting should be kept as simple as possible. There is a need for guidelines containing simple algorithms for case reporting.

2d. HIV incidence – next steps

- Several serological methods can be used to improve the estimation of HIV incidence, but different countries are using different methods that are not necessarily comparable. There needs to be a standardization of methods, preferably with all Member States using the same serological method. There is also a problem in determining the denominator for the population. This is more of a problem for some countries/groups than for others.
Increased collaboration with the Statistical Office of the European Communities (Eurostat) may prove to be helpful in determining denominator information;

- Alternative methods and sources of data for improving HIV incidence estimates include:
  - Use of patient history information, such as data on previous negative test results, patient’s own opinion, results of CD4 counts, information on acute symptoms and AIDS symptoms;
  - Use of dynamic cohorts as proxies for risk populations, these would include pregnant women that seroconvert, blood donors that seroconvert etc. However, clear guidelines are required on how to describe and report the data and how to calculate incidence based on the data available.

- It may be possible to use several monitoring options and triangulate between different data sources. However, whichever method was used, there would need to be validation of results both within and between countries;

- WHO/ECDC should establish an expert group to determine:
  - Which test to choose for determining incidence, and how should tests be validated?
  - What is needed in addition to a “good” test?
  - What are the options for different countries?
  - What is relevant for countries with developed surveillance (gold standard)?
  - What are the basic (minimal) options?
  - What are the barriers to accurate incidence estimates?

- Countries should be given support to more effectively document what they do with regard to estimating incidence and how they arrived at the results (both methods used and incidence estimated);

- Sub-populations to be targeted first in a study on HIV incidence should include, in order of priority:
  - IDU (particularly eastern countries)
  - MSM (particularly western and central countries)
  - Migrants from high prevalence countries (particularly western and central countries)

- Countries must choose which specific groups they find most relevant to include. However, care must be taken over how and where monitoring is carried out, to avoid increasing stigmatization already imposed on the risk groups.
Annex 2. Programme

Annual meeting
European network for HIV/ AIDS surveillance
Agenda
Copenhagen, 11-12 November 2008

<table>
<thead>
<tr>
<th>Day 1. 11 November 2008</th>
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Day 2, 12 November 2008

**Session III: Working Groups on improving HIV/AIDS surveillance**
Chair: Edward van Straten

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<th>Time</th>
<th>Session</th>
<th>Speaker</th>
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<tbody>
<tr>
<td>9:00 – 9:20</td>
<td>Plenary: Technical experience for 2007 data collection</td>
<td>Marita van de Laar</td>
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<tr>
<td>9:20 – 9:40</td>
<td>Plenary: HIV/AIDS surveillance in Europe: the link between epidemiological surveillance and M&amp;E data collection</td>
<td>Srdan Matic</td>
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<td>9:40-11:00</td>
<td>Review HIV/AIDS surveillance issues (1)</td>
<td>4 parallel working groups on the same topic</td>
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<td>• surveillance objectives</td>
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<td>• 2007 data collection</td>
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<tr>
<td>11:00 – 11:30</td>
<td>Coffee break</td>
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<tr>
<td>11:30 – 12:30</td>
<td>Review HIV/AIDS surveillance issues (2)</td>
<td>4 working groups as per indicated preferences</td>
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<td>1a Heterosexual transmission and migrants</td>
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<td>1b Heterosexual transmission and high risk partners</td>
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<td>2. Late diagnosis (CD4 cells) and HIV/AIDS mortality surveillance</td>
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<td>3. HIV incidence – next steps</td>
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<td>12:30 – 13:30</td>
<td>Lunch break</td>
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**Session IV: Feedback from working groups**
Chair: Martin Donoghoe

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<th>Time</th>
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<tr>
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<td>Feedback from working groups (1)</td>
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<td>14:30 – 15:30</td>
<td>Feedback from working groups (2)</td>
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<td>15:30 – 15:45</td>
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**Session V: Final discussion and summary of next steps**
Marita van de Laar and David Mercer

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<td>15:45 – 16:15</td>
<td>Session V: Final discussion and summary of next steps</td>
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16:15 Closure
Annex 3. List of working papers and materials


- **Background documents**
- **Working papers for session III: Working groups on HIV/AIDS surveillance**

  **Session (1)**
  1. HIV/AIDS surveillance objectives

  **Session (2)**
  1a. Heterosexual transmission and migrants
  1b. Heterosexual transmission and high-risk partners
  2. Late diagnosis (CD4 cells) and HIV/AIDS mortality surveillance
  3. HIV incidence – next steps

- **Meeting presentations**
HIV surveillance focal points meeting

Copenhagen, Denmark, 10–13 November 2008

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