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MEETING REPORT

Meeting of the Joint ECDC/WHO European Network for HIV/AIDS Surveillance

22 May 2014, Dubrovnik, Croatia

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Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EU	European Union
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug Use(r)
MSM	Men who have Sex with Men
TESSy	The European Surveillance System
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

1. Introduction

Andrew Amato (ECDC) and **Martin Donoghoe** (WHO Regional Office for Europe) welcomed participants to the joint meeting. The main focus of the meeting was to review proposed revision of HIV/AIDS surveillance in the European region, specifically combining the HIV and AIDS datasets and improving monitoring of the continuum of care. Specific objectives were:

- To present the most recent HIV/AIDS surveillance data (2013 data collection).
- To provide an overview of the HIV continuum of care and implications for monitoring.
- To present and discuss the results of the pilot of the revision of HIV and AIDS surveillance.
- To share country experience and seek feedback on proposed revision of HIV surveillance in the European region.

This report provides a summary of the main points from the meeting. More detailed information is available in the presentations, which have been provided to all participants.

1.1 Community perspective on data for action

Lella Cosmaro and **Anna Zakowicz** (representatives from civil society) gave a community perspective on the role of data in providing the evidence base for effective responses to HIV and the contribution that civil society organisations (CSOs) can make to data collection and use. Key points included:

- Good surveillance data are critical to track the epidemic and assess progress, to plan and budget for interventions, and to support advocacy. Behavioural data are also critical, but it must be collected in an ethical way.
- Civil society is supportive of data collection on key populations, including migrants; key considerations include how these data are collected, used and communicated, in order to avoid stigmatising these populations or supporting anti-migrant agendas.
- Civil society has been involved in reporting of data, for example, through Dublin Declaration monitoring, and can play an important role in collecting behavioural data, because many CSOs provide services to, and have good relationships with, key populations. However, it is also important to recognise that some CSOs lack human and financial capacity.
- Specific issues for civil society include accurate estimation of the number of people living with HIV and the undiagnosed fraction, establishing targets for each stage of the treatment cascade and monitoring progress towards these targets, and improved notification of cause of death.

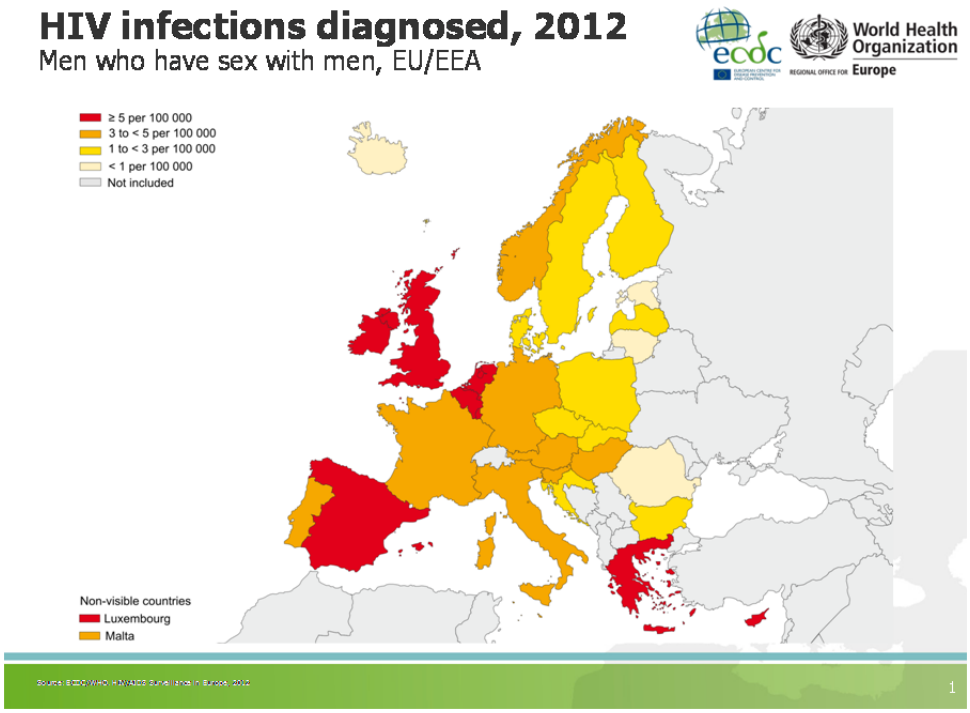
1.2 Overview of 2012 HIV surveillance data

Anastasia Pharris (ECDC) and **Annemarie Stengaard** (WHO Regional Office for Europe) presented an overview of 2012 surveillance data for the European Union/European Economic Area (EU/EEA) and for the WHO European Region.

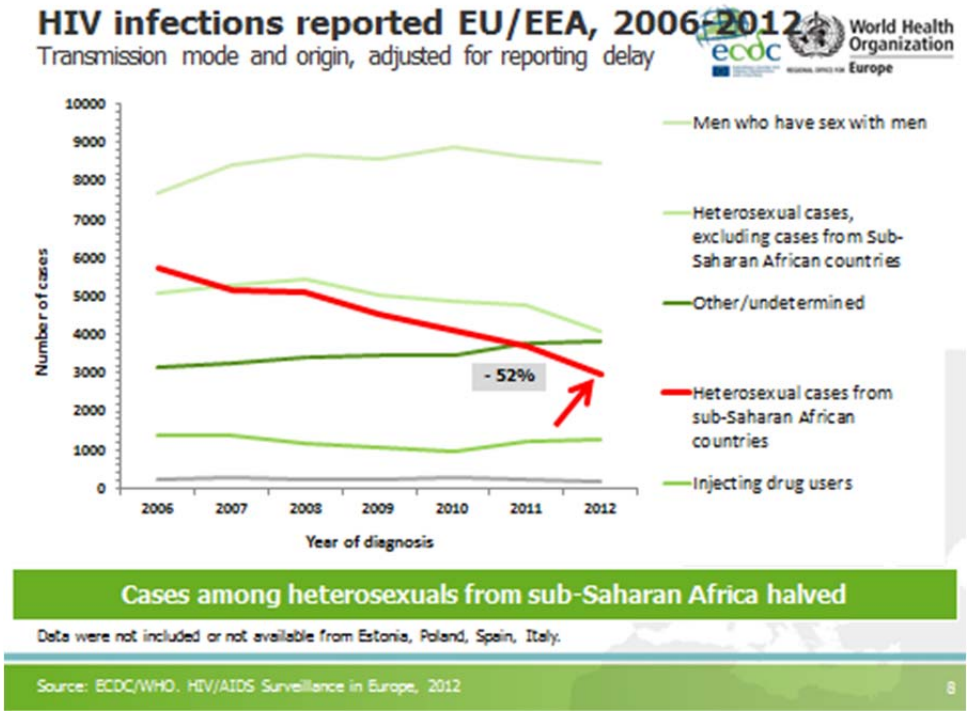
In the EU/EEA, the rate of newly diagnosed HIV infections has increased from less than 1.0/100,000 population in 1984 to 5.8/100,000 population in 2012. In 2012, 29,381 HIV cases were reported in the EU/EEA. Older age groups and men are most affected: only 10.6% of HIV diagnoses were in those aged 15-24 and the male-to-female ratio was 3.2. Around 40% of cases reported were in men who have sex with men (MSM), 33.6% were due to heterosexual transmission and 6.1% to injecting drug use (IDU); 18.7% had an unknown mode of transmission.

Sex between men is the predominant mode of transmission in the EU/EEA, although rates vary between countries (see map below). Data reported by 15 countries for the period 2003-2012 show that the

number of new HIV diagnoses in MSM has increased among those aged 20-29; in other age groups the number has been relatively stable or decreased. Despite low levels of HIV reported among IDU, increases have been seen due to outbreaks in Greece and Romania.

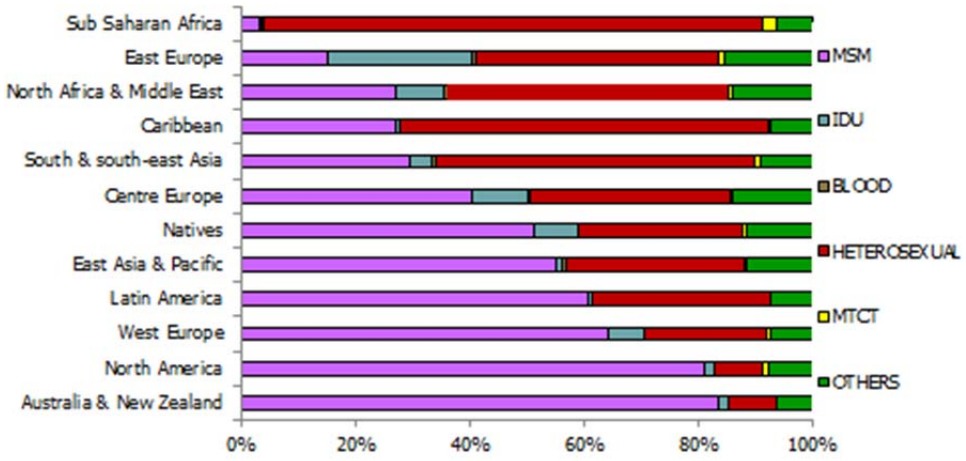


There has been a significant decline in HIV cases reported due to heterosexual transmission among people from sub-Saharan Africa (see figure below). Nevertheless, migrants account for an important proportion of HIV cases reported in the EU/EEA.



The main modes of transmission among non-natives vary considerably, depending on the region of origin (see figure below).

Route of transmission among non-native HIV cases, by geographic origin, EU/EEA, 2007-2012



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Overall, in 2012, 49% of HIV cases where CD4 count was reported were diagnosed late, i.e. with a CD4 cell count of <350/mm^3. Heterosexuals from sub-Saharan Africa and IDU are more likely to be diagnosed late than MSM.

In the WHO European Region, 55,494 HIV cases were reported in 2012: 27,315 in the West, 3,715 in the Centre and 24,464 in the East of the region. Those aged 30-39 accounted for more than a third (37%) of these cases. There are significant differences in rates of new infections, male-to-female ratios and predominant modes of transmission between the three sub-regions (see table below).

New HIV infections diagnosed in 2012 WHO European Region

Geographical areas	WHO European Region	West	Centre	East
Reporting countries/ number of countries	51/53	23/23	15/15	13/15
Number of HIV diagnoses	55 494 *(>130 000)*	27 315	3715	24 464 *(>100 000)*
Diagnoses per 100 000 population	7.8	6.6	1.9	22.0
Percentage aged 15-24 years *30-39 y: 37%*	10.3%	9.8%	15.4%	10.1%
Male-to-female ratio	2.1	3.1	4.5	1.4
Transmission mode (percentage)				
Heterosexual contact	46%	35%	25%	60%
Men who have sex with men	23%	42%	26%	1.2%
Injecting drug use	18%	5%	7%	34%
Unknown	12%	17%	37%	3%

No data from the Russian Federation and Uzbekistan. Countries with missing data on age or transmission mode excluded.

Source: ECDC/WHO HIV/AIDS Surveillance in Europe, 2013

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In the West, MSM-related transmission predominates although heterosexual transmission is high, with a substantial contribution from migrant populations from countries with generalised epidemics. Although the number of new infections diagnosed in the Centre between 2006 and 2012 has remained relatively stable, the relative increase is steeper than in the other geographical areas and there is evidence of a rise in transmission among MSM. Similarly in the East, where heterosexual transmission predominates and IDU-related transmission continues, the steepest relative increase has been seen among MSM. During the same period, the number of HIV cases in women rose, due to an increase in cases among older women i.e. those aged 30-39, 40-49 and 50+. Better data are needed about the sexual partners of these women, including mode of transmission (history of drug use or male sexual contacts), and about probable country of infection.

Figures for late diagnosis are similar to those for the EU/EEA. In 2012, 50% of new infections were diagnosed with a CD4 cell count of <350/mm^3 and 30% with a CD4 cell count of<200/mm^3. The proportion of new cases for which CD4 cell count is available remains low, despite an increase of completeness from 14% of cases in 2010 to 33% in 2012.

Between 2006 and 2012, the rate of AIDS cases diagnosed per 100,000 population increased in the East, remained stable in the Centre and decreased in the West of the region[1]. During the same period, the number of deaths among AIDS cases increased by 57% in the East and decreased by 21% in the Centre and by 77% in the West of the region[2]. There is a need to increase access to and uptake of early HIV testing across the region and to improve access to antiretroviral treatment in the East.

Key points raised in response to this presentation included:

- Despite high treatment coverage in the West, HIV transmission continues. Reasons include the proportion of people with HIV who are undiagnosed, late diagnosis, and the time taken to achieve viral suppression after initiating treatment.
- Improved reporting of CD4 cell count as well as better and timely access to HIV testing is needed.
- Work by the WHO Collaborating Centre in Zagreb suggests that there may be a substantial number of cases of 'hidden' MSM transmission among those recorded as heterosexual transmission in countries in the East of the region. Approaches to ensure more accurate recording of mode of transmission are required.

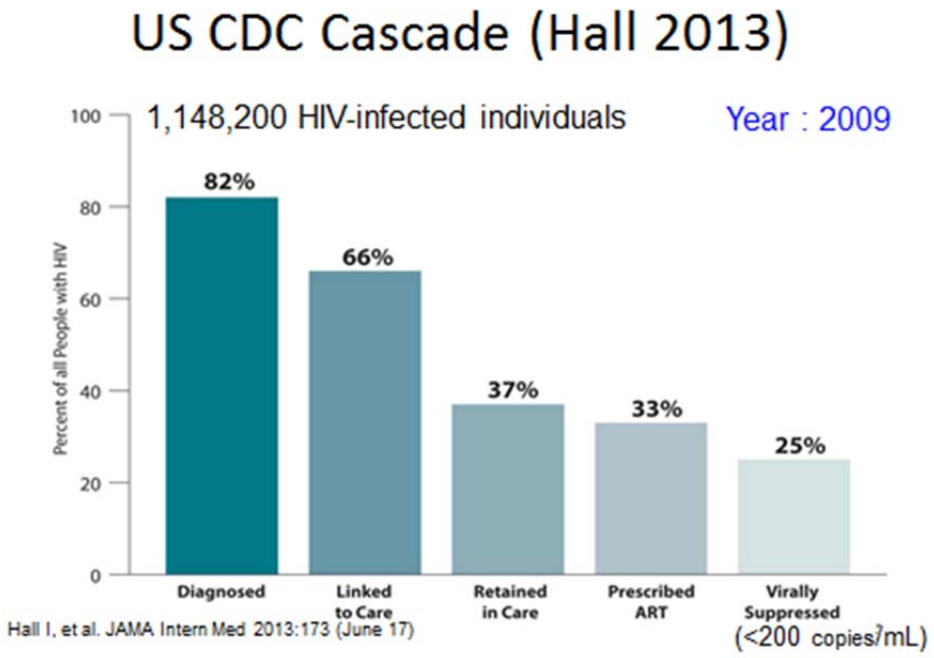
1.3 Monitoring the impact of HIV care on key populations: the treatment cascade and other indicators of HIV care

In her keynote presentation, **Valerie Delpech** (Public Health England) highlighted the importance of monitoring the public health impact of HIV testing, treatment and care. She gave an overview of the 'treatment cascade', using examples from the United States, France and the United Kingdom, of other indicators for monitoring the continuum of care, and of implications and challenges for data collection.

The treatment cascades from the three countries show the range of data sources used. Two versions of the treatment cascade from the US were presented. The Gardner cascade, the first to be developed, had a number of limitations. The number of people infected with HIV and the number diagnosed were based on estimates, and data for different stages of the cascade were drawn from different sources and years.

[1] Russia, Sweden and Uzbekistan not included.
[2] Russia, Sweden, Ukraine and Uzbekistan not included.

Despite this, it highlighted attrition at each stage of the continuum of care, with only 19% of those estimated to have HIV infection achieving viral suppression.



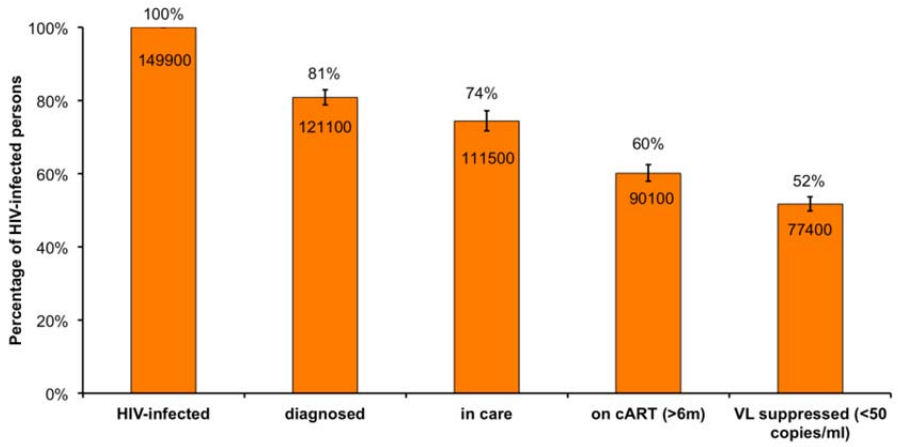
The CDC version of the cascade, shown above, was based on better estimates and improved sources of data – the National HIV Surveillance System was used as the source of data on prevalence, number of people living with HIV and linkage to care and the Medical Monitoring Project as a source of data on retention in care, prescribed ART and viral suppression. However, it shows a similar picture to the Gardner cascade, with little difference in the number or proportion who are undiagnosed and only 25% of those estimated to have HIV infection achieving viral suppression.

The treatment cascade from France (see figure below) shows that retention rates are higher than in the US, with 52% of those estimated to have HIV infection achieving viral suppression, but that there is a similar proportion of those who are undiagnosed. Different data sources were used. For example, HIV surveillance data and a back calculation model were used to estimate the undiagnosed fraction of those living with HIV and cohort data[1] to estimate those diagnosed but not in care, hospital and health insurance[2] data to estimate the number diagnosed and in care, and cohort data to monitor retention in care.

The UK treatment cascade (see figure below) is similar to that for France, with a similar proportion undiagnosed and 62% of those estimated to have HIV infection achieving viral suppression. The number estimated to be infected with HIV is based on a multi-parameter evidence synthesis (MPES); this relies on a range of data sources with variable representativeness and coverage and updates are not available annually. Data for the other stages of the cascade are drawn from comprehensive national surveillance systems including new HIV diagnoses and information for each patient in care on CD4, viral load and last visit date.

[1] The FHDH-ANRS-CO4 cohort is a nationwide hospital-based cohort that covers approximately 50% of those diagnosed with HIV.
[2] The French health insurance scheme CNAMTS covers 87% of insured people in France.

Global engagement in HIV care in France in 2010



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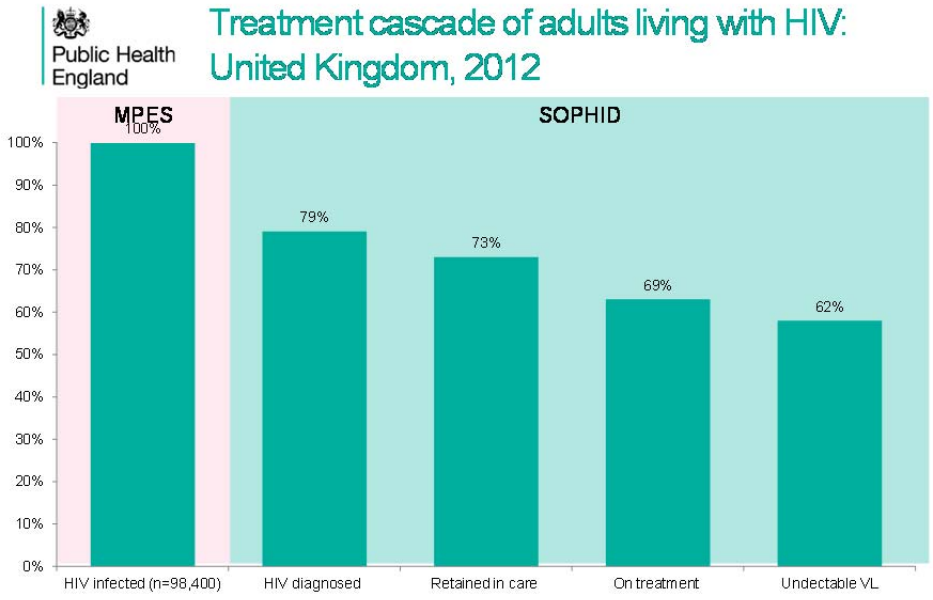

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Definitions used for the cascade in the United Kingdom, and data challenges, are as follows:

- Diagnosed – proportion of persons in care.
- Link to care – proportion with a CD4 count within 3 months of diagnosis. CD4 count is used as a proxy – some sites include CD4 test at time of confirmation of diagnosis.
- Retention in care – proportion seen for care the following year. Relies on good cohort data.
- Treatment – proportion on ARV at date last seen.
- Viral suppression – proportion with viral load (VL) <50 (also use <200). Relies on accuracy of reports.

Once linked to care, retention and results are good, and there is little difference between population groups. Among the approximately 77,600 people living with diagnosed HIV in the United Kingdom, 97% are linked to care after diagnosis within 3 months, 95% are retained in care annually, 92% in need of treatment are on treatment, and 95% of those on treatment achieve VL <200 copies/ml. The main challenge is the failure of testing programmes to decrease the undiagnosed fraction and late diagnosis.

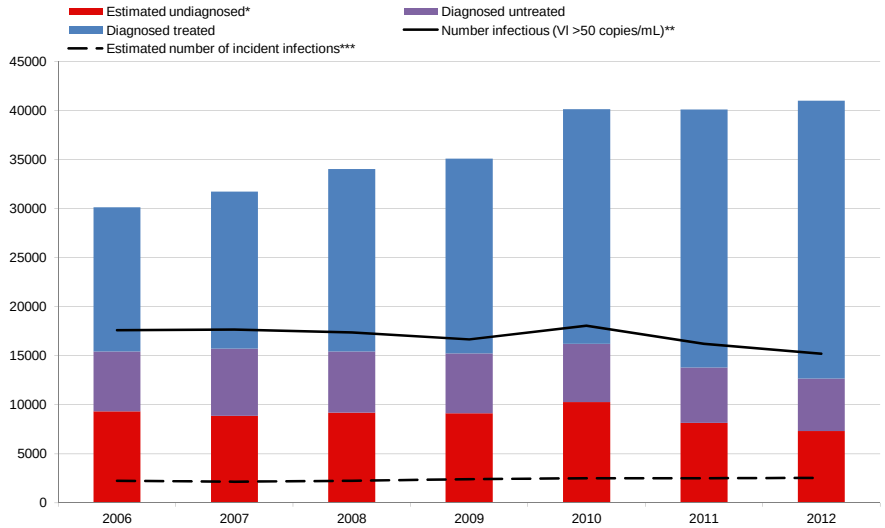
In countries where it may not be feasible to monitor the whole cascade, a more feasible option might be to use four key indicators to monitor the first year of care:

- Late diagnosis.
- Link to care.
- Uptake of ART.
- 1-year mortality rates.

These indicators can tell us, for example, if specific population groups need to be better targeted with interventions to promote early HIV testing, what proportion of people diagnosed are linked to care and how quickly, and how well treatment programmes are working. In the United Kingdom, late diagnosis is the most important marker of poor clinical outcome, resulting in the majority of deaths in the first 12 months.

In conclusion, the 'treatment cascade' and 'first year of care' indicators can provide important insights into the success of testing programmes and of health care delivery, and enable success or failure to be measured for key population groups and over time. For example, the figure below shows that there was little change in the estimated number of incident infections and of undiagnosed infections among MSM in the United Kingdom between 2006 and 2012.

MSM living with HIV by diagnostic and treatment status and viral suppression, UK, 2006-2012



* MPES model, Presanis et al
** Assuming undiagnosed had same proportion with VL >50 copies/mL as those newly diagnosed and untreated
*** Birrell, data for England and Wales only, pers comm

ECDC, WHO and others could support countries to monitor the treatment cascade and first year of care by:

- Improving methodologies to estimate the undiagnosed.
- Developing standardised European-wide definitions for the continuum of care and first year of care indicators.

Key points raised in response to this presentation included:

- The value of the treatment cascade in identifying which populations are not being reached by testing, treatment and care and the stages of the continuum at which people are being lost.
- The value of the cascade as an advocacy tool. To maximise its usefulness, it is important to include numbers as well as proportions in the cascade. In some countries, while the proportions have not changed, the denominator, i.e. the number of people estimated to be infected with HIV, is increasing and this is a critical issue to communicate to policy makers.
- The cascade could also help to counter perceptions about low adherence among some population groups, such as IDU. The United Kingdom data, for example, show that there is not a significant difference between different risk groups at each stage of the continuum.

2. Revision of HIV surveillance in the European region: Pilot project

2.1 Background and introduction

Following recommendations from the European HIV surveillance network meeting in Stockholm in February 2012, ECDC, in collaboration with the WHO Regional Office for Europe, commissioned Public Health England (PHE) to develop a proposal for revision of European HIV and AIDS surveillance. This is intended to simplify and combine current HIV and AIDS reporting, reduce reporting burden by merging variables into a single dataset and provide options for submission of data to construct the continuum of care.

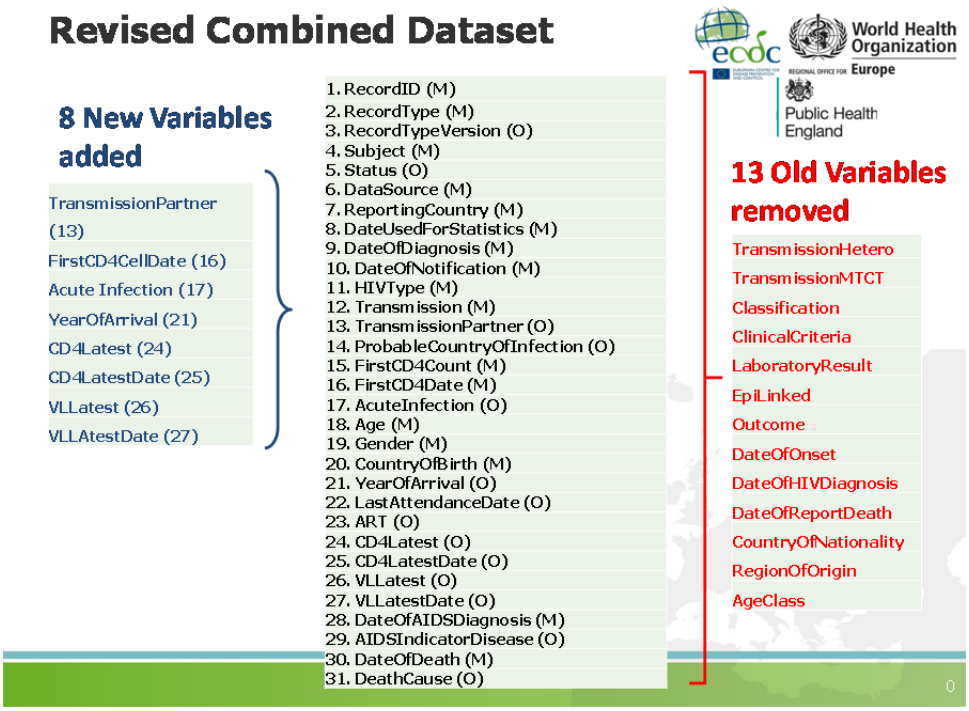
Alison Brown (PHE) provided a brief background to revision of HIV and AIDS surveillance, noting that a revised dataset is needed as HIV is now a chronic infection and the focus has shifted away from AIDS and deaths, surveillance needs to move beyond HIV diagnosis, and monitoring access to treatment and outcomes is important to understand points of attrition in the continuum of care and reduce potential for onward transmission. The approach taken to revision has included: analysis of the usefulness and completeness of TESSy variables; a rapid survey of 24 EU countries to determine the feasibility of collecting data on a range of variables; consultation with national contact points; and a pilot of the proposed new dataset in nine countries: five EU (Belgium, Denmark, Ireland, Netherlands, United Kingdom) and four non-EU (Azerbaijan, The former Yugoslav Republic of Macedonia, Serbia, Tajikistan) countries[1].

The previous HIV and AIDS datasets each included 33 variables. The revised combined dataset includes 31 variables (17 mandatory and 14 optional), 8 of which are new (see figure below), covering four topic areas (TESSy-related variables and diagnosis, demographic and clinical information). Key features of the revised combined dataset are:

- Integration of HIV and AIDS surveillance.
- Mandatory and optional reporting.
- Simplified data relating to HIV exposure.
- Improve information on migrants.

[1] Feedback was also received from Croatia.

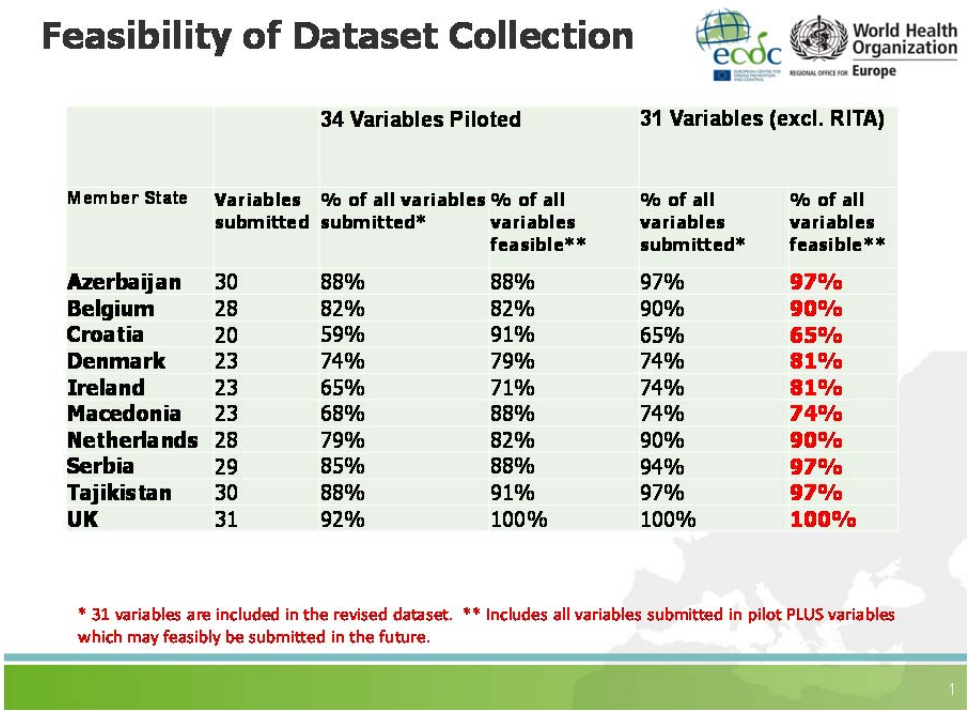
- Inclusion of biomedical markers such as CD4 count and viral load.
- Opportunity to monitor co-infections.



2.2 Results and feedback

Melvina Woode Owusu (PHE) presented the results of the pilot project on combining the HIV and AIDS datasets. The pilot assessed the feasibility of collecting data and the quality of data submitted. This included evaluating availability and completeness of the data, and validating the pilot data with previous data submitted to TESSy in 2013.

Availability and completeness of data was assessed for 34 variables initially – three of these variables, which related to recent infection, were removed from the dataset as none of the pilot countries collected data on them. The number of countries collecting data on the remaining 31 variables and data completeness (among those countries collecting data on the variable) varied. While all 10 countries could provide data on variables transferred from the existing datasets, fewer were able to do so for some of the new variables. Nevertheless, six of the 10 countries could provide data on at least 90% of the 31 variables (see figure below).



Overall, review of data submitted by the pilot countries showed that data was of a high quality, that data collection for the combined dataset was feasible, and that pilot data were congruent with TESSy data. Feedback from the pilot countries suggests that combining the datasets is relatively straightforward and is also preferable, as it more accurately reflects the current management of HIV as a chronic infection and it also reduces duplication in reporting in both an HIV and AIDS dataset. In some countries, HIV and AIDS data are already combined and TESSy currently requires them to separate these data for submission purposes. However, countries also highlighted challenges for data submission, including limited financial and human resources and multiple and overlapping requests for data. Areas where countries would like support from ECDC and WHO to enable them to report on the revised dataset include:

- Models for chronic disease surveillance.
- Guidance on linking or matching between registers to obtain and update information.
- Guidance on conducting periodic surveys to collect data on specific variables.
- Political pressure and scientific rationale, for example, for making reporting on some specific variables mandatory.
- Technical support and a rapid response helpdesk.

Specific feedback was provided by two of the pilot countries.

Derval Igoe reported that Ireland can provide data on all of the mandatory variables in the combined dataset but does not currently have data on 10 of the 14 optional variables. Of these, it would be feasible to add four variables, but it would not be feasible to add the other six without significant changes. The Irish HIV/AIDS surveillance model is centred on data at time of diagnosis and a new clinical dataset would require a fundamental change. There is no nationally agreed standardised electronic HIV patient record or register. However, information could be reported from a survey of people attending HIV specialist care, which is due to be repeated in 2015. There is also currently no direct link with laboratories to access data on CD4 count, this is reported by those completing the surveillance form; reporting of no CD4 count may mean that this information is not available rather than that the individual is not accessing care.

Shahin Khasiyev reported on Azerbaijan's experience of the pilot project. The process of collecting and coding data took more time than expected, although collecting and coding data for variables from previous years was not difficult; for new variables data were collected for the first time.

Additional variables suggested by Ireland and Azerbaijan include:

- Mode of transmission of infection of the mother in MTCT cases.
- Previous positive HIV test – to avoid double counting of cases that have been diagnosed elsewhere in the region and allow for separate analysis of those who are newly diagnosed – in Ireland 15% of 'new diagnoses' have had a positive HIV test elsewhere.
- Region of origin – for cases where country of origin is not known.
- Co-infection with other infectious diseases.
- Date of AIDS notification – to help determine the proportion of patients who have previously been registered (as HIV-positive) and who were not on the stage of AIDS in the reporting year.
- Date of reported death – to help determine the delay between the date of death and date of death registration.

Key points raised in response to these presentations included:

- The extent to which countries that expressed interest and participated in the pilot were better placed to collect and report data on the combined dataset than countries that did not. This is possible but the broad range of countries expressing initial interest in being part of the pilot suggests that the findings could be extrapolated; in addition, the survey to assess feasibility covered a larger number of countries.
- Some countries may not be able to report on some variables. Countries should focus on what is feasible and most relevant; there is also the option to report 'unknown' for all mandatory variables.

Giedrius Likatavičius (WHO Consultant) presented examples of outputs that can be derived from the variables in the combined dataset to monitor continuum of care (CoC) including its components. Proposed definitions for derived outputs that could be used to construct the continuum of care through surveillance data, which were discussed by working groups in the next session of the meeting, are included in Annex 3.

The pilot project highlighted the following challenges for developing the continuum of care:

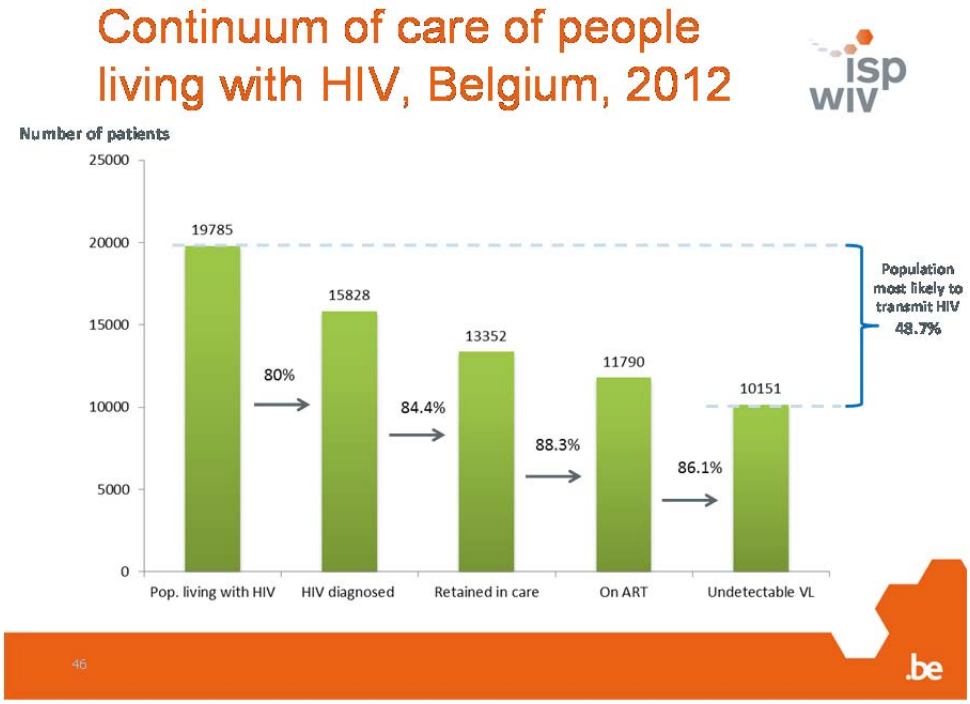
- Due to complexity and varying data sources not all data needed for the continuum of care were available.
- Varying ability of countries to update their historical data (e.g. death, AIDS).
- Several countries preferred alternative or combined data sources.
- Specific comparable derived outputs/components of CoC were much more feasible to collect (e.g. ART coverage; linkage to care).
- The need for clear definitions (e.g. undetectable viral load or cut off; ARV coverage) and agreed time periods for each component (e.g. linkage to care; retention in care).
- Data for monitoring CoC or derived outputs from surveillance data provide wider opportunities to analyse data by age group, gender, transmission mode.
- Although quality of data has increased during recent years, there are several methods proposed to adjust for incomplete data.

Two countries presented their experience of monitoring the continuum of care. **André Sasse** reported that this is done in Belgium by linking two datasets, from laboratories and from clinicians, which provide data on new HIV diagnoses (diagnosis and demographic information) and medical follow up – HIV cohort (clinical and death information) respectively. The two datasets can be linked through a patient identifier that is included in both. However, analysis of both datasets found that it was only possible to do this for

85% of patients – for example, some in the HIV cohort were not included in the HIV diagnosis dataset – so those that could not be linked were excluded from the pilot database.

A continuum of care was constructed (see figure below). In Belgium, 15-20% of HIV infections are estimated to be undiagnosed; data sources for this estimate and for each stage of the continuum are described in detail in the full presentation. Suggestions for improving data on the continuum of care in Belgium include:

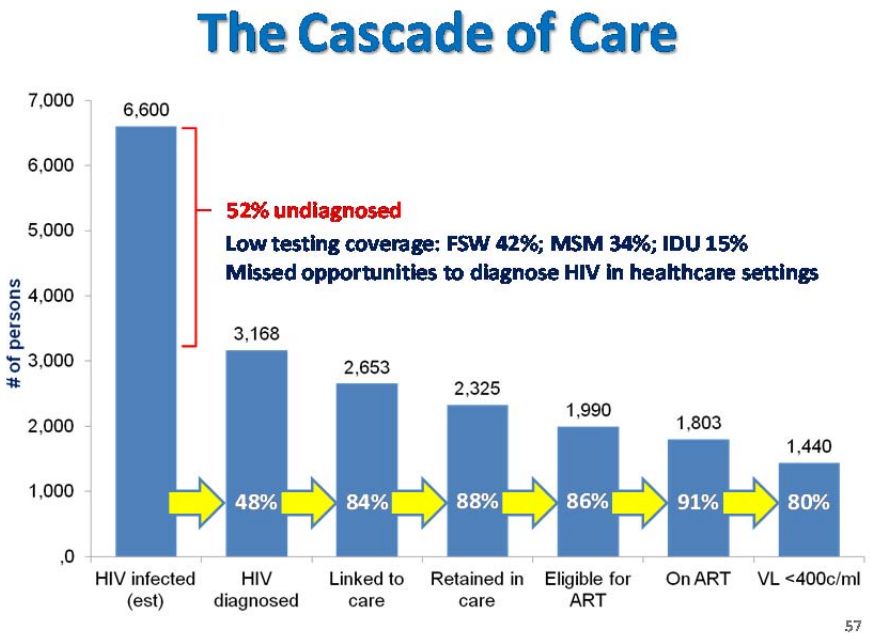
- Improve links between databases by using a more appropriate identifier: i.e. the social security number coded by a trusted third party. Improve the denominator i.e. the estimate of the number of people with HIV.
- Increase support for longitudinal surveillance i.e. HIV cohort. The plans for a prospective observational cohort have been included in the Belgian HIV Plan.



Otar Chokoshvili presented Georgia's approach to the treatment cascade. In Georgia, demographic, epidemiological, clinical and laboratory data are collected for all HIV-positive patients and managed through an electronic data collection system. Definitions used for the cascade are:

- HIV diagnosis – positive HIV test using any method confirmed by Western blot or nucleic acid-based test.
- Link to care – at least one documented clinical visit (CD4 cell count or HIV-1 viral load measurement) after diagnosis.
- Retention in care – at least one documented clinical visit (CD4 cell count or HIV-1 viral load measurement) within 12 months prior to date of censoring.
- Eligible for ART – CD4 cell count <350 or presence of AIDS-defining illness.
- ART – at least one documented prescription refill within three months prior to date of censoring (ART = combination of at least three ARVs).
- Viral suppression – plasma HIV RNA level <400 copies.

The cascade (see figure below) shows that a high undiagnosed fraction, and the need to increase HIV testing coverage, is the main challenge in Georgia.



Key points raised in response to these presentations included:

- Countries are using a range of definitions for different stages of the cascade. Caution is therefore needed when making cross-country comparisons.
- Data protection issues, at both EU and national levels, could limit the extent to which countries can link different datasets.

3. Revision of HIV surveillance in the European region: Working groups

Participants divided into four working groups to discuss:

- Combining HIV and AIDS reporting.
- Variables to monitor the continuum of care.
- Derived outputs to construct the continuum of HIV care through surveillance data.
- Variables to measure co-infections and recent infection.

Specific questions for working group discussion are included in Annex 3. The following summarises the feedback from the working groups. All groups discussed the first two topics but due to limited time, not all groups discussed the last two topics.

3.1 Combining HIV and AIDS reporting

Feasibility of producing a combined dataset

In general countries were supportive of proposals to combine HIV and AIDS datasets. Although country systems vary – some have separate databases, others already have a combined registry – most consider that producing a combined dataset will be feasible. Key points were as follows:

- In countries where datasets are currently separate, combining them may take some time. Issues that will need to be addressed include coding and unique identifiers; completeness of data in countries that do not have national HIV cohorts; and the need for consent for cohort data.
- Some countries noted that legal issues, specifically data protection, could be an obstacle to combining datasets and, specifically, for example, to linking HIV cases with death registration, or cause and date of death data. EU legislation could mean that this becomes an issue for all Member States.
- For some countries, updating information on AIDS diagnosis and death annually will be a challenge, for example, where reporting of AIDS cases is voluntary, where national surveillance systems do not have ready access to national clinical data, or where there is no national cohort.

Feasibility of constructing a combined dataset for historical cases

The extent to which countries reported that it would be feasible to construct a combined dataset for historical cases varied. Key points were as follows:

- There are differences between countries in how many years back in time a combined dataset for historical cases is possible.
- Most countries reported that this would be feasible for data from 2004, although some noted that data for some variables, for example, CD4 count, were only available from 2005 or 2006 or later for some countries.
- A realistic start date that is feasible for the majority of countries should be agreed.

Support needed from ECDC and WHO to implement these changes

Suggested ways in which ECDC and WHO could provide support, both for combining datasets and the proposed variables for monitoring the continuum of care, included:

- Sending a joint letter to the relevant authorities setting out the rationale for the revised approach to reporting and to obtain support for addressing data protection issues, in countries where there are legal barriers to accessing data.
- Advocating with decision makers for reporting of ‘mandatory’ variables, in countries where data on these variables are not currently collected.
- Making the case for investment in longitudinal surveillance and developing protocols for new national cohorts.
- Providing guidelines, technical support and training.
- Sharing models of good practice and promoting partnerships and exchange of experience between countries with common systems and challenges.

3.2 Variables to monitor the continuum of care

Comments on proposed variables and feasibility of reporting

The extent to which countries would be able to submit data on the proposed variables (see Annex 3) varied – while a few countries noted that it would be possible for report on all of the proposed variables, others stated that they do not have enough information to be able to do this. Overall, there was support for inclusion of these variables in the revised dataset, but with some caveats. Key points were as follows:

- Most countries would be able to report data on the first CD4 count and death-related variables, although there were some exceptions. Some countries that do not currently collect data on first CD4 count noted that making this a 'mandatory' variable could help to encourage reporting. As noted above, capturing or verifying data on death-related variables will be a challenge in some countries because of data protection issues.
- Reporting data on clinical variables would be more problematic, particularly for countries that do not have access to national clinical data or do not have a nationally representative cohort. In these countries, reporting would require obtaining this information from laboratories and clinicians. Concerns were raised about the burden this would place on clinicians and public health staff and about the extent to which clinicians would be willing to provide these data, for example, because of confidentiality issues. In addition, in some countries, it is difficult to obtain data from separate systems, for example, the prison system.
- The extent to which it will be feasible for countries to submit data on these variables in 2015 varied. A number of countries reported that this would be feasible; others noted that they would not be able to do this in 2015 but potentially could in future.
- The extent to which countries will be able to update each case on a rolling basis varied. Again, legal issues were cited as an obstacle.
- The extent to which countries will be able to provide a historical dataset with the proposed variables for monitoring the continuum of care also varied. Some participants noted that this may be easier for smaller than for larger countries. Others suggested taking a prospective approach.

Specific comments included:

- For first CD4 count the definition needs to be revised to specify whether this relates to at diagnosis/pre-ART, current/ever on ART; some groups recommended that it should relate to pre-treatment.
- For all variables it will be important to be able to distinguish between unknown in general and not available for specific cases.

Utility of reporting data to monitor newly diagnosed cases only

For some but not all countries unable to provide a full historical case-based dataset, it would be useful to report data to monitor newly diagnosed cases only.

Preferred format and process for reporting on the continuum of care

Preferences differed between countries with some preferring ECDC/WHO regional surveillance only (case-based format) while others expressed a preference for a combination of the aggregate reporting and case-based reporting. Specific comments included:

- The need to compare definitions used by countriesThe difficulty of making cross-country comparisons.
- The potential for improved TESSy data to support Dublin data reporting, thereby reducing double-reporting.

3.3 Derived outputs to construct the continuum of care

Working groups made the following comments on the proposed definitions (see Annex 3).

Late diagnosis

There were some concerns about the three months cut off point in the proposed definition. It was suggested that sensitivity analysis would be helpful to compare a three month vs. one year cut off. Different countries take different approaches to using 'AIDS' at diagnosis; some do not use this, others use it as a proxy for late diagnosis. Persons diagnosed elsewhere should be considered to be excluded, when analysing data.

Enrolment in care

Most countries agreed with the proposed definition. There were some questions about whether a having CD4 count means that a person is in care. Some expressed a preference for the first of the two definitions (page 27) as date of last clinic attendance would be more difficult to track.

Retention in care

No revisions were suggested to the proposed definition. It will be important to adjust for delay in reporting, to ensure those who are in care are not excluded.

On treatment

It was noted, that HIV on treatment should be stratified by origin, as those diagnosed elsewhere may enter the country already with low CD4 cell counts and may affect treatment coverage. Viral suppression

Different countries use different thresholds. For example, some use <200 copies/ml rather than the <50 copies/ml proposed. There were also some questions about the issue of measuring viral load after one year on treatment; measuring this would require data also on the date of starting treatment and in some countries it would be difficult to obtain data on how long people have been on treatment. The definition also needs to specify that this refers to viral load in people with HIV-1.

3.4 Variables to measure co-infections and recent infection

Two groups provided feedback. There was a consensus that it is important to report data on co-infections and that this is potentially feasible. However:

- Challenges may include: data completeness; linking data for different diseases when patients are registered with different codes; different data sources; different approaches to testing; and obtaining data from clinics.
- More specific variables would be needed for some infectious diseases, for example, form of TB.
- Co-infection data collection capacity may differ across the region: linkage with clinical databases may be needed in the West, except, where data are already received from cohorts, while clinical data are generally more readily available in many countries in the East.

4. Summary and closing of the meeting

Andrew Amato (ECDC) and **Martin Donoghoe** (WHO Regional Office for Europe) provided a brief summary of some of the key issues emerging from the meeting. Firstly, surveillance data highlight areas where greater efforts are required to address HIV in the European region, in particular the need for better approaches to tackle the continued increase in new HIV diagnoses among MSM and the significant proportion of people with HIV who remain undiagnosed.

Secondly, revised surveillance can play an important role in improving monitoring of the epidemic and of the effectiveness of prevention, treatment and care. Feedback from the pilot project and the participants suggests that there is broad support for combining the HIV and AIDS datasets and for the use of improved surveillance to monitor the continuum of care, although there is also recognition that implementation of the latter will be challenging.

Annex 1: Programme

Thursday, 22 May 2014	
8:00	**Registration**
9:00	**Session I: Opening** **Chairs:** Andrew Amato (ECDC) and Martin Donoghoe (WHO Regional Office for Europe)
9:10	Community perspectives on data for action (Anna Zakowicz and Lella Cosmaro, EU Civil Society)
9:25	Overview of HIV surveillance data, 2012 (Anastasia Pharris, ECDC, and Annemarie Stengaard, WHO Regional Office for Europe)
9:45	**Keynote lecture:** Monitoring the impact of HIV care on key populations: The treatment cascade and other continuum of care indicators (Valerie Delpech, Public Health England)
10:15	Discussion
10:30	**Coffee break**
11:00	**Session II: Revision of HIV surveillance in the European Region** **Chairs:** Annemarie Stengaard (WHO Regional Office for Europe) and Anastasia Pharris (ECDC)
	Background and introduction (Alison Brown, Public Health England) <u>Combining the HIV and AIDS datasets</u> • Pilot country results (Giedrius Likatavicius, WHO consultant and Melvina Woode-Owusu, Public Health England) • Pilot country feedback: Ireland and Azerbaijan <u>Monitoring the continuum of care</u> • Pilot country results (Giedrius Likatavicius and Melvina Woode-Owusu) • Pilot country feedback: Belgium • Country presentation: Georgia
12:25	Discussion
12:45 - 14:00	**Lunch**

Annex 2: List of participants

Nominated country experts

Name	Country
Marjeta Dervishi	Albania
Jean Paul Klein	Austria
Shahin Khasiyev	Azerbaijan
André Sasse	Belgium
Zlatko Cardaklija	Bosnia and Herzegovina
Serifa Godinjak	Bosnia and Herzegovina
Stela Stojisavljevic	Bosnia and Herzegovina
Tonka Varleva	Bulgaria
Mirjana Lana Kosanović	Croatia
Vratislav Němeček	Czech Republic
Susan Cowan	Denmark
Kristi Rüütel	Estonia
Kirsi Liitsola	Finland
Florence Lot	France
Otar Chokoshvili	Georgia
Barbara Gunsenheimer-Bartmeyer	Germany
Chryssa Tsiara	Greece
Vasileia Konte	Greece
Mária Dudás	Hungary
Guðrún Sigmundsdóttir	Iceland
Derval Igoe	Ireland
Daniel Chemtob	Israel
Laura Camoni	Italy
Lolita Ganina	Kazakhstan
Šarlote Konova	Latvia
Saulius Čaplinskas	Lithuania
Patrick Hoffmann	Luxembourg
Joanne Farrugia	Malta
Silvia Stratulat	Moldova
Aleksandra Marjanovic	Montenegro
Birgit van Benthem	Netherlands
Hans Blystad	Norway
Janusz Janiec	Poland
António Diniz	Portugal
Mariana Mardarescu	Romania
Natalia Ladnaia	Russian Federation
Danijela Simic	Serbia

Peter Truska	Slovak Republic
Tanja Kustec	Slovenia
Mercedes Díez	Spain
Maria Axelsson	Sweden
Martin Gebhardt	Switzerland
Zukhra Nurlaminova	Tajikistan
Zharko Karadzovski	The former Yugoslav Republic of Macedonia
Nurcan Ersöz	Turkey
Maysa Annagulyyeva	Turkmenistan
Ihor Kuzin	Ukraine
Valerie Delpech	United Kingdom

Consultants, Guests and Speakers

Name	Affiliation
Angelos Hatzakis	Athens Medical University
Alessandra Martini	European Commission (DG Research)
Alison Brown	Public Health England
Anders Sönnerborg	Karolinska Institute
Anna Zakowicz	Civil Society Forum
Ard van Sighem	Stichting HIV Monitoring
Fumiyo Nakagawa	HIV in Europe
Gaetano Marrone	Karolinska Institutet
Isabelle Giraudon	EMCDDA
Luljeta Gashi	Kosovo*
Jurja-Ivana Cakalo	WHO Collaborating Centre on HIV surveillance
Jordi Casabona	Euro HIV-EDAT
Kathy Attawell	ECDC consultant
Keith Sabin	UNAIDS
Lella Cosmaro	Civil Society Forum
Massimo Mirandola	SIALON II
Matthias Schuppe	European Commission (DG SANCO)
Melvina Woode Owusu	Public Health England
Osamah Hamouda	Robert Koch Institute
Vana Sypsa	Athens Medical University
Zheng Yin	Public Health England

* This designation is without prejudice to positions on status, and is in line with UNSCR 1244/99 and the ICJ Opinion on the Kosovo Declaration of Independence

ECDC

Name	Affiliation
Andrew Amato	ECDC
Otilia Sfectu	ECDC
Gianfranco Spiteri	ECDC
Anastasia Pharris	ECDC
Teymur Noori	ECDC
Chantal Quinten	ECDC
Karin Haar	ECDC
Julien Beaute	ECDC
Gaetan Guyodo	ECDC
Luisa De Leo	ECDC
Alexandra Hardiman	ECDC

WHO Regional Office for Europe and Headquarters

Name	Affiliation
Martin Donoghoe	WHO Regional Office for Europe
Annemarie Stengaard	WHO Regional Office for Europe
Bente Drachmann	WHO Regional Office for Europe
Javahir Suleymaniva	WHO Country Office Azerbaijan
Giedrius Likatavicius	WHO Consultant
Txema Garcia Calleja	WHO Headquarters

Interpreters

Name	Affiliation
Georgy Pignastyy	Interpreter
Elena Gornaya	Interpreter

Annex 3: Questions for the working groups

Combined HIV and AIDS reporting

1. The combined dataset requires countries to update information about AIDS diagnosis and death on a rolling basis (i.e. each year upon submission to TESSy all previously reported cases need to be updated). How much effort is this foreseen to be for your country?
2. Will your country be able to construct a combined dataset for the historical cases and, if so, for how many years back in time?
3. What support would you need from ECDC and WHO to implement these changes?

Variables to monitor the continuum of care

The following variables are suggested in the revised reporting protocol to improve surveillance of additional elements of HIV care, including:

	Variable no. and name	Mandatory or optional	Old or new variable	Possible derived outputs
First CD4 count	15. FirstCD4Count	M	Old	Late diagnosis Linkage to care
Date of first CD4 count	16. FirstCD4Date	M	New	Linkage to care
Date of last clinic attendance	22. LastAttendanceDate	O	New	Enrolment in care Retention in care
Latest CD4	24. CD4Latest	O	New	ART eligibility
Date of last CD4 count	25. CD4LatestDate	O	New	Enrolment in care Retention in care
Receiving ART	23. ART	O	Old	Receiving ART
Latest viral load	26. VLLatest	O	New	Viral suppression
Date of latest viral load	27. VLLatestDate	O	New	Viral suppression Retention in care
Date of death	30. DateofDeath	M	Old	Diagnosed people living with HIV
Cause of death	31. DeathCause	O	New	Treatment access/ success

1. Do you have any comments on the new proposed variables? Note that more information on the variable definitions and values is available in the revised reporting protocol.
2. Will your country be able to:
   Submit the above variables for data submission in 2015?
   Update each case with the above information on a rolling basis (each year for all previously reported cases)?
   Provide a historical dataset with the above variables and (if yes) for how many years?
3. Do you agree to add these variables? If so, what support would you need from ECDC and WHO to implement the change?
4. For countries that are unable to provide a full historical case-based dataset please discuss the utility of reporting data to monitor the HIV continuum of care for newly diagnosed cases only.
5. Given that some aggregate data on the continuum of care are already collected through existing global and regional reporting mechanisms, what is your country's preferred format and process for reporting this information? Through:

Existing global and regional reporting processes only (aggregate format)?
ECDC/WHO regional surveillance only (case-based format)?
A combination of both (aggregate reporting and case-based reporting to the extent possible)?

Derived outputs to monitor the continuum of care

In the proposed revised dataset, outputs could be derived on late diagnosis, enrolment and retention in care, and treatment and treatment outcomes. Some of these outputs can be combined to construct a continuum of HIV care. The following definitions are proposed:

	Proposed definitions
Late diagnosis	For countries that have a valid FirstCD4Count and a firstCD4Date, a late diagnosis is defined as a first CD4 count <350 cells/mm^3 within three months of HIV diagnosis For countries with <50% of FirstCD4Count and FirstCD4Date available, AIDS at diagnosis (DateofAIDSDiagnosis within 91 days of DateofDiagnosis) will be used as a proxy for late diagnosis
Enrolment in care	Proportion of patients with FirstCD4Count and FirstCD4Date within one year of HIV diagnosis (DateofDiagnosis) *or* Proportion of patients whose date of last clinic attendance is within one year of HIV diagnosis
Retention in care	The proportion of all patients seen in year 201X out of those seen in year 201X + 1 will be defined as the proportion of patients retained in care year on year. Patients known to have died will be excluded *or* The proportion of all patients enrolled in care (cumulative) who are retained in care in year 201X
On treatment	The proportion of patients receiving ART will be calculated for those diagnosed and living with HIV
Viral suppression	Patients with a viral load <50 copies/ml after one year on treatment

1. Do you suggest any revisions to the proposed definitions?

Variables to measure co-infections and recent infection

The following variables, which are not part of the information required for the continuum of care, are proposed for addition to the combined dataset.

Co-infection variables were considered for the pilot protocol but are not yet included. Co-infection rates with TB, hepatitis C and syphilis are high in many European countries and solid data are lacking at European level.

Measuring recent infection. Four variables to measure recent infection were included in the pilot protocol. Three of these were dropped following the pilots as standardised definitions are lacking. One variable is proposed for inclusion: 17. Acute infection (evidence of recent infection).

1. Would it be feasible to report data on co-infections (TB, HCV/HBV, syphilis) as part of annual HIV data submission (status at time of HIV diagnosis and/or last clinic visit)?
2. Is the proposed variable for measuring recent infection feasible to report?