



ECDC/WHO Joint Meeting on European HIV/AIDS Surveillance

10-11 March 2016
Bratislava, Slovakia

Meeting report

Address requests about publications of the WHO Regional Office for Europe to:

Publications
WHO Regional Office for Europe
United Nations City, Marmorvej 51
DK-2100 Copenhagen Ø, Denmark

Alternatively, complete an online request form for documentation, health information, or for permission to quote or translate, on the Regional Office web site (<http://www.euro.who.int/pubrequest>).

© **World Health Organization 2016**

All rights reserved. The Regional Office for Europe of the World Health Organization welcomes requests for permission to reproduce or translate its publications, in part or in full.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either express or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use. The views expressed by authors, editors, or expert groups do not necessarily represent the decisions or the stated policy of the World Health Organization.

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral drug
CDC	US Centres for Disease Control
CSO	Civil society organisation
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
PHE	Public Health England
PLHIV	People living with HIV
PrEP	Pre-Exposure Prophylaxis
SDG	Sustainable Development Goal
STI	Sexually Transmitted Infection
TESSy	The European Surveillance System
VL	Viral load
WHO	World Health Organization

1. Introduction

Andrew Amato (ECDC) and Martin Donoghoe (WHO Regional Office for Europe) welcomed participants to the meeting (see agenda in Annex 1 and list of participants in Annex 2). Some key developments since the last joint meeting in 2014 include: the launch of new global targets for HIV, to ensure that 90% of people living with HIV (PLHIV) know their status, 90% of PLHIV diagnosed receive treatment and 90% of those on treatment are virally suppressed; the development of a new WHO regional action plan for the prevention and control of HIV/AIDS; and the START study which led to global and regional recommendations on test and treat.

The main focus of this meeting was to discuss how HIV surveillance data can contribute to measurement of the HIV continuum of care. Following an update on global and regional data and trends, subsequent sessions would:

- Provide an update on HIV modelling and how case surveillance data can be used to estimate the number of people living with HIV.
- Explore ways to improve the measurement and effectiveness of HIV testing.
- Consider ways to improve case surveillance.
- Explore options for measuring linkage to and retention in care using case surveillance data.
- Consider issues relating to measurement of treatment, viral suppression and mortality.

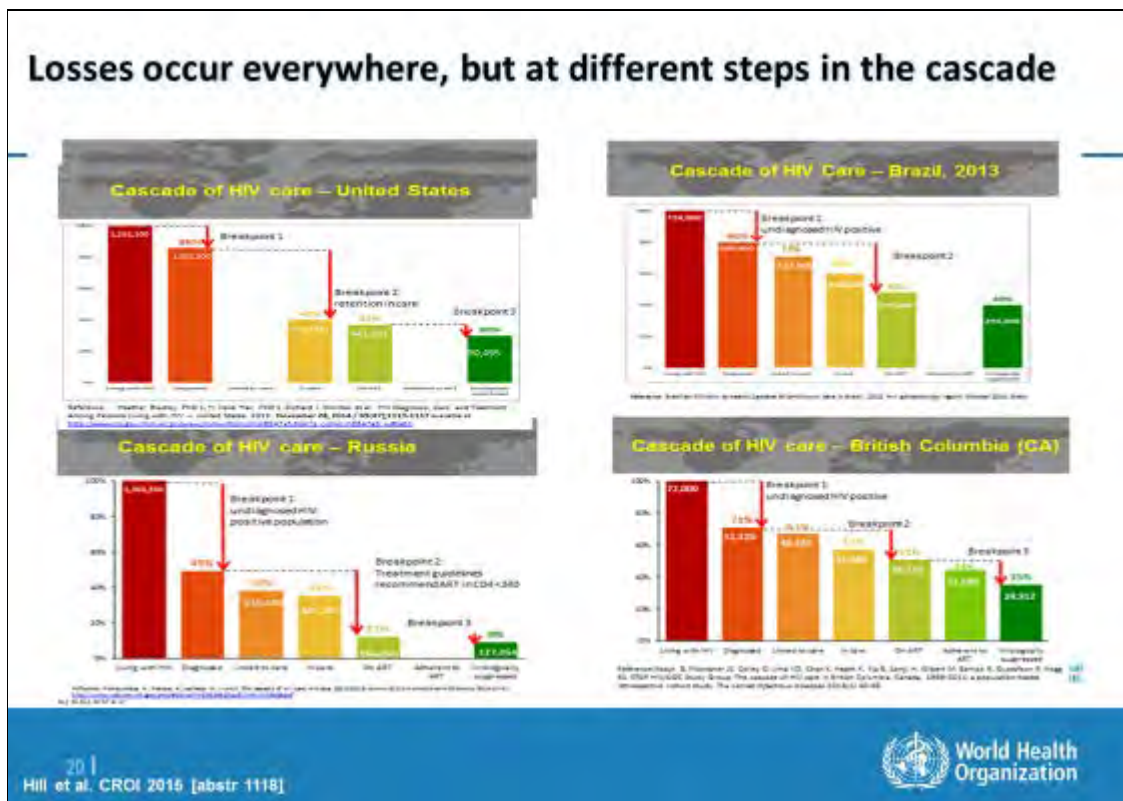
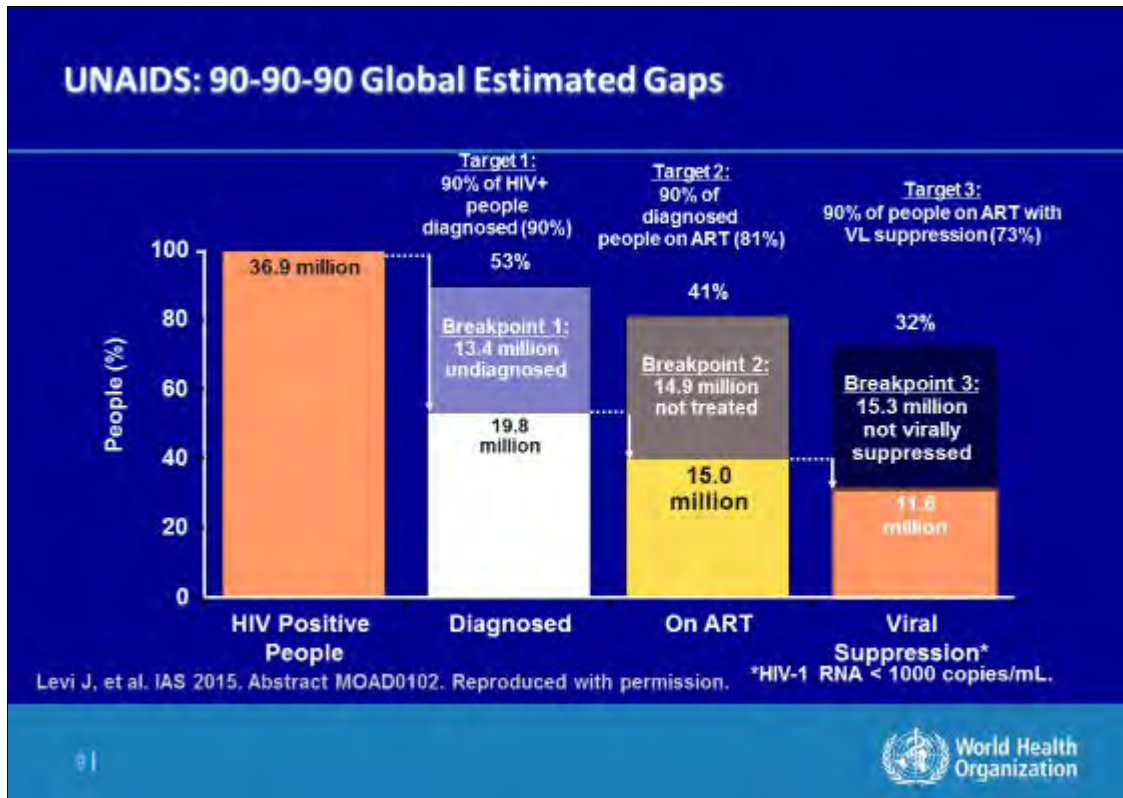
This report provides a summary of the main points from the meeting. More detailed information is available in the presentations, which have been disseminated to meeting participants.

1.1 Global data and trends

Txema Garcia Calleja (WHO) provided an overview of developments in global strategic information frameworks for HIV and of global data and trends. Key points included:

- The 2015 Sustainable Development Goals (SDGs) include a target of ending the AIDS epidemic as a public health threat by 2030. Targets in the new UNAIDS strategy are aligned to the SDGs. Global AIDS response reporting is being revised to reflect changes in global targets. Response rates have increased over time and, in 2015, 177 of 193 countries reported (34/42 in West and Central Europe and 11/12 in Eastern Europe and Central Asia). The new WHO HIV health sector strategy aims to reduce incidence by 75% and ensure universal access to prevention, testing and treatment by 2020; WHO issued strategic information guidelines for HIV strategic information in the health sector, which include standard indicators, in May 2015.
- Achieving 90:90:90 will be challenging. Available data suggests that losses occur in the continuum of care in all countries but there are differences between countries in where these losses occur (see figure below). Key data-related issues include prioritising indicators and data sources to enable construction of continuums and identify gaps, improving routine data, including patient and case reporting, and improving use of data for programme decision making. It is especially key to improve monitoring and data availability around the HIV continuum of care for key populations that are most at risk for HIV.
- Recent trends in surveillance include increased emphasis on case-based surveillance, population-based surveys extended to include incidence and viral load assays, patient monitoring systems and continued focus on HIV prevalence among key populations. With respect to the latter, an increasing number of countries are developing population size estimates and have relatively

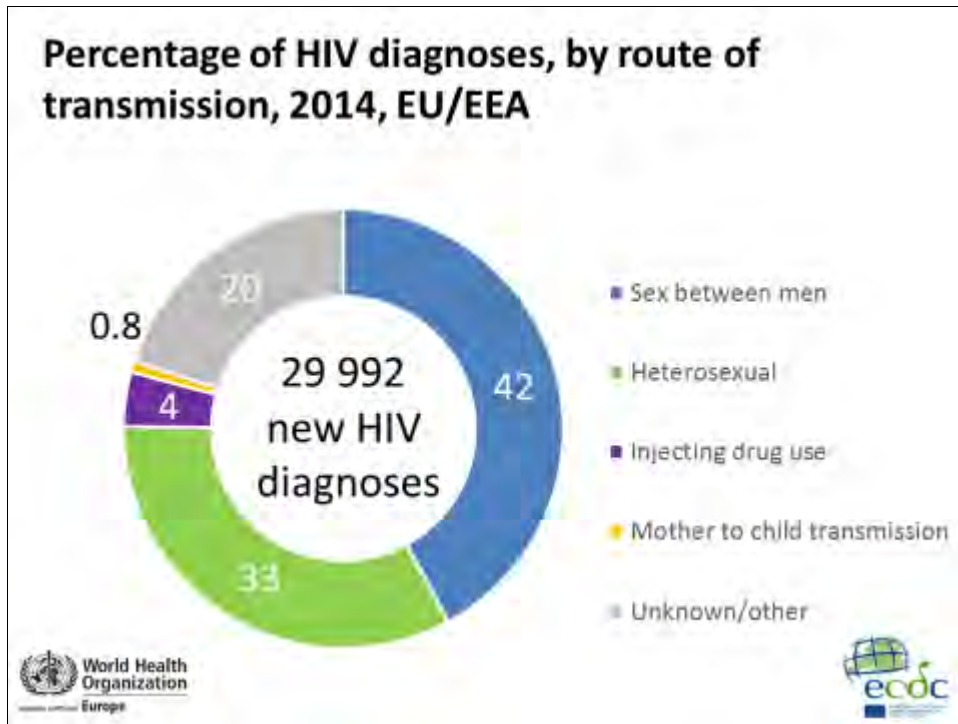
recent data from integrated bio-behavioural surveys. Better data is required to allow key population continuums of care to be constructed, as available data suggests that these populations often have poorer care outcomes.



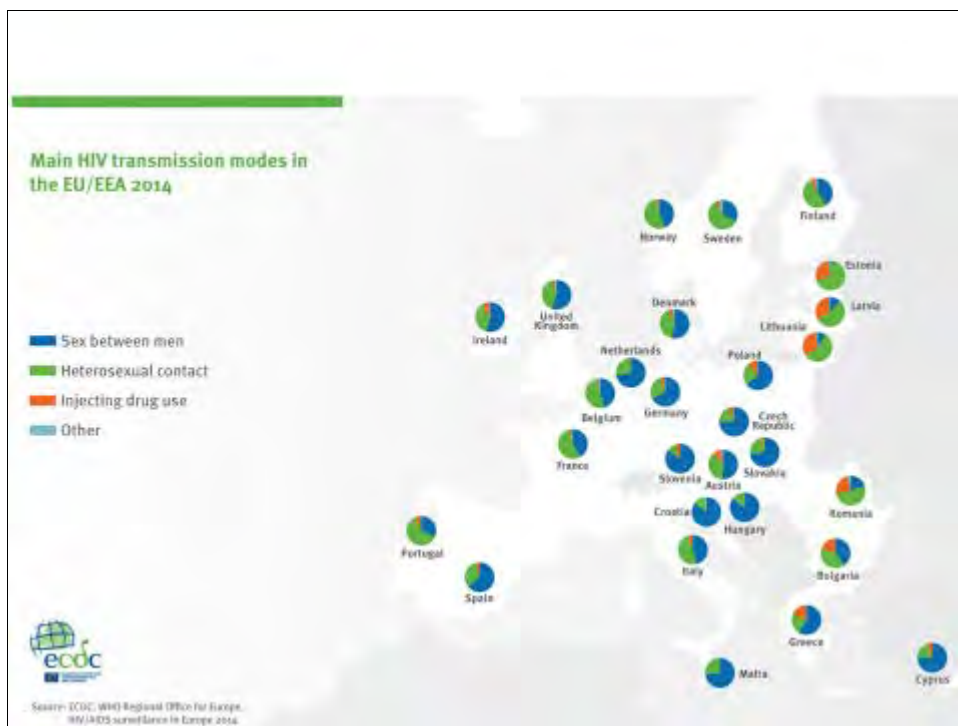
1.2 European surveillance data and trends

Anastasia Pharris (ECDC) and Annemarie Stengaard (WHO Regional Office for Europe) presented an overview of 2014 surveillance data for the EU/EEA and for the WHO European Region.

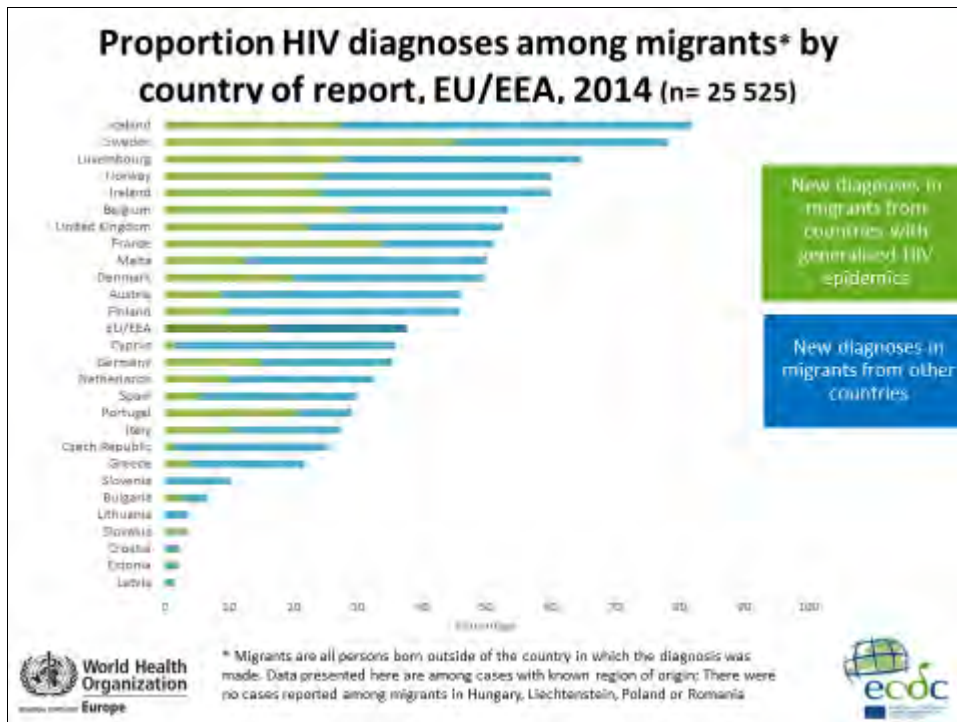
In the EU/EEA, 29,992 new HIV diagnoses were reported by 31 countries in 2014. Overall there are more cases in men than in women and men aged 25-39 years are most affected. More than 40% of new diagnoses were reported in MSM (see figure below).



However, as the figure below shows, the predominant mode of transmission varies between countries.



In the EU/EEA, people born abroad accounted for 37% of all newly diagnosed cases in 2014 but, again, there is considerable variation between countries (see figure below).



Analysis of new diagnoses for which CD4 cell count data is available shows that 47% of all people in the EU/EEA are diagnosed late (i.e. CD4 cell count of $<350/\text{mm}^3$ at diagnosis). Migrants from sub-Saharan Africa and South and South-east Asia are more likely to be diagnosed late than people who are native born or migrants from within Europe.

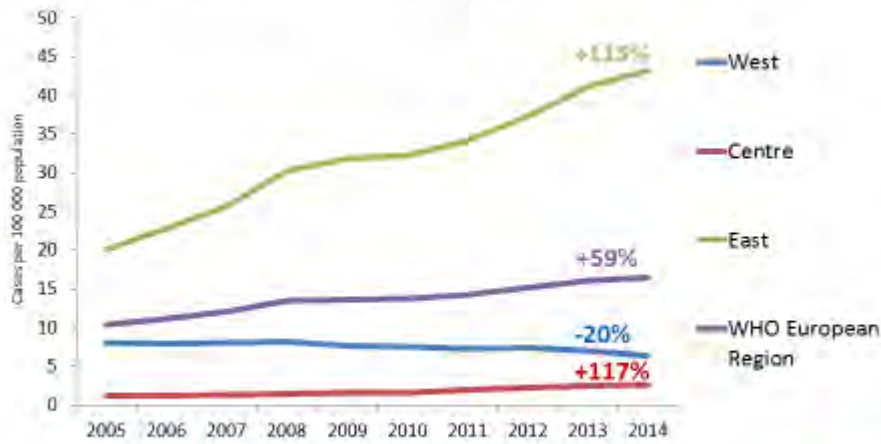
The rate of new AIDS diagnoses in the EU/EEA declined between 2005 and 2014, but the rate of new HIV diagnoses did not. During this period, the number of new diagnoses due to heterosexual transmission and to injecting drug use decreased, but the number of new diagnoses among MSM increased. The decline in new diagnoses due to heterosexual transmission is largely due to the decline in cases in people from sub-Saharan Africa and, consequently, migrants from other countries, including countries within Europe, now account for the majority of newly diagnosed cases among migrants.

In the WHO European region, 142,197 newly diagnosed HIV cases were reported in 2014: 77% in the East, 19% in the West and 3% in the Centre. Between 2005 and 2014, the rate of new diagnoses increased by 59% in the Region overall, but this masks significant differences within the Region, with the most significant increase in rates between 2005 and 2014 seen in the East (see figure below).

There are differences in predominant modes of transmission between the three sub-regions (see table below). In the West, MSM-related transmission predominates although heterosexual transmission is high. In the East, heterosexual transmission predominates but IDU-related transmission continues to be significant.

Figures for late diagnosis are similar to those for the EU/EEA. In 2014, 48% of new infections were diagnosed with a CD4 cell count of $<350/\text{mm}^3$. IDU are most likely to be diagnosed late; more than 60% of IDU newly diagnosed with HIV in 2014 were late presenters.

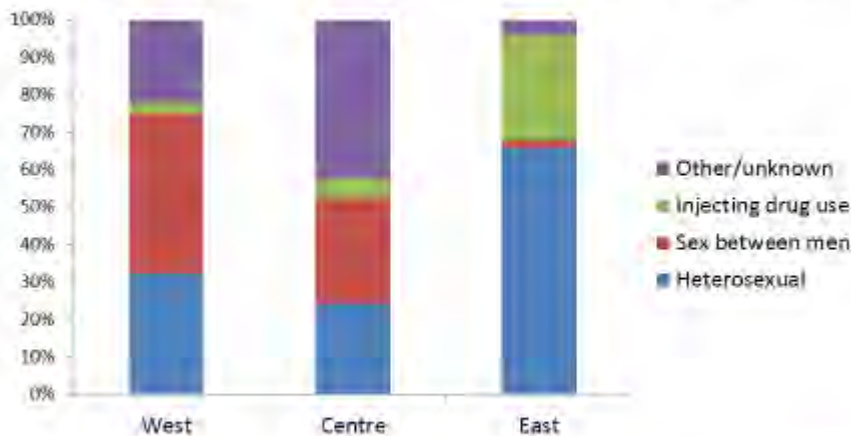
Rate of new HIV diagnoses, by year of diagnosis, WHO European Region, 2005-2014



Data from Bosnia and Herzegovina, Turkmenistan and Uzbekistan excluded due to inconsistent reporting during the period.



New HIV diagnoses by transmission mode and geographical area, WHO European Region, 2014



No data from Bosnia and Herzegovina, Russian Federation, Turkmenistan and Uzbekistan.



In the Centre of the Region, the epidemic remains at relatively low levels, but the rate of new HIV diagnoses more than doubled over the last decade, with this increase mainly driven by sexual transmission, particularly among MSM. In the East of the Region, increasing numbers of new diagnoses are reported by almost all countries, transmission through heterosexual transmission continues to increase, and transmission through sex between men has increased ten-fold between 2005 and 2014. Rates of AIDS diagnosis in the East are high and increasing, reflecting high levels of late HIV diagnosis, delayed ART initiation and low treatment coverage.

Key points raised in response to these presentations included:

- The continuum of care can help to convey information to policy makers and could also be used to set targets e.g. for testing and treatment. To maximise the value of the continuum, precise and agreed estimates of the number of people living with HIV are required. There is also a need to develop continuums for key populations to improve programmes and monitoring of progress.
- The use of different definitions makes it difficult to make comparisons between national continuums; ECDC is trying to address this through work to establish standard definitions.
- There is a need to sustain investment in prevention; advocacy for investment, particularly in prevention programmes targeting MSM, would be strengthening by highlighting population rates of new diagnoses among MSM and the high lifetime risk of acquiring HIV among this population.
- There is a need to differentiate new infections from new cases diagnosed; an increase in the latter can be an indicator of success i.e. reflecting increased uptake of testing among those who are infected. Modelling can help to address this.
- There may be a substantial number of cases of MSM and IDU-related transmission among those recorded as heterosexual transmission in countries in the East of the Region, and some concerns were also raised about whether the current separation of modes of transmission is sufficiently flexible to capture the probable route of transmission in cases with more than one risk behaviour e.g. MSM or sex workers or migrants who inject drugs. Approaches to ensure more accurate recording of mode of transmission are required.

2. Estimating the number of PLHIV

Chantal Quinten (ECDC) provided an update on the [ECDC modelling tool](#), which was developed to support Member States to develop accurate estimates of the number of PLHIV. This is important to inform effective responses to HIV, to monitor the continuum of care and to estimate the number of people with HIV who are not aware of their infection (i.e. the undiagnosed fraction) and who are therefore not receiving treatment and not taking steps to prevent onward transmission.

The modelling tool is the outcome of an ECDC project that reviewed existing methods and data requirements for estimating the number of PLHIV. It is based on two methods – the Incidence Method and the London Method – which differ in terms of data requirements and outputs (see presentation for details about the methods). In 2015, the tool was made available on the ECDC website and training was conducted for EU/EEA Member States. In February 2016, ECDC and UNAIDS organised a joint meeting to compare country experience of using the ECDC modelling tool and the updated version of Spectrum. The project is currently validating the estimates produced by the ECDC modelling tool in partnership with five countries (Belgium, Greece, Ireland, Luxembourg and Portugal). Next steps will include improving the tool and addressing data quality issues and other challenges identified by Member States.

Mary Mahy (UNAIDS) presented on UNAIDS' estimation approach, focusing on [Spectrum](#). UNAIDS has used the Estimation and Projection Package (EPP) and Spectrum to calculate global HIV estimates since 2002. There have been improvements in estimates over time, resulting from enhanced availability, quality and completeness of country data and modifications in modelling software. Consequently, it is not appropriate to compare previously derived and current Spectrum estimates.

Spectrum and EPP have worked less well in countries with low-level HIV epidemics; the ECDC modelling tool was developed because Spectrum previously only used prevalence data which many countries in Europe did not have. UNAIDS believes it is important to have a consistent global estimation process that allows aggregation and comparison of country-derived estimates and has therefore developed an updated version of Spectrum, which can now use case-based data and which was made available in early

February 2016. She described the AIM module of the Spectrum software, country data required and the results that can be generated. UNAIDS anticipates that some results will be available for the High-Level Meeting in June 2016 and the AIDS Conference in July 2016. Next steps will include working with ECDC and WHO to compile estimates for the European region.

Otar Chokoshvili (Georgia) and Georgios Nikolopoulos (Greece) provided feedback on country experience of using Spectrum and the ECDC modelling tool to develop national HIV estimates. The ECDC modelling tool provides a useful set of indicators, does not depend on the results of research or behavioural studies, and the CD4 category models provide more accurate estimates but require the input of good quality CD4 data. The tool does not provide projections for future years. Spectrum allows the use of programme data and does provide forecasts for future years. With both tools the quality of the results depends on the quality of input data and users need to exercise caution in interpreting the results. In Greece, the ECDC modelling tool and Spectrum generated different estimates for PLHIV, with the Spectrum estimates being lower and not capturing the recent HIV outbreak that occurred among people who inject drugs.

Key points raised in response to these presentations included:

- It is positive that more tools are becoming available for use in European HIV epidemic settings.
- It may make sense to try both tools and triangulate the findings if the country has the time and resources.
- Some countries are still not convinced that Spectrum is relevant to their situation, e.g. there are concerns that the model does not capture sudden changes.
- Neither model captures the issue of migration, which is a significant factor in many European epidemics. ECDC plans a small expert meeting in 2016 to discuss how to better model and interpret data with regard to migration.

3. HIV testing

This session focused on improving the measurement and effectiveness of testing in the region. Jens Lundgren (CHIP) presented an overview of developments in HIV testing since 2010 and highlighted some of the key implications of testing trends for surveillance. Testing has both individual and public health benefits. Experience with prevention of mother-to-child transmission of HIV demonstrates that comprehensive screening programmes can be implemented effectively in the region. However, testing programmes for populations most affected by HIV have been less effective. The rate of newly diagnosed cases remained relatively stable between 2004 and 2013 and there has been little change in the proportion of late presenters among newly diagnosed cases. Therefore some PLHIV are not being diagnosed and others are being diagnosed late.

Relatively few countries in the European region report data on testing, especially in the West, as the indicator relates to the rate of testing in the overall population and this is not particularly useful in a context where the epidemic is concentrated in key populations. Among countries that reported data in 2014, rates of testing in the overall population ranged from 1% to around 14%. However, some countries reporting high rates of testing are not targeting key populations for testing; conducting large numbers of test among those who are at low risk is not a good use of resources.

Data from the UK, where a high proportion of MSM diagnosed with HIV are on treatment and a high proportion of these MSM achieve viral suppression, indicates that the epidemic in this population is being driven by a small proportion of undiagnosed MSM. This highlights the need to better target the most affected sub-groups of MSM for testing, in order reduce the undiagnosed fraction and increase the proportion of HIV-positive MSM who are on treatment. It also suggests that achieving 90:90:90 will not be enough to reduce the incidence of new infections among MSM in Europe.

There is evidence that targeted testing using innovative approaches can reach PLHIV who have not been diagnosed. For example, routine testing in emergency departments and acute admissions units in the UK found a positivity rate of 0.28% and 0.61% respectively, an outreach programme in Italy targeting those at high risk of HIV found a positivity rates of 2.9%, and community testing through the BCN checkpoint in Barcelona has achieved a positivity rate of between 3% and 6% between 2007 and 2014 (a positivity rate of >0.1% is considered to be cost effective). With outreach and community approaches the issue of linkage to care is critical. However, as of July 2015, WHO recommended that trained lay providers can deliver HIV testing services using rapid diagnostic tests.

More evidence is required to inform recommendations on best practice models for delivery of HIV testing in different country contexts and for different key populations, as well as to improve understanding of what works and of barriers to provision and uptake of testing. Standardised approaches to evaluation of the performance of testing programmes, using standard performance indicators, will be critical. Possible performance indicators include: number of tests, coverage rate of the population targeted, positivity rate (i.e. >0.1% positivity rate to be cost effective) and linkage to care rate (i.e. goal should be 100%).

Kristi Rüütel (Estonia) and Irena Klavs (Slovenia) presented country perspectives on measurement of testing activities.

In Estonia, HIV testing is decentralised and provided by medical professionals in primary and specialist care, both in in- and out-patient settings; community-based testing is organised in collaboration with health care organisation. National testing guidance issued in 2012 recommends testing based on risk behaviours and indicator conditions, including special settings (STI and TB care, drug treatment, prisons, pregnancy care) and in epidemic regions for all aged 16-49 years, but there have been challenges with implementation.

HIV-testing among PWID and knowlegde of HIV status, according to study sites, different years

	Tallinn		Kohtla-Järve		Narva	
	2007	2013	2007	2012	2010	2014
HIV testing lifetime	85%	94%	76%	90%	81%	87%
Aware of HIV-positivity (among those tested positive during the study)	63%	88%	67%	84%	76%	93%

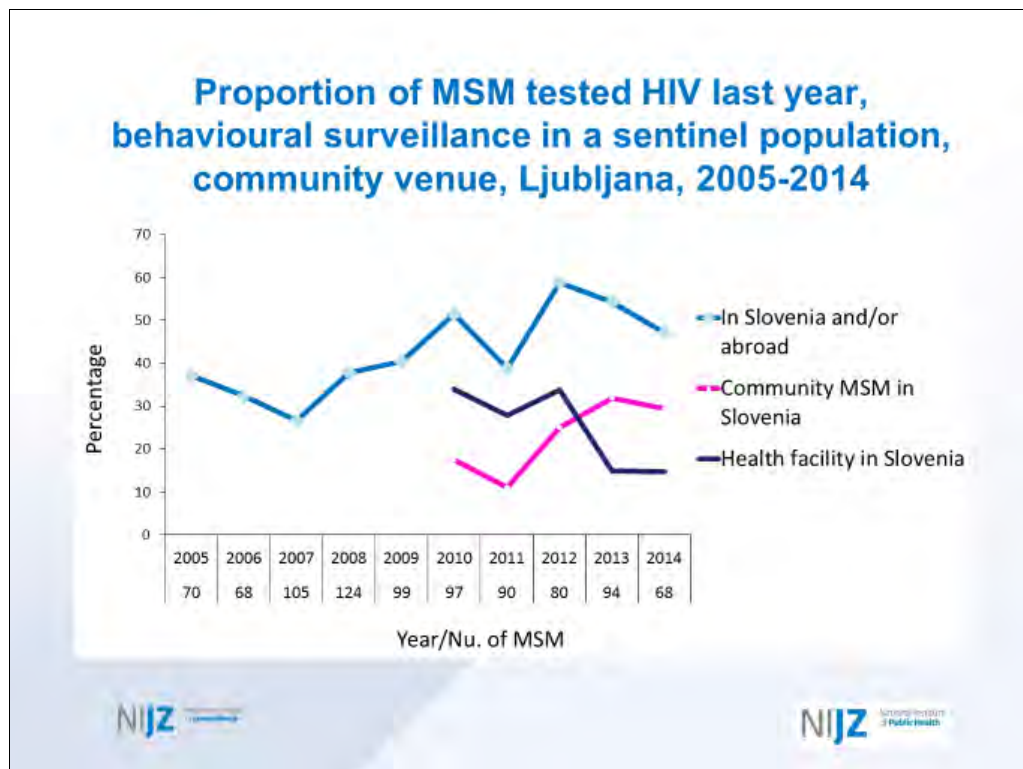
Tartu University and NIHD

The number of tests performed annually has increased since 2003 but a large proportion of tests are conducted in pregnant women and blood donors. In 2014, the overall positivity rate (for all those tested including pregnant women and blood donors) was 0.2%; the positivity rate among those tested in anonymous HIV counselling and testing sites was higher at around 0.6%. However, the data collection system does not distinguish between number of tests and number of people tested or between positive

cases and newly diagnosed cases. In the future, the National Health Insurance Fund may provide better data on the number of tests performed and some patient clinical data. Other potential data sources include cross-sectional studies, which could provide data for different populations, for example, on the proportion tested in the last 12 months and ever tested and the proportion aware of their status (see figure above).

In Slovenia, early diagnosis and, hence HIV testing, is a priority in the national HIV strategy. The strategy recommends testing for patients with symptoms or diseases indicating HIV infection, STI clinic patients, populations with high risk behaviours e.g. MSM and IDU, partners of people diagnosed with HIV, etc. HIV voluntary and confidential testing by general practitioners has also been promoted.

Slovenia monitors national HIV testing rates and positivity rates, and the percentage of MSM (a key population with high-risk behaviour) tested in the last 12 months who know their result. Data on testing among MSM is collected through behavioural surveillance. Behavioural surveillance data suggests that the overall testing rate among MSM has not changed; more MSM have sought community-based testing but fewer have sought testing at a health facility (see figure below). The selected indicators developed in the COBATEST project and currently used in the [Euro HIV EDAT project](#) (both co-funded by CHAFEA) are used to monitor and evaluate community based voluntary counselling and testing of MSM in a community setting (LEGEBITRA). The most important indicators are: number of clients tested for HIV with a screening test; percentage of clients with a reactive screening result; and percentage of clients who tested HIV positive at a community-based site who were linked to health care. Preliminary data suggests that the positivity rate at the community-based site is higher than the overall national positivity rate. Slovenia plans to link community-based data with national surveillance data using a common unique identifier to estimate the latter indicator.



Future plans include updating targets and indicators in the 2016-2020 national HIV strategy, considering the development of national HIV testing guidelines covering health care settings, community-based testing, self-sampling and self-testing; and further development of monitoring and evaluation of HIV

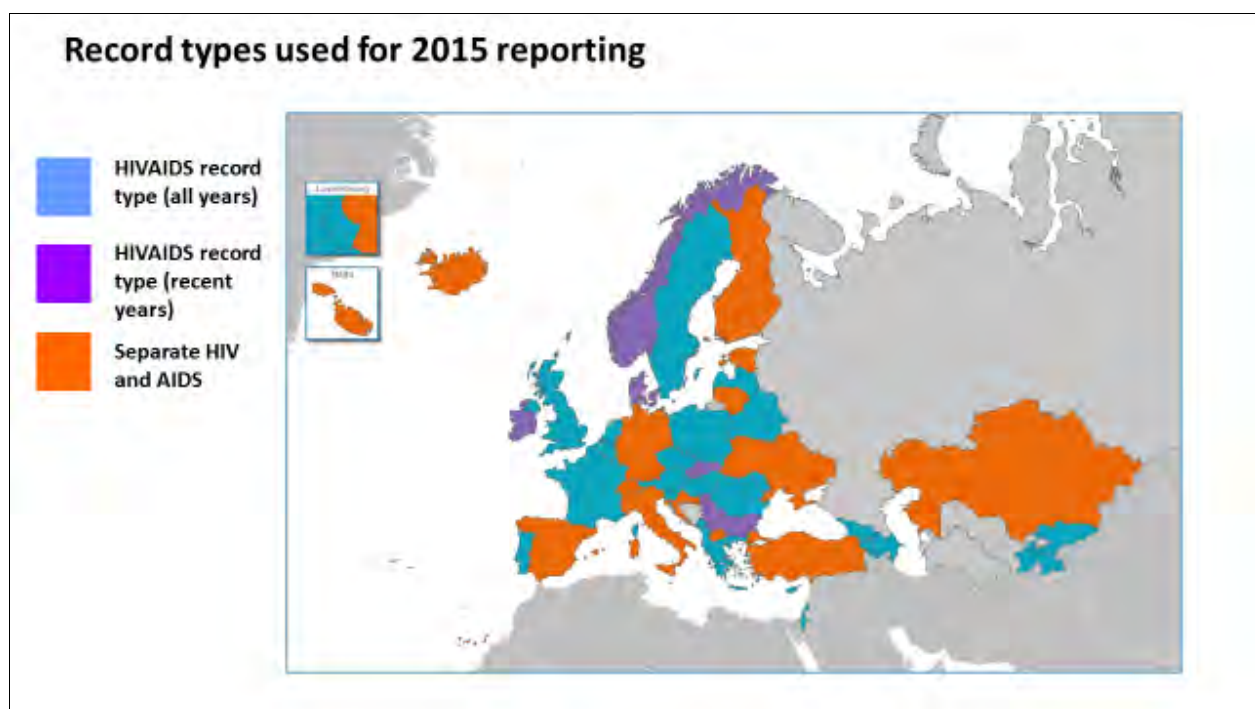
testing to understand differences in the extent of testing, positivity rates and linkage to health care for different approaches to HIV testing.

Key points raised in response to these presentations included:

- Increasing testing and diagnosis of HIV will require a shift from exceptional to routine or opt out testing in health care settings; informed consent should be a given for any diagnostic test.
- Self-sampling and self-testing raise issues concerning linkage to care. WHO guidelines on self-testing will be available later this year.

4. The number of people diagnosed with HIV

Anastasia Pharris (ECDC) provided an update on implementation of the combined and revised HIV/AIDS dataset for reporting. The map below shows the extent to which countries applied the combined dataset format in 2015 reporting.



Regional completeness for different variables varies – e.g. completeness is high for age and gender and low for probable country of infection; completeness for CD4 at diagnosis has improved but needs to improve further as does completeness for mode of transmission – and completeness for different variables also varies across countries. Availability and completeness of data for new variables added in 2015 also varies across countries (see figure below).

Challenges encountered include: timeliness; data management and recoding, particularly for countries without electronic national databases; reporting of AIDS and death as outcomes in the current year; creation of new data sources; duplicate data in TESSy; and the acute infection and transmission partner variables.

Despite these challenges, the new dataset offers the potential to differentiate and describe how HIV and AIDS diagnoses relate to each other, to use new variables to construct measures of linkage to and retention in care and HIV continuum of care constructs such as on treatment, in care, and viral suppression, and to use year of arrival + first CD4 to objectively estimate the probable country of

infection. Further consultation with countries is required to inform future analysis with regards to AIDS and migration.

In 2016, the dataset for reporting will remain the same and the data call letter and reporting protocol will be sent in April 2016; countries are requested to report before the summer if possible or by 15 September at the latest.

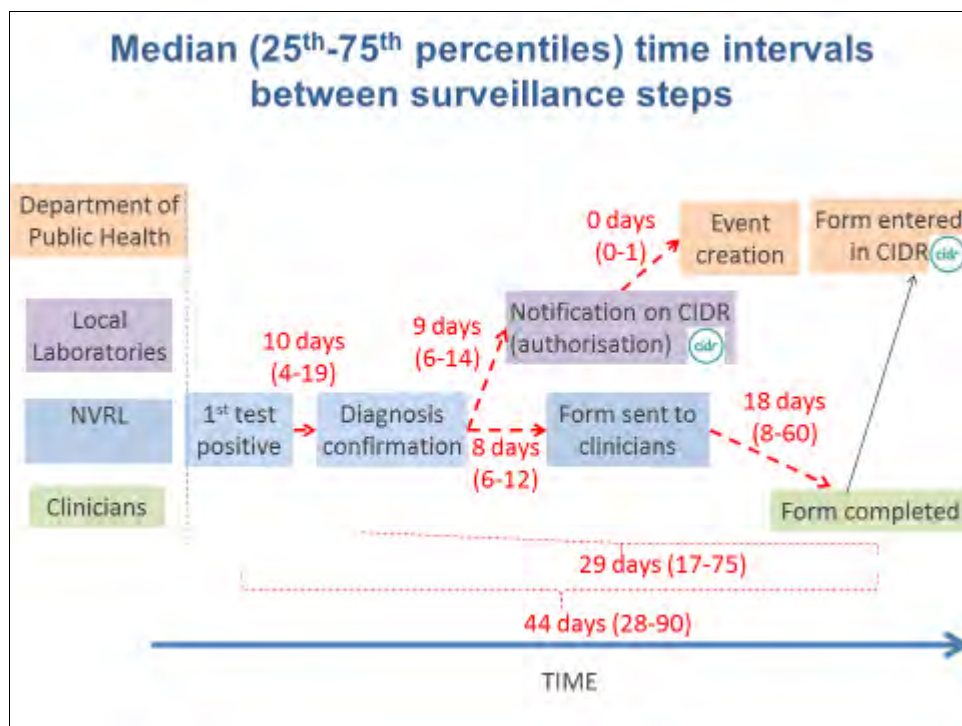
Availability & Completeness of New Variables

Variable Name	# Countries reporting (of 33 using new dataset)	Completeness	Range
FirstCD4Date	27	64%	2 - 100%
ART	18	77%	2 - 100%
Last Attendance Date	17	79%	11 - 100%
Latest Viral Load	20	56%	16 - 96%
Year of Arrival	8	73%	29 - 93%

Derval Igoe (Ireland) described the findings of an evaluation of the timeliness of the HIV surveillance system in Ireland with respect to timely trend analysis. Ireland shifted from voluntary case-based reporting to mandatory notification in 2011 and HIV was included in the national Computerised Infectious Disease Reporting (CIDR) system in 2012. The objectives of the evaluation were to identify time intervals between the surveillance steps, use this knowledge to aid interpretation of trends and recommend how intervals might be shortened. The main methods were assessment of the median time interval between surveillance steps, using 2012 and 2013 data from CIDR and the National Virus Reference Laboratory (NVRL) databases, and comparison of these time intervals with national requirements and US CDC standards.

As the figure below shows, the total time from diagnosis confirmation to entry into the CIDR database was 29 days; the total time from the first positive HIV test to entry into the CIDR database was 44 days. CDC standards are 66% of forms completed within 6 months; Irish guidelines recommend notification by laboratory within 1 week (achieved for 38% of cases) and reporting of clinical information within 3 months (achieved for 73% of cases).

The evaluation concluded that the HIV surveillance system is timely for monitoring trends – enhanced data is available for 81% of cases within 6 months of diagnosis – but probably not timely enough to detect increases in new diagnoses by sub-group rapidly. It recommended that Ireland, in the short term, move to one-sample notification and allocate more resources to shorten time to notification and, in the longer term, move to electronic reporting by clinicians. In addition, consideration should be given to developing a gold standard for timeliness at European level.



Chantal Quinten (ECDC) presented briefly on adjusting HIV data for reporting delay, which is one of a number of limitations that affect the usefulness of surveillance data. Reporting delay relates to the time between diagnosis and notification at national level. During the period 2010-2014, 53 countries uploaded 102,427 newly HIV diagnosed cases to TESSy; of these 17,166 cases were reported to national systems one or more years after year of diagnosis ($\pm 17\%$). There can be a considerable delay between date of diagnosis and date of notification e.g. for cases in migrants diagnosed before arriving in the country of destination, but 99% of cases are reported within 4 years of diagnosis.

There are three possible approaches to addressing reporting delay: accept it and accept that there will be under-estimation of burden of disease; delay the data call to allow countries more time; or account for it by applying delay estimates. The latter option allows for more precise determination of trends and burden of disease and provides more reliable data for decision making. Currently ECDC uses a back calculation method using historical data, and includes adjusted and unadjusted data in the surveillance report. This method has limitations e.g. it needs consistent reporting over time in order to calculate delay probabilities.

Following the presentations, participants divided into working groups to discuss: experience of using the combined dataset, the objectives of European-level AIDS surveillance, and the collection and reporting of data on variables related to migration. Key points from feedback from the working groups were:

Experience of the revised and combined dataset

- Most countries had no difficulties with the new combined dataset, especially those with existing combined datasets or national cohorts, although for some this involved a significant amount of work (e.g. because of the need for manual updating, inputting of clinical data from paper records or combining two sets of records) and for others uploading the data to TESSy was time consuming, but no different than previous years.
- Other countries have yet to use the combined system (e.g. because it is not a political priority, because of legal or regulatory barriers or because of technical challenges including lack of a national

electronic surveillance system); a clear communication or request to countries from ECDC and WHO may help to address some of these challenges.

- Routine surveillance does not include all the required variables and many countries experienced problems with reporting on some of the new variables, in particular last CD4, last VL, year of arrival and probable country of infection (e.g. because there is paper reporting or anonymous reporting or because there is no data or no national cohort). Some countries also noted that lack of staff trained in TESSy is a challenge.

AIDS surveillance

- There was no clear consensus. Some countries suggested that monitoring of AIDS cases is no longer relevant or noted that reporting of AIDS cases is not mandatory in their country.
- Some proposed a focus on AIDS indicator diseases and revision of indicator disease reporting to match ICD-10, but others were not sure that monitoring indicator diseases is very useful for surveillance.
- Some countries support the idea of trying to differentiate between AIDS at diagnosis due to failures in the public health system (e.g. late diagnosis or delays in getting treatment) and due to migration (migrant status is therefore a critical variable for analysis of AIDS diagnoses), e.g. Belgium noted that most AIDS cases are migrants who are diagnosed very late, but others noted that this differentiation would not be feasible.
- There was support for the proposed analysis of AIDS within 90 days although some countries felt this was not important and others, e.g. Ireland, only collect AIDS data at time of HIV diagnosis so the analysis would be misleading.
- It was noted that AIDS at time of HIV diagnosis is important for the modelling tool if CD4 data are not available; the variable CD4 count at diagnosis could become less complete as countries shift to test and treat (and it is noted that public health authorities should stress to clinicians the usefulness of the variable).
- Some countries suggested that monitoring cause of death could provide useful data, but in some countries data on AIDS collected at the time of diagnosis is not linked to mortality statistics.
- Clarification on reporting cases of co-infection may be helpful as national protocols differ.

Migration variables

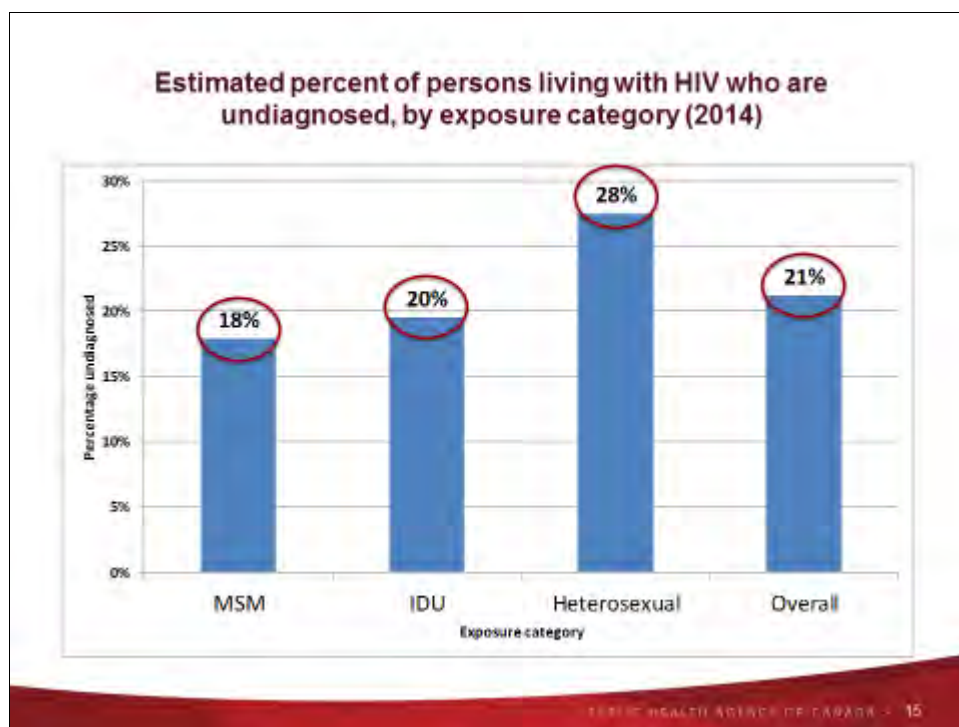
- Migration issues are not equally relevant for all countries, definitions and migration patterns vary, and migration issues are politically sensitive.
- Completeness of migration-related variables is expected to improve over time but clinicians may need to be convinced about the importance of some of these variables (e.g. country of birth, year of arrival).
- There are challenges related to how report cases in migrants who are new to a country but are not new cases. Countries are encouraged to report these new cases and the existing optional variable "HIV Status" is suggested to be used to differentiate new diagnoses from previous diagnoses who are new to the country. Some suggested it might also be useful to include a variable with the date of the previous positive test; in some countries this data is already collected as well as data on transfer of care.
- It was suggested to keep and improve the probable country of infection variable but expand coding to allow 'region of infection'; interpretation may need to take account of visits to country of origin after migrants' arrival in Europe.
- Some countries highlighted challenges in getting data on undocumented migrants and reporting on variables such as country of birth (e.g. because variables such as nationality or country of origin are recorded) and transmission partner (e.g. because in some countries only some patients, such as heterosexual men, are asked about partners or because of the risk of misclassification by clinicians).
- There is potential for double-counting at European level if migrants move within the region.

- Lack of consistency in the reporting of new diagnoses among non-residents or non-nationals across countries and lack of clarity as to what is expected from countries for European level reporting to avoid duplication.

5. Linkage to and retention in care

Claudia Rank and Kristina Tomas (Public Health Agency Canada) started the session with a keynote presentation on HIV surveillance, estimates and cascade measurements in Canada. Responsibility for health in Canada is shared between federal and provincial/territorial governments, there is no legislation for reporting to the federal government by provinces/territories and national monitoring of notifiable diseases is achieved through consensus and voluntary reporting. National HIV and AIDS surveillance is based on a passive case-based system, HIV and AIDS databases are separate and unlinked, and data is reported on age, sex, race/ethnicity, country of birth, exposure categories, laboratory confirmation, vital status and AIDS indicator diseases for reported AIDS cases.

National and provincial level HIV incidence and prevalence estimates are produced every 3 years based on surveillance data (case surveillance and biological and behavioral surveillance data), modelling and data from research studies. The estimated number of new infections has declined in recent years and the estimated number of PLHIV has increased to around 75,000, due to availability of treatment and a decline in deaths. In 2014, more than 50% of estimated new infections were in MSM and more than 10% were in IDU. In the same year, it was estimated that around 16,000 or 21% of PLHIV were undiagnosed, but the proportion differs depending on mode of transmission (see figure below).



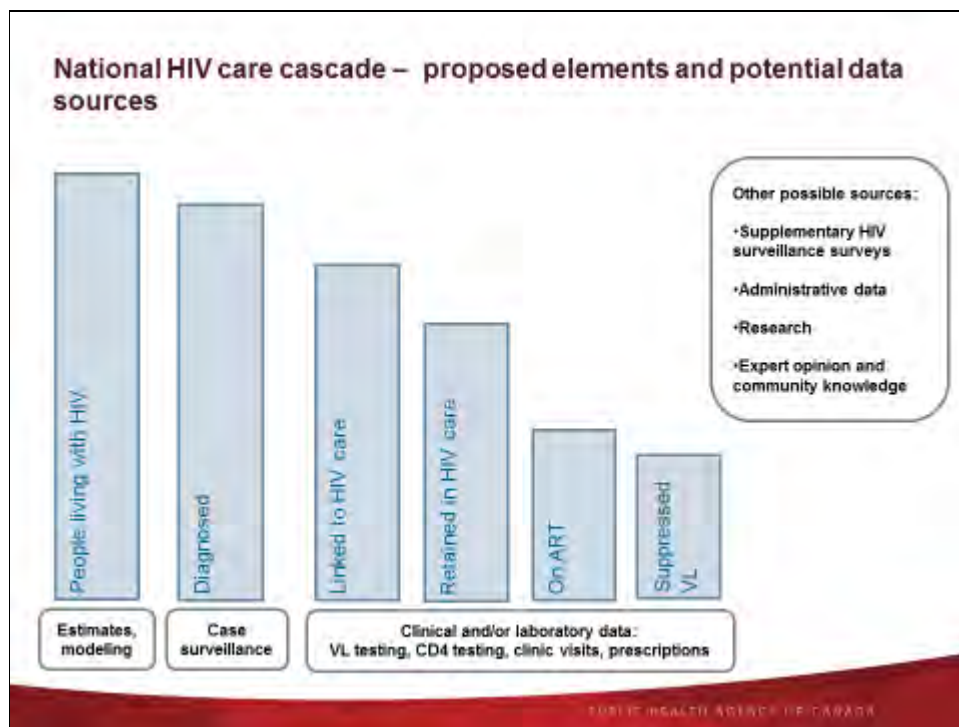
Of the 2,044 HIV cases diagnosed in 2014, almost 50% were in MSM, 13% in IDU and 2.8% were in the combined MSM-IDU exposure category. Reported AIDS cases, HIV-related mortality and AIDS deaths have all declined in recent years.

Key challenges and developments include: improving case surveillance and integrating case surveillance with the HIV care cascade; and estimating the undiagnosed fraction and elements of the care cascade.

Enhanced surveillance includes drug resistance surveillance, i.e. monitoring circulating HIV subtypes and transmitted drug resistance among antiretroviral treatment-naïve persons newly diagnosed with HIV, and integrated biological and behavioural sentinel surveillance through repeated cross-sectional surveys at selected sites, which monitors prevalence of HIV, hepatitis C, syphilis and other sexually transmitted blood-borne infections and associated risk behaviours among IDU, MSM, people from HIV-endemic countries, aboriginal people, and street youth.

Considerations with respect to the cascade include: there is no national dataset and HIV care and treatment is monitored at provincial or regional level; there are diverse guidelines and practices across jurisdictions; HIV surveillance and clinical data are often separate and linking data from different sources is not feasible in all provinces; and different populations are represented by different data sources. The approach taken involves development of national definitions and alignment of indicators, support for production of provincial/regional cascade measures; collation of measures for development of a national cascade; and triangulation of findings and estimation where necessary.

The figure below illustrates the components of the HIV care cascade for which PHAC aims to develop national measures. While the first two are already monitored using existing efforts, a coordinated approach utilising information currently residing within provinces and territories is needed to address linkage and retention in care as well as treatment and viral suppression. Draft working definitions have been developed for linked to care (people who had ≥ 1 HIV clinic visit *or* ≥ 1 viral load test in a 12 month period) and retention in care (people who had ≥ 2 HIV clinic visits *or* ≥ 2 viral load tests in a 12 month period); CD4 data is not available for population-based analyses in all jurisdictions, so visit or VL is used as a proxy.



Future plans include: assessing the potential to collect additional data elements as part of case surveillance; a revised surveillance framework for HIV drug resistance monitoring; and triangulation of information from various sources and use of enhanced surveillance to measure continuum of care indicators in key populations.

Questions and answers were:

- HIV trends in MSM – The proportion of new cases in MSM has not changed.
- Addressing the issue of migration in surveillance – This is more relevant for prevalence than incidence in Canada, migration screening is the main data source and there appears to be an increase in the number of cases in people born outside the country, but how to address migration in surveillance is a province-level decision.
- Testing data – There is no routine data on testing and data collection is a province-level decision.
- Drug resistance – Preliminary data suggest that MSM have a greater prevalence of resistance compared to other groups.

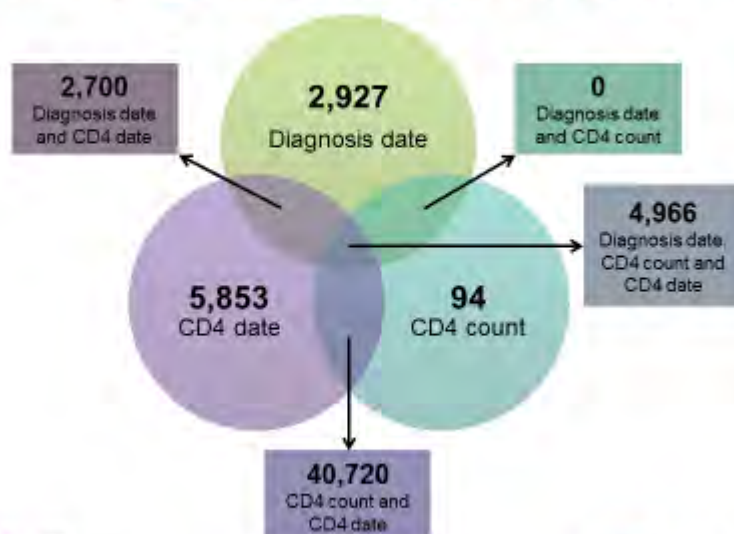
The session then focused on using HIV surveillance to measure linkage to and retention in care. Teymur Noori (ECDC) noted that Dublin Declaration monitoring in 2014 showed that these are the two elements of the continuum for which there is the most diversity in definitions and the least availability of data.

Sara Croxford (Public Health England) presented work by the [OptTEST](#) project to assess the feasibility of using TESSy data to monitor linkage to care in Europe. Linkage to care is entry into care following diagnosis with HIV. This is often measured as the time between a patient’s diagnosis and their attendance at an HIV specialist care provider but review of the literature identified a wide range of definitions. The ECDC expert meeting on the continuum of care in September 2015 agreed on a working definition for linkage to care: the proportion of patients seen for HIV care (measured by first CD4 count and/or viral load and/or attendance date and/or treatment start date) within 3 months of diagnosis.

To assess the feasibility of using TESSy data to monitor this definition, OptTEST analysed data submitted in the revised and old formats (2010-2014) separately. Analysis of the revised dataset focused on linkage to care measured by time from diagnosis to first CD4 count, looking at the percentage linked within 1 year and linked within 3 months of diagnosis. Of the 122,364 patients included in analysis, 67,878 (55%) were linked within a year of diagnosis; of those linked within a year, 61,159 (90%) were linked within 3 months. Estimates of linkage to care varied by country. However, incomplete/partial data, including missing or partial diagnosis dates and CD4 dates, resulted in analysis being restricted to only half of individuals newly diagnosed between 2010 and 2014 (see below).

Analysis of the data submitted in the old format was less reliable as all CD4 counts reported were assumed to be within 3 months of diagnosis.

Missing ttcd4 data (N=57,260)

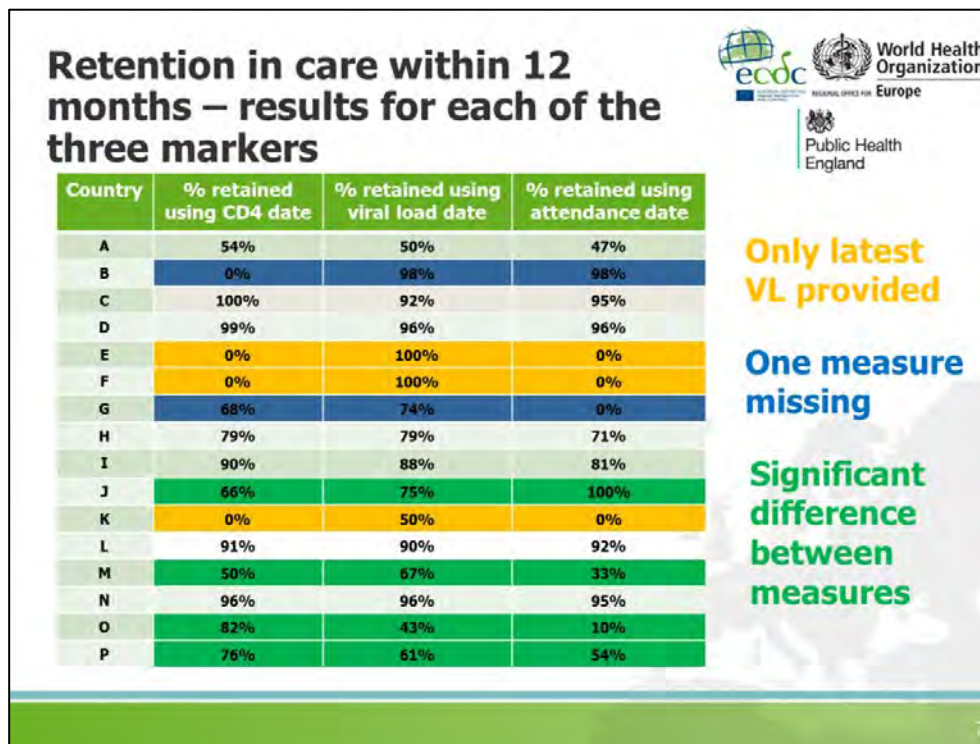


The analysis suggests that variability in reporting and surveillance systems makes interpreting TESSy linkage to care estimates and changes over time difficult. It also highlights the importance of complete date reporting as almost half of patients were excluded due to missing information. It is also important to note that date of diagnosis is not always date the patient is notified of their HIV status, and as such, linkage to care may be underestimated. There is more work to do to evaluate whether it is feasible to use TESSy to monitor linkage to care including examining other measures (e.g. viral load, attendance date) and incorporating deaths. OptTEST, supported by its partner organisation, ECDC, will be administering a short survey to countries to further explore linkage to care and understand the caveats that need to be considered when interpreting estimates. This will be circulated in the next month or so.

Cuong Chau (Public Health England) discussed the feasibility of using TESSy data to monitor retention in care. Retention in care measures continued engagement in HIV care following linkage. People who are not retained after linkage are considered lost to follow-up. Retention in care is usually reported as a percentage of those linked to care who re-attend at a certain time point but, as with linkage to care, definitions vary and there is no consensus on when someone becomes not retained.


The 2015 TESSy dataset in the revised format was analysed. Analysis included only patients with first CD4 count between January-June 2014. A patient was considered to be retained in care if they had a marker of attendance (latest CD4 count and/or viral load and/or attendance date) available during the 12 month period following the date of first CD4 count. Analysis could not use ART as date of ART initiation is not currently collected.

The number of countries able to report complete fields for these was: first CD4 date 19; latest CD4 date 12; latest viral load date 16; latest attendance date 12. Of the 19 countries who could report first CD4 date, 6,123 records had first CD4 date reported. Of these only 30% had data available to allow measurement of retention in care; 70% could not be analysed as there was no data for the latest CD4, viral load or attendance dates. The results of analyses by country where retention could be generated are shown below for each of the three markers individually.



Overall rates of retention in care within 12 months are high when a combination of the three markers are used, but improve for some countries if the timeframe is extended to 18 months (see table below).

Retention in care within 12 months - overall



Country	A: % retained (denominator all linked to care)	B: % retained (denominator at least one latest marker reported)	C: % retained (denominator as B - extend to 18 months)
A	57%	57%	100%
B	94%	98%	98%
C	92%	96%	96%
D	99%	99%	100%
E	100%	100%	100%
F	100%	100%	100%
G	62%	75%	100%
H	79%	79%	100%
I	94%	94%	100%
J	77%	97%	99%
K	12%	50%	50%
L	89%	93%	93%
M	67%	67%	100%
N	38%	98%	98%
O	77%	83%	100%
P	80%	80%	100%

High rates of retention overall

Retention improves when with different denominator

% not retained were retained >12 months

Due to small numbers

The results highlight the importance of quality and completeness of data for calculation of retention in care and the need to acknowledge caveats when interpreting TESSy data to measure retention i.e. cross sectional analysis of a longitudinal concept.

Key points raised following these presentations were:

- The need for a clear, agreed definition of 'diagnosed', i.e. minimum laboratory criteria, given variations in the region, increasing numbers being tested in community settings and concerns about the extent to which all organisations providing testing services are reporting and referring.
- The possibility of using ART status to measure linkage and retention; this is not currently feasible as TESSy does not collect data on date of ART initiation. Inclusion of ART start date should be considered in the future.

6. Treatment, viral suppression and mortality

The session started with a keynote presentation from Manuel Battegay (European AIDS Clinical Society) on the need to increase collaboration between clinicians and public health professionals and support for clinicians, in order to improve patient care and public health data.

Despite progress, there are still too many new infections in Europe each year, too many people are undiagnosed or diagnosed late. Clinicians can play a critical role in reducing the undiagnosed fraction and late diagnosis and in ensuring that PLHIV start treatment as early as possible, with benefits for individual patients and for reducing transmission of HIV. More needs to be done to encourage and support routine

provider-initiated HIV testing and to promote indicator-condition guided testing and to improve clinical management of HIV. Clinicians also play a critical role in improving public health data, in particular through networks such as EuroCoord, which includes several of the largest HIV cohorts in Europe e.g. CASCADE, COHERE, EuroSIDA and PENTA. In addition, clinicians often detect new epidemics or trends before these are identified by surveillance, e.g. increased HCV among MSM.

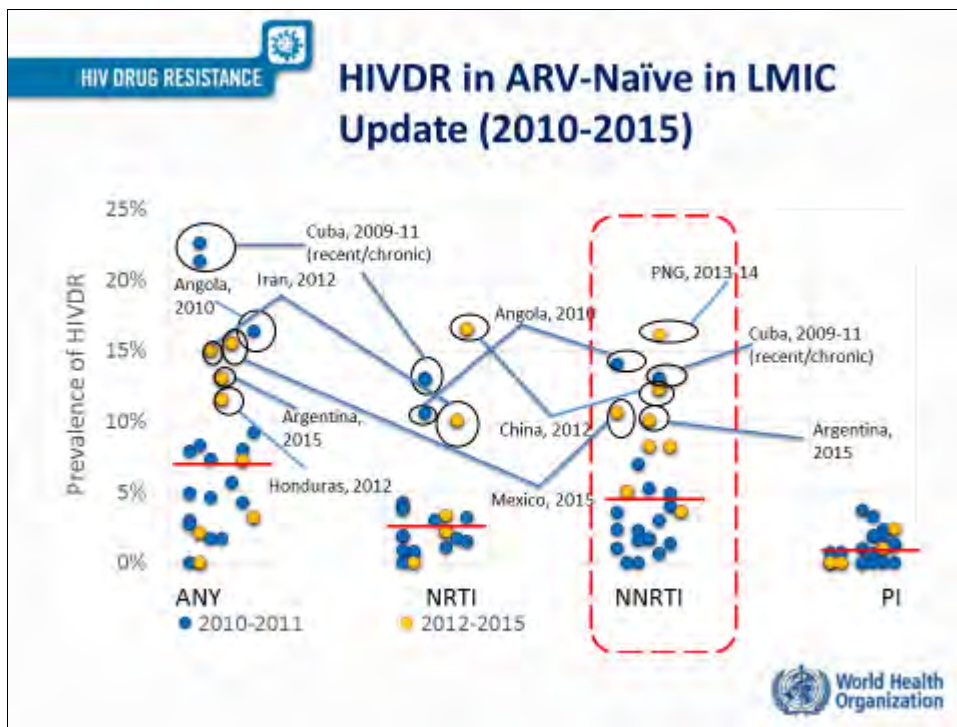
Ensuring that this role is maximised requires clinicians to be better supported and motivated, through clear and accessible guidance, education and training, which is available from EACS as well as other sources, through integration of services and support for successful team work within health care settings, through better communication between health authorities and health workers and feedback on analysis of data reported, and through better understanding of what motivates clinicians and provision of incentives to attract the best staff to work in HIV.

Key points raised following the presentation were:

- The need for a more integrated approach to service delivery is clear, given co-infections, e.g. with TB, HCV and other STI, and problematic drug use among some at risk of or living with HIV.
- The EACS could help to improve support to clinicians in the East of the region.

Michael Jordan (WHO) provided an overview of HIV drug resistance and the WHO global HIV drug resistance [surveillance strategy](#) and how HIV drug resistance and related programme factors can impact the continuum of care. Test and treat and use of PrEP will decrease HIV incidence but are, paradoxically, likely to contribute to an increase in HIV drug resistance among those who are infected. Resistance may be a consequence of incomplete viral suppression (in populations failing ART); resistance may also be the cause of incomplete viral suppression (if resistance existed prior to start of therapy). Globally most transmitted drug resistance is derived from populations failing ART who then transmit resistant virus to previously uninfected individuals.

The emergence of acquired and transmitted HIV drug resistance may compromise the success of HIV treatment; therefore efforts to measure and respond to drug resistance are critical to achieve sustained population level viral suppression. The figure below shows findings from 28 studies. Focusing on resistance to the NNRTI drug class, because of its greater clinical relevance and public health impact, there are studies with NNRTI resistance levels above 10% in populations naïve to treatment in several low and middle income countries (e.g. in Angola, Argentina, China, Cuba, Honduras, Mexico and Papua New Guinea).



Data from 26 European countries published in early 2016 by the SPREAD programme for HIV molecular surveillance, which has collected data from newly diagnosed HIV-infected patients in Europe since 2002, shows an overall prevalence of any class transmitted drug resistance of 10.1% (4.7% transmitted drug resistance to the NRTI class, 3.8% to the NNRTI class and 2.4% to the PI class). SPREAD data indicates that the prevalence of transmitted drug resistance in Europe has remained fairly stable from 2002 to 2010.

In response to concerns about drug resistance, WHO is leading efforts to develop a global action plan for HIV drug resistance, which encompasses generating evidence to inform policy, prevention and response to HIV drug resistance, strengthening laboratory capacity and research. WHO has also issued updated HIV drug resistance surveillance guidance, which recommends that ART scale up should be accompanied by routine HIV drug resistance surveillance, with surveillance activities integrated into routine monitoring and evaluation. WHO recommended HIVDR surveillance and monitoring activities include: monitoring clinic-level early warning indicators, and surveillance of pre-treatment and acquired HIVDR as well as HIVDR in infants infected with HIV. In certain circumstances when sufficient data are available to make nationally representative statements, routinely available program- (patient-level) data may be used.

The WHO early warning indicators emphasize nationally representative reporting of data. Ideally all clinics report data, but if this is not feasible then WHO recommends an approach whereby randomly sampled sites are progressively added year after year until all sites are reporting data.

Most people initiating ART will be naïve to ART but some will have been exposed e.g. those who are re-initiating treatment or who have had ART during pregnancy to prevent mother-to-child transmission. Surveillance of pre-treatment HIV drug resistance aims to provide a nationally representative estimate of the prevalence of HIV drug resistance in populations initiating ART in order to inform the choice of first-line regimens. WHO recommends this be done through surveys with an average sample size of around 400 and the survey is performed at 15-40 representatively sampled clinics. Surveillance of acquired HIV drug resistance or drug resistance as a result of treatment failure aims to provide a nationally representative estimate of viral suppression and inform the choice of second- and third-line regimens. Like the pre-treatment survey, the sample size is about 400, and the survey method is designed to assess resistance at two time points (12 months and more than 48 months). Surveys are designed to be

performed at 17-40 representatively sampled clinics. Countries are encouraged to implement pre-treatment and acquired resistance surveillance surveys at the same time and to repeat the surveys every 3 years.

Countries need to assess the extent to which it is feasible to use routine data, including less than ideal routine data. A framework for assessing representativeness of routine programme data is shown below. Key questions include what percentage is representative, what is an appropriate threshold or a percentage that is conditionally representative (see presentation for more detail).

HIV DRUG RESISTANCE

Considerations Around a Framework for Assessing Representativeness of Routine Programme Data

- Define goal of surveillance
 - E.g. inform second-line regimen selection
- Define target population
 - E.g. 1st line failure
- Define accessible population
 - E.g. 1st line failure
- Perform two assessments:
 - Quantitative: What proportion of the target population receives a routine VL and HIVDR test? (coverage of the measurement)
 - Qualitative: If coverage is not 100%, how different is the available dataset from the overall population of interest?

World Health Organization

Andrew Amato (ECDC) described the rationale for [HIV drug resistance surveillance in Europe](#) and requested feedback from Member States on how ECDC can support this. European data on newly diagnosed patients from 26 countries reported an overall prevalence of transmitted drug resistance of 9.2% in 2008–2010. During the same period, the number of new diagnoses with NNRTI-resistance mutations increased by 35%. This, and evidence presented at the 2016 Conference on Retroviruses and Opportunistic Infections, highlight the need to monitor HIV drug resistance in Europe.

Monitoring is essential to understand patterns of emergence and spread of transmitted and acquired drug resistance, to estimate the prevalence of resistance, and to inform treatment protocols. Combining existing data from Europe would allow better identification of resistance trends across Member States and provide a more robust evidence base for developing preventive interventions and treatment protocols. ECDC is considering how best to take forward monitoring and use of existing data and would welcome feedback from Member States about whether this should be done and, if so, how e.g. through case-based data, sentinel sampling or periodic surveys on pre-treatment resistance and acquired resistance results.

A quick voting exercise was held in order to solicit country feedback on HIV drug resistance (HIVDR) surveillance. The results below, suggest that there is a need to enhance drug resistance surveillance and related capacity in the region:

Does your country currently conduct surveys of HIV drug resistance or use routine surveillance or programme data for measuring HIV drug resistance?

- Yes, transmitted drug resistance 20%
- Yes pre-treatment HIVDR 6%
- Yes acquired HIVDR 6%
- Yes both pre-treatment and acquired HIV DR 29%
- No 37%

Does or would your country be able to conduct repeat pre-treatment and acquired HIVDR surveys every 3 years?

- Yes, only pre-treatment HIVDR 3%
- Yes, only acquired HIVDR 0%
- Yes both pre-treatment and acquired HIVDR 34%
- No 38%
- Unsure 25%

Do you agree that representative HIVDR data are needed to inform national policy?

- Strongly agree 51%
- Somewhat agree 31%
- Disagree 5%
- No opinion 13%

If HIVDR indicator data are derived from a non-representative sub-set of the eligible population, can these indicator results be reported as "national"?

- Yes 8%
- No as results may be biased 75%
- Don't know 11%
- Other 6%

To increase HIVDR survey uptake or use of representative routine HIVDR programme/surveillance/cohort data, who should be targeted for advocacy in your country?

- National ART programme director/public health authorities 62%
- Academics 5%
- National M&E 5%
- National laboratory 22%
- Other 5%

Cuong Chau (Public Health England) discussed the use of HIV surveillance data to monitor treatment, viral suppression and mortality. He focused on the findings of an analysis of new clinical variables (e.g. ART coverage, viral suppression) in the revised TESSy dataset to assess the quality of patient care within 12 months of diagnosis and use of this data to develop continuums of care using standard definitions for country comparison.

The analysis looked at the 2015 TESSy dataset in the revised format, included patients diagnosed in 2014, excluded patients reported to have died, and defined the stages of the 12-month continuum as follows:

- Total HIV infected – total diagnosed in respective year
- Engaged in care – marker of attendance (latest CD4 count and/or viral load and/or attendance date) available during the 12 month period following the date of diagnosis

- On treatment – ART reported as 'Y' at the last attendance
- Virally suppressed – Latest VL reported is <200/<1,000 within 12 months

As the table below shows, only 10 countries reported data on all of the six markers required to generate the continuum. Completeness of variables varied among the countries reporting for all six (first CD4 71%; latest CD4 72%; latest VL 66%; latest VL date 66%; latest attendance date 71%; ART 86%).

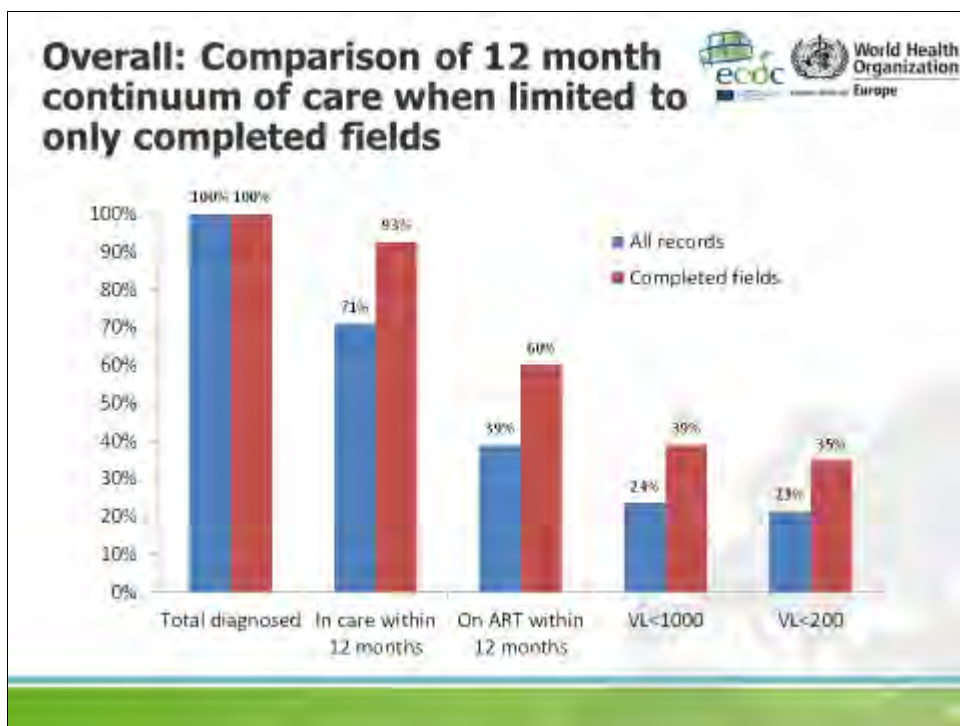
Results

Summary of the number of countries reporting data to inform the continuum of care

	Number of countries - 2014 diagnoses
Data reported in revised format	33
Date of diagnosis	32
Latest CD4 date	14
Latest Attendance	13
ART	18
VL Latest	20
VL Latest date	17
All 6 markers	10

Analysis on 2014 diagnoses by country for the 10 countries where the continuum could be generated showed a considerable a range for each marker: % in care within 12 months 51-87%; % on ART within 12 months 11-52%; % virally suppressed (<1,000) 6-52%; and % virally suppressed (<200) 2-46%. The percentages were higher when analysis was restricted to patients with complete data (see figure below). Country examples (see presentation) show where the break points are and that patients are lost at different stages of the continuum in different countries.

Completeness of records, specifically first and latest CD4, VL and attendance, is critical to be able to monitor the 12-month continuum of care. However, lack of completeness is a challenge e.g. viral load latest date was only 66% complete. Analysis of ART retention is not possible due to lack of data on ART initiation date. Reliance on latest CD4/VL/attendance also has challenges as historical cohorts with a diagnosis date more than 12 months before latest CD4/VL/attendance cannot be used, patients diagnosed towards the end of 2014 may not have had a latest CD4/VL/attendance reported and, of the 66% with complete VL latest date, 83% were within the 12 month window, further limiting the records that could be included in the analyses.



Analysis of mortality data showed that, in 2014, 37 countries reported deaths (1,585; 952 with full date) and 25 countries reported cause of death (1,246; 79%). The number of deaths in 2014 that were within 3 months of HIV diagnosis was 160 (19%) and within 12 months was 242 (29%).

Key conclusions were:

- The revised TESSy dataset can be used to inform the 12-month HIV continuum of care, but there are limitations that must be considered in interpretation.
- Analyses highlight the importance of data completeness.
- The continuum will be more complete and higher quality for the most recent year of diagnosis, but issues remain for those diagnosed towards the end of the year.
- Under-reporting of deaths may affect the continuum of care.

Following the presentations, participants divided into working groups to review: linkage to and retention in care definitions and measures; and case-based surveillance measures of the continuum of care including mortality. Key points from feedback from the working groups were:

Linkage to and retention in care

Considerations when interpreting TESSy data with regard to linkage to care and prompt linkage to care include:

- Need to reach consensus on definitions of care and linkage and the most appropriate indicators, though this may depend on the country and what is collected.
- Most useful measures are probably date of first CD4 or VL or attendance, but if first CD4 or VL is done at diagnosis this should not be interpreted as linkage to care.
- Need for common agreement on definition of prompt linkage to care, some agree that 3 months is an appropriate timeframe, others would prefer 12 months and measurement of any indication of linkage to care.
- Limitations due to inadequate supplies of diagnostic and laboratory tests at time of HIV diagnosis in some countries.

- Data availability, completeness, including standardised reporting within countries, and timeliness.
- The interpretation of missing data can depend on the data source i.e. missing data reported by clinical sources may be due to not reporting e.g. CD4.
- How to address:
 - Non-residents tested in a country, diagnoses made outside the country, migration shortly after diagnosis i.e. linked to care in another country
 - Patients who are re-linked to care after having been off of treatment
 - Anonymous testing and expanded testing outside of traditional settings (e.g. home testing, low threshold testing) which are not currently captured in TESSy.
- Exclude previous positive cases (ie transfer of care, persons previously diagnosed but newly migrated and reported in the country of report).
- Countries will need to review measures of linkage to care generated by ECDC/WHO.

Considerations when interpreting TESSy data on retention in care include:

- Need to collect first and last CD4 count dates for reporting period.
- Use of 12 month period when patients are in care for many years (ie more stable/adherent patients may have less frequent monitoring in some settings).
- Delays in entering data i.e. countries may submit data after 12 months.
- Relies on reporting by clinicians.
- Impact of migration.
- Logistical and resource implications of monitoring retention in care in surveillance.
- Lack of clarity about frequency of VL testing within 12 month period.
- More frequent visits may reflect problems with treatment rather than better quality of care or retention.
- Scope for collaboration with cohorts to monitor stages in the continuum after linkage to care.
- Focus on retention on treatment in line with GARPR reporting though this is not possible without a variable to measure the date of ART initiation.

Case-based surveillance measures of the continuum of care

Barriers to obtaining data on clinical variables (VL, ART etc.) among people diagnosed with HIV include:

- No national electronic databases and separation of epidemiological and clinical databases.
- Lack of cohorts or cohort-like structure in surveillance.
- Lack of unique identifiers.
- Workload for public health and clinical staff.
- Country guidelines vs. test and treat.

Feedback on suggested 12 month continuum measures included:

- The most important measures for countries and for the Region are the number of people living with HIV and the number who are virally suppressed.
- Definitions for the measures are relevant but collecting data may be challenging for some countries.
- Concerns about the feasibility of generating 12-month measures for people diagnosed in the preceding reporting year as (too) many will not reach 12 month from date of diagnosis
- Consider use of survey-based measurements and aggregate data measurements.
- For public health, higher viral load cut-offs than are used for individual clinical monitoring are acceptable (ie VL <200).

Mortality

There is considerable diversity between countries in terms of definitions used and data collected. For some countries, HIV/AIDS mortality is decreasing and, thus, surveillance focus on this is not a priority whereas in countries with high and increasing mortality, death surveillance remains important. Barriers to obtaining accurate and complete data on deaths among HIV and/or AIDS cases include:

- Delays in reporting deaths e.g. due to matching with the national death registry.
- Delays in verification of cause of death.
- Difficulties in linking between registries e.g. due to lack of unique identifier.
- Misclassification for incomplete notified cause of death.
- Lack of clarity about whether a case has died or left the country.
- Differentiating AIDS-related deaths from deaths due to other causes.
- Under-reporting e.g. only deaths in hospital.

Participants also made some general points including: raising concerns about whether proposals for additional reporting related to HIV care and treatment moves TESSy beyond surveillance; exercising caution in comparing data across countries; and allowing countries enough time to adapt to changes in reporting requirements. ECDC and WHO noted that more discussion and consultation with countries on the issues raised is required.

Andrew Amato and Martin Donoghoe closed the meeting by reiterating the importance of linking surveillance and clinical work and thanking the participants for productive and useful discussions as well as the ECDC and WHO technical and administrative staff who organised the meeting and the translators.

Annex 1: Programme

THURSDAY 10 MARCH	
08:30 – 09:00	REGISTRATION
<p>Session 1: Opening Chairs: Martin Donoghoe (WHO/Europe) and Andrew Amato (ECDC)</p>	
<p>Session objective: To provide a framework for the meeting discussion and an update on recent global and regional developments which impact HIV case surveillance</p>	
09:00 – 09:15	Welcome, scope, purpose, objectives (Martin Donoghoe and Andrew Amato)
09:15 – 09:45	Global HIV strategic information frameworks, data and trends (Txema Garcia Calleja, WHO HQ)
09:45–10:15	European HIV surveillance data and trends (Anastasia Pharris, ECDC and Annemarie Stengaard, WHO/Europe)
10:15–10:30	Discussion
10:30 – 11:00	COFFEE
<p>Session 2: Estimating the number of people living with HIV Chairs: Txema Garcia Calleja (WHO HQ) and Anastasia Pharris (ECDC)</p>	
<p>Session objective: To provide an update and share experiences on using case surveillance to estimate the number of PLHIV</p>	
11:00 – 11:20	Using Spectrum to develop HIV estimates in a European context (Mary Mahy, UNAIDS)
11:20 – 11:40	Using case surveillance to estimate the number of people living with HIV: the ECDC Modelling Tool (Chantal Quinten, ECDC)
11:40 – 12:10	Country experiences using Spectrum and the ECDC Modelling Tool to develop national HIV estimates: <ul style="list-style-type: none"> ▪ Georgia (Otar Chokoshvili) ▪ Greece (Georgios Nikolopoulos)
12:10 – 12:30	Questions and plenary discussion: experiences and next steps
12:30 – 13:30	LUNCH

Session 3: HIV TESTING	
Chairs: Lara Tavoschi (ECDC) and Lali Khotenashvili (WHO/Europe)	
Session objective: To explore ways to improve the measurement and effectiveness of HIV Testing in Europe and Central Asia	
13:30 – 14:00	Keynote presentation: How has HIV testing changed during the last decade and how should surveillance adapt to measure testing trends? (Jens Lundgren, CHIP)
14:00 – 14:20	Country presentations: How can measurements of HIV testing activities be improved? <ul style="list-style-type: none"> ▪ Estonia (Kristi Rüütel) ▪ Slovenia (Irena Klavs)
14:20 – 14:30	Discussion
Session 4: Measuring the number of people diagnosed with HIV	
Chairs: Annemarie Stengaard (WHO/Europe) and Shahin Khasiyev (Azerbaijan)	
Session objective: To review the performance of the revised record type currently in use	
14:30 – 14:45	Review of data from the 2015 HIV and AIDS data collection (Annemarie Stengaard and Anastasia Pharris)
14:45–14:55	HIV surveillance in Ireland: a timely system for timely trend analysis (Derval Igoe, Ireland)
14:55–15:05	Adjusting HIV data for reporting delay (Chantal Quinten, ECDC)
15:05–15:15	Introduction to group work topics on improved data interpretation and presentation (Annemarie Stengaard and Anastasia Pharris)
15:15 – 15:45	COFFEE
15:45 – 17:00	Working Groups
17:00 – 18:00	Feedback from working groups and plenary discussion
19:30	ECDC and WHO-hosted dinner (Crowne Plaza Hotel, Meeting room "Rome")

FRIDAY 11 MARCH	
Chairs: Teymur Noori (ECDC) and Ivana Bozicevic (WHO Collaborating Centre on HIV Surveillance)	
09:00–09:30	Keynote presentation: Challenges and developments in HIV surveillance, estimates and cascade measurements in the Canadian context (Claudia Rank and Kristina Tomas, Public Health Agency of Canada)
Session 5: Linkage to and retention in care	
Chairs: Ivana Bozicevic (WHO Collaborating Centre on HIV Surveillance) and Teymur Noori (ECDC)	
Session objective: To explore possibilities for measuring linkage to and retention in care using HIV case surveillance at European level	
09:30 – 09:50	OptTEST: monitoring linkage to care in Europe (Sara Croxford, OptTEST)
09:50 – 10:05	HIV surveillance data on linkage to and retention in care (Cuong Chau/Peter Kirwan, Public Health England)
10:05 – 10:20	Country perspectives on the measurement of linkage and retention

10:20 – 10:30	Questions and discussion
10:30 – 11:00	COFFEE
Session 6: Measuring treatment, viral suppression and mortality	
Chairs: Anastasia Pharris (ECDC) and Antonio Diniz (Portugal)	
Session objective: To review the performance of the revised dataset and future directions for improved data collection and analysis with regard to treatment, viral suppression and death	
11:00 – 11:30	Keynote presentation: Increasing collaboration of health authorities with clinicians - how to reach better public health data for HIV and how to support clinicians in their work (Manuel Battegay, EACS)
11:30 – 11:50	Global surveillance of HIV drug resistance: approaches and linkage with monitoring of the HIV continuum of care (Michael Jordan, WHO HQ)
11:50 – 12:00	Reflections on the surveillance of HIV drug resistance in Europe (Andrew Amato, ECDC)
12:00 – 12:15	HIV surveillance data on treatment, viral suppression and death (Cuong Chau/Peter Kirwan, Public Health England)
12:15 – 12:30	Introduction to working group topics (Annemarie Stengaard and Anastasia Pharris)
12:30 – 14:00	LUNCH
<i>13:30 – 14:00</i>	<i>Optional TESSy question and answer session (Russian and English language): TESSy helpdesk linked from Stockholm (Valentina Lazdina, Anastasia Pharris, Annemarie Stengaard, Shahin Khasiyev)</i>
14:00 – 15:15	Working Groups
15:15 – 15:30	COFFEE
15:15 – 16:00	Feedback from working groups and plenary discussion
Session 7: Summary and closing	
Chairs: Martin Donoghoe (WHO/Europe) and Andrew Amato (ECDC)	
16:15 – 16:45	Plenary summary discussion: priorities and future ambition for European level surveillance, analysis and reporting
16:45 – 17:00	Summary and closing

Annex 2: List of Participants

Nominated country experts

Name	Country
Marjeta Dervishi	Albania
Trdat Grigoryan	Armenia
Alexander Spina	Austria
Farhad Singatulov	Azerbaijan
Anna Rusanovich	Belarus
André Sasse	Belgium
Ljubica Jandric	Bosnia and Herzegovina
Sanjin Musa	Bosnia and Herzegovina
Tonka Varleva	Bulgaria
Tatjana Nemeth Blažić	Croatia
Vratislav Němeček	Czech Republic
Marek Malý	Czech Republic
Susan Cowan	Denmark
Kristi Rüütel	Estonia
Kirsi Liitsola	Finland
Florence Lot	France
Ana Aslanikashvili	Georgia
Otar Chokoshvili	Georgia
Barbara Gunsenheimer-Bartmeyer	Germany
Viviane Bremer	Germany
Georgios Nikolopoulos	Greece
Ágnes Csohán	Hungary
Guðrún Sigmundsdóttir	Iceland
Derval Igoe	Ireland
Daniel Chemtob	Israel
Barbara Suligoj	Italy
Lolita Ganina	Kazakhstan
Aigul Solpueva	Kyrgyzstan
Saulius Caplinskas	Lithuania
Alma Cicic	Montenegro
Eline Op de Coul	Netherlands
Hans Blystad	Norway
Magdalena Rosińska	Poland

Antonio Diniz	Portugal
Silvia Stratulat	Republic of Moldova
Mariana Mardarescu	Romania
Natalia Ladnaia	Russian Federation
Danijela Simic	Serbia
Danica Staneková	Slovakia
Peter Truska	Slovakia
Irena Klavs	Slovenia
Maria Asuncion Diaz Franco	Spain
Maria Axelsson	Sweden
Martin Gebhardt	Switzerland
Zukhra Nurlyaminova	Tajikistan
Zarko Karadzovski	The former Yugoslav Republic of Macedonia
Emel Özdemir Şahin	Turkey
Fusun Civil Karaşahin	Turkey
Ogulmenli Orunova	Turkmenistan
Iryna Chybisova	Ukraine
Ihor Kuzin	Ukraine
Violeta Martsinovska	Ukraine
Andrew Skingsley	United Kingdom
Ramil Gareev	Uzbekistan

Consultants, Guests, Observers and Speakers

Name	Affiliation
Adam Bourne	London School of Hygiene & Tropical Medicine
Amanda Mocroft	University College London
Annabelle Gourlay	University College London
Ard Van Sighem	Stichting HIV Monitoring
Charles Vitek	CDC Ukraine
Claudia Rank	Public Health Agency of Canada
Cuong Chau	Public Health England
David Kokiashvili,	The Global Fund
Georgia Vourli	Athens University Medical School
Gisela Leierer	Medical University of Innsbruck, Department of Dermatology and Venereology
Irina Savtchenko	UNAIDS
Isabelle Giraudon	EMCDDA

Name	Affiliation
Ivana Bozicevic	WHO Collaborating Centre for HIV Surveillance
Janusz Janiec	National Institute of Public Health Poland
Jens Lundgren	Centre for Health and Infectious Disease Research
Kathy Lowndes	Consultant Scientist
Kathy Attawell	Meeting Rapporteur
Kristina Tomas	Public Health Agency of Canada
Luis Mendao	Civil Society Forum on HIV/AIDS
Luljeta Gashi	Kosovo *
Manuel Battegay	University Hospital Basel/EACS
Michael Jordan	WHO HQ consultant Tufts University Boston
Nikos Pantazis	Athens University Medical School
Nino Mdivani	The Global Fund
Peter Kirwan	Public Health England
Roksolana Kulchynska	CDC Ukraine
Ruslan Malyuta	UNICEF
Sara Croxford	Public Health England
Sean Howell	Hornet Gay Social Network
Shahin Khasiyev	Ministry of Health, Department of Health Statistics and Informatics
Sini Pasanen	Civil Society Forum on HIV/AIDS
Vasileia Konte	Hellenic Centre for Disease Control and Prevention
Velina Pendolovska	European Commission

ECDC Staff

Name	Affiliation
Andrew Amato	ECDC
Otilia Mårdh	ECDC
Gianfranco Spiteri	ECDC
Anastasia Pharris	ECDC
Teymur Noori	ECDC
Chantal Quinten	ECDC
Lara Tavoschi	ECDC

* In accordance with UNSCR 1244 (1999).

Joanna Syczewka	ECDC
-----------------	------

WHO Regional Office for Europe and Headquarters

Name	Affiliation
Martin Donoghoe	WHO Regional Office for Europe
Lali Khotenashvili	WHO Regional Office for Europe
Annemarie Stengaard	WHO Regional Office for Europe
Bente Drachmann	WHO Regional Office for Europe
Txema Garcia Calleja	WHO Headquarters

Interpreters

Name	Affiliation
Georgy Pignastyy	Interpreter
Elena Gornaya	Interpreter