

## HIV data

### Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia – 2014 progress report

#### Dublin Declaration

This ECDC evidence brief summarises key issues and priorities for action in Europe. It draws on country data reported to ECDC for Dublin Declaration monitoring and UNAIDS global reporting in 2012 and 2014 and surveillance data reported by countries to ECDC and WHO Europe since 2004.



Following ECDC's 2010 and 2012 progress reports, a new series of thematic reports and evidence briefs present the main findings, discuss key issues, and assess the progress made since 2012 in Europe's response to HIV.

#### What are the concerns about HIV data?

Good data are essential for effective public health planning and action. Lack of critical HIV data weakens the ability of countries across the region to plan, implement and monitor their responses to the epidemic. Three strategic areas are particularly problematic:

- State of the epidemic (e.g. HIV incidence, HIV prevalence, co-infections)
- State of the response (e.g. testing uptake, late diagnosis, treatment access, adequacy and tracking of funding, efficacy of interventions)
- Key populations (e.g. demographics, risk behaviours, factors that influence risk and uptake of services, subpopulations at increased risk, overlapping risk behaviours)

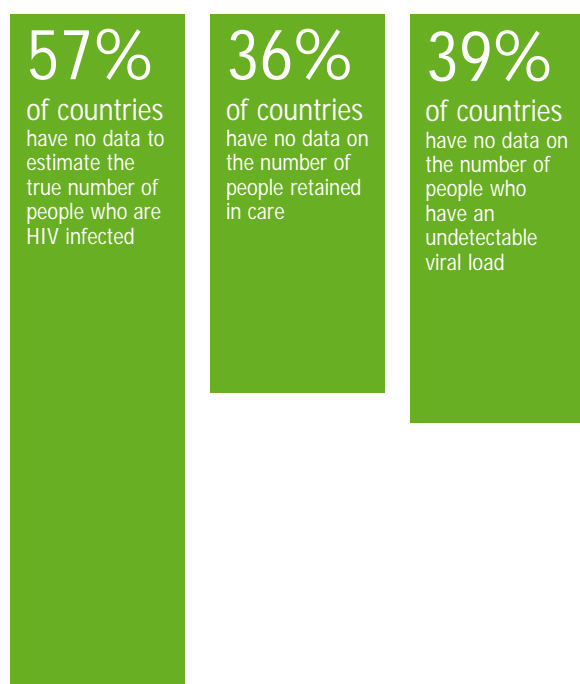
With HIV and health budgets under pressure and an increasing focus on evidence-based decision-making, high-quality data on these aspects of the HIV situation are essential.

#### What are the main challenges in Europe?

##### Data availability

**Data required for evidence-based decision-making are often not complete.** Multiple rounds of reporting on the implementation of the Dublin Declaration have highlighted significant and wide-ranging gaps in the data that are available in countries for use in tracking and improving their HIV response. Many of the gaps revolve around the populations that are most affected by HIV, including men who have sex with men (MSM), migrants, people who inject drugs, and sex workers. The gaps are even more significant for subgroups of these populations who are at the greatest risk of acquiring or transmitting HIV. In addition, a high percentage of countries in the region report major data gaps related to key aspects of the continuum of HIV care: 57% do not have data to estimate the true number of people who are HIV infected; 36% do not have data on the number of people retained in care; and 39% do not have data on the number of people who have an undetectable viral load.

**Figure 1: Missing crucial data on HIV in EU/EEA countries**



**There is a significant lack of behavioural data for key populations.** Few countries in the region report having current and representative behavioural data that can be used to improve key aspects of the response, particularly the targeting of prevention programmes. For example, only 10 EU/EEA countries report having data on risk behaviours in MSM subgroups at increased risk of HIV infection; only seven countries report having data on risk reduction behaviours among MSM; and only five countries have data on both risk behaviours and risk reduction behaviours.

**Behavioural data to capture changing patterns of risk behaviour are not collected on a regular basis.** The findings of the 2010 comprehensive European MSM Internet Survey (EMIS)<sup>1</sup> provided valuable insights. However, the survey has not been repeated, so the data are now five years old. No similar regional or large-scale surveys for other key populations have been conducted in recent years.

**Most countries are not able to estimate the percentage of HIV funding allocated to prevention or treatment.** Only 41% of the countries in the region can estimate the percentage of HIV funds allocated to prevention; only 48% can estimate the percentage allocated to treatment. If countries want to improve the efficiency and cost-effectiveness of their HIV responses, they need more robust mechanisms to monitor how funds are allocated and spent.

**There are limited data in a wide range of programmatic areas.** These areas include coverage, uptake, performance, effectiveness, and

impact of HIV services. For example, only four countries report having data on the number of cases detected by HIV testing services in MSM subgroups at increased risk of HIV infection. Better monitoring can improve data on some aspects of services, but addressing more than just a few gaps will require a long-term commitment to special studies, rapid assessments, and formal evaluations.

**Table 1. Percentage of EU/EEA countries reporting critical data gaps on the uptake of HIV testing among key populations**

Percentage	Key population
46%	MSM overall
71%	MSM subgroups at increased risk of HIV infection
71%	Migrants in general
80%	Undocumented migrants

## Data comparability

**Data on the same topics are collected differently in different countries, which makes it difficult to compare findings.** The various programmes, projects and studies within a country have different strategies, protocols and approaches for collecting data. Variations in data collection methodology, time frame, sample size, number of sites, location, disaggregation, terminology, and other factors make it difficult to compare data across countries as well as over time.

**Data that may seem comparable can be misleading when aggregated.** Data from different countries on the same topic may at first seem comparable, particularly if no contextual data are presented. For example, many countries report data on the availability and accessibility of HIV testing among MSM; these data are collected in different ways, with different population sample sizes, over different time frames, and in different locations/facilities. As a result, the aggregation of these data may not accurately portray the situation across the region.

## Data quality

**There are no agreed HIV data quality standards in Europe.** There is growing recognition in the region that data quality needs to improve if data are to be useful in informing and improving national responses to HIV. For example, a lack of standards can lead to concerns about the accuracy and credibility of the data, which makes it difficult to assess the performance of programmes and projects. In addition, concerns about the quality of the data can reduce their influence on policymakers and programme planners. Inconsistent data quality in the region also limits the ability to accurately compare data across countries, which makes it more difficult to share lessons learned.

<sup>1</sup> The EMIS Network. EMIS 2010: The European Men-Who-Have-Sex-With-Men Internet Survey. Findings from 38 countries. Stockholm: European Centre for Disease Prevention and Control, 2013.

## Data utility

**Shared data can provide invaluable lessons on the strengths and weaknesses of different interventions.** The ability to learn from national experiences is compromised by the lack of a systematic approach to sharing compatible data on the performance of HIV interventions. While countries do share data on a limited, *ad hoc* basis, there is a significant opportunity to capitalise on the utility and value of data on interventions by developing robust systems to share these data. (Sharing data on the performance of HIV interventions must not violate laws and policies related to the confidentiality of patient data.)

## What needs to be done?

Decision-makers need data that are meaningful and useful. Given the limited resources available in most countries for monitoring national HIV programmes, the priority should be to **collect quality data that are meaningful and useful** for understanding the situation and improving the response.

**Data for reporting to international organisations should be drawn from existing national datasets.** Initiatives to compel countries to collect data solely for reporting purposes should be reduced or eliminated. In a time of limited financial and human resources, international organisations should focus on identifying, requesting and using data points that are also relevant to the reporting country.

**Identify and address priority gaps in data about populations and programming** that limit the ability to make sound, evidence-based decisions on the response to HIV. Reporting on the implementation of the Dublin Declaration indicates that several areas are affected: there are, for example, substantial data gaps in behavioural data on population subgroups at heightened risk of infection. Further gaps exist in crucial programme areas, e.g. in uptake of testing, late diagnosis, and ART adherence/retention.

**Collect periodic behavioural data on key populations** to better inform the HIV response. The 2010 EMIS study clearly demonstrated the value of an innovative approach to collecting behavioural data in the region. Since the survey was completed, countries have continued to use the data to understand the epidemic among this population and refine their response. A commitment to periodic surveys which collect behavioural data on key populations would provide countries with much-needed information on risk behaviours, risk reduction behaviours and factors that limit uptake of prevention, testing and treatment services. There is a parallel opportunity to develop and agree on basic standards and protocols for collecting behavioural data that will help ensure the quality and comparability of data in the region. Opportunities for countries to collaborate should also be explored as a means to cost-effectively collect and analyse high-quality data.

**Agree on pragmatic approaches to improve the quality and comparability of data** on the HIV response. There is a pressing need to develop and agree on monitoring and evaluation guidance to help countries align their data collection strategies, protocols and approaches. This guidance would improve the quality and comparability of HIV data in the region. The guidance should include metrics for collecting behavioural data among key populations as well as information on data quality standards and quality assurance tools to ensure the overall integrity of the data.

**Improve systems for sharing data on programme performance** between countries and across government and civil society. This would help ensure that key stakeholders have access to critical data, which would strengthen their understanding of the situation and improve planning, budgeting and implementation.

**Focus on collecting data that can and will be used.** Countries across the region have limited resources to collect and analyse data on the HIV situation. Consequently, it is essential for countries to focus on collecting and analysing data that are directly applicable to understanding the situation and improving the response. International requests for national data should not be a reporting burden for countries. International organisations should harmonise and minimise their requests for data (e.g. coordinated, biennial reporting cycles) and they should use existing data whenever possible. In addition, they should recognise and respect the importance of national and regional relevance when requesting and using data.

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