European Monitoring Centre for Drugs and Drug Addiction

An overview of the drug-related infectious diseases (DRID) key indicator

Summary

- This key indicator collects data on the extent of infectious diseases — primarily HIV, hepatitis B and hepatitis C — among injecting drug users (IDUs).
- Data should preferably be collected from people who have injected drugs at least once in the last 12 months ('recent IDUs') and be reported by calendar year. However in practice many data relate to 'ever-IDUs' i.e. any person who has ever in their lifetime injected a drug for non-medical purposes. Data should be collected on the proportion infected — prevalence — from either surveys of injecting drugs users or from diagnostic testing of injecting drug users.
- Data on case reports of diagnoses, such as data from notification systems, are also collected.
- The EMCCDA collaborates closely with the EU Member States and other agencies to collect these data in Europe and has produced guidance on how this can be done in the most valid, reliable and comparable way.

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About this document

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Introduction to the indicator

Overview

This document summarises the nature of European Union (EU) level surveillance of drug-related infectious diseases by describing the general context, purpose and activities of the EMCDDA’s key indicator (KI) on drug-related infectious diseases (DRID). It provides a concise overview of the indicator and the associated guidelines for monitoring human immunodeficiency virus (HIV), hepatitis B virus (HBV) and hepatitis C virus (HCV) in injecting drug users (IDUs) at EU level. The focus of this key indicator is to obtain reliable and comparable measures of HIV, HBV and HCV infection among IDUs, and in particular measure trends in the proportion infected over time.

The DRID KI has been developed over a number of years through a gradual evolution of data collection in collaboration with the national focal points. This development has focused on improving the comparability, timeliness, quality and coverage of the data collected on HCV, HBV and HIV among IDUs in the EU.

Context

Drug-related infectious diseases are one of five key epidemiological indicators used by the EMCDDA to monitor drug use and its health consequences. The implementation of the EMCDDA’s five KIs is supported by resolutions of the Council of the EU and they are key to informing the actions in the EU drug strategy. The EMCDDA has collaboration agreements with the ECDC and WHO on the collection of data on infectious disease among drug users in the Europe.

Infectious diseases are among the most serious health consequences of injecting drug use, and can lead to important healthcare costs. IDUs can act as a 'core group', or pocket of infection, that may pose a risk of spread to the general population. The key infections among IDUs that are monitored by the EMCDDA are HCV, HBV and HIV, which are the main causes of the infectious disease burden related to injecting drug use in the EU. This burden reflects a range of costs to the individual and society, including those related to healthcare and treatment, which result from adverse impacts of these infections.

Background information

Injecting drug user (IDU):
IDUs are the target group for measuring prevalence of drug-related infections. They are defined as any person who has ever in their lifetime injected a drug for non-medical purposes. In practice, almost all data on IDUs collected by the EMCDDA relate to ‘ever injectors’ among active drug users who are in contact with drug services. However, discussions are ongoing on how to further define the data collection (see Draft DRID protocol) and for monitoring purposes data might preferably be collected from people who have injected drugs at least once in the last 12 months (‘recent IDUs’).

Human immunodeficiency virus (HIV): Transmission of HIV through injecting drug use was recognised early in the HIV epidemic at the beginning of the 1980s. HIV can be very easily transmitted by injecting drug use and explosive outbreaks of HIV infection among IDUs have occurred worldwide. HIV infection results in damage to the immune system usually over a period of many years. This damage leads to AIDS and, if untreated, eventually to premature death. HIV cannot be cured, but treatment using combinations of anti-viral drug can prevent progression of the illness.

Hepatitis B virus (HBV): In Europe HBV infection is usually acquired in adulthood, with sexual activity or injecting drug use being the most commonly reported routes of infection. Infection with the HBV typically causes a debilitating acute infection lasting many months, with a small number of those infected going on to develop chronic disease. Infection with HBV is preventable using a safe and effective vaccine.

Hepatitis C virus (HCV): This is currently the most important infectious disease affecting those who inject drugs, with very high prevalence having been reported among IDUs in many countries. Up to four-fifths of those acquiring hepatitis C may go on to develop chronic infection, and are then at risk of developing cirrhosis and liver cancer. The recent development of more effective anti-viral therapies means that the infection can now be treated, however the treatment dose not work for all, and outcomes are particularly poor with some types of the virus.

Purpose of the key indicator

Purpose

The purpose of this key indicator is to obtain valid, reliable and comparable measures of HIV, HBV and HCV infection among drug users, and in particular: (a) to measure levels of infection (prevalence) in IDU populations and key sub-groups; and (b) to monitor trends over time (increases or decreases in prevalence) among these groups. This is to inform identification of priorities for preventing further infections, for forecasting healthcare needs and costs, and for monitoring the impact of preventive interventions. Key sub-groups are young or new IDUs as changes in prevalence among these is often a reflection of changes in the rate of occurrence of new infections (incidence) among IDUs overall. The EMCDDA data on prevalence of HIV and hepatitis B and C infection among IDUs are complemented by case reports or notifications of diagnosed cases of infection in IDUs that are also collected by the Member States.

In addition, the data can be used to generate indirect estimates of the incidence, prevalence and trends in drug injecting (see the EMCDDA key indicator on problem drug use).

Development

To achieve these purposes a robust indicator which can permit the monitoring of geographic and temporal differences is required. The continuing development of this indicator has thus focused on ensuring more valid, reliable and comparable monitoring of HCV, HBV and HIV in IDUs at both EU and national levels.

This development started with the formulation of draft guidelines and an Excel data collection tool (‘standard table 9’) around the year 2000, and has continued through annual expert meetings and the recent production of a more detailed protocol for the DRID indicator. The indicator will continue to evolve further so as to reflect changing patterns of infectious diseases among IDUs, which may include future data collection on other infections, such as hepatitis A, tuberculosis (TB), wound botulism and sexually transmitted infections (STIs).

A recent development is the piloting of the collection of key behavioural data related to infection risk and protective factors from surveys and other studies, in line with WHO guidance on Second Generation HIV surveillance.

Method

Overview

The collection of data at EU level has focused on compiling existing national data (or sub-national data) that is recent, and as representative as possible on the levels of HCV, HBV and HIV infections among IDUs.

Geographic and sub-group breakdowns are sought as well. This data is collected through the Reitox national focal points.

The EMCDDA currently aims at collection of EU-level monitoring data on the prevalence of infection (proportion infected) with HCV, HBV, and HIV among IDUs. Case reports of HIV, HBV and HCV diagnoses and data on AIDS cases are collected by the ECDC and WHO. All these data will be shared between the agencies to avoid double reporting and duplication of efforts and to make the best use of the data.

The EMCDDA has developed draft guidelines and a standard data reporting tool (previously an Excel form called ‘standard table 9 (ST9)', now implemented in an online data collection system named ‘Fonte’) which the national focal points use to collect the prevalence data.

Data from prevalence studies, when compared to that from case report sources, is often more informative as the studies have usually been specifically designed to look at IDU populations, thus providing IDU specific prevalence data. They also tend to be more useful because they include information on recent and undiagnosed infections, and prevalence studies can more easily provide behavioural data. The data from studies, however, often lack national coverage and can also have poor continuity over time as a result of studies being resource-intensive to carry out.

Data that are collected through case reporting systems, such as HIV case reports or notifications of cases of HBV and HCV, usually have good geographic coverage. These can have limitations, in particular, there can be data quality issues, such as limited or incomplete information on the most likely exposure risk (transmission category). Whilst these often provide data that gives a good insight into the extent of diagnosed infection in the population, they may have more limited use in providing data on the total prevalence of infection, this may be particularly a problem where uptake of the diagnostic tests among IDUs is low (under diagnosis) or diagnosed infections are often not reported (under reporting) or reported with a delay (reporting delay). For example, in the case of hepatitis B and C, a very large proportion of new infections are asymptomatic, thus notifications of diagnosed cases provide a very large underestimation of the real incidence of infection.

The data provided to the EMCCDA is aggregated population level prevalence data, however, the actual systems providing these data will involve collecting information from individuals. It is thus important to ensure that these systems operate in an ethically acceptable way. For example, whilst informed consent is usually not required for notification and anonymous laboratory based systems, it will be needed for most studies. For all systems, ethical and data protection issues must be addressed with in the appropriate national polices and international guidelines.

A key issue for studies among IDUs is their representativeness. Due to the illicit nature of drug use there is limited information available on the size and characteristics of drug using populations. As a result, it is not possible to use probability approaches to produce sampling frames. Thus, studies of IDUs have made

extensive use of non-probability samples as they are often found to be the most pragmatic way to sample 'hard-to-reach' groups. There are number of such sampling approaches (e.g. time-location sampling, respondent-driven sampling, sampling through representative/sentinel services, etc.) and the approaches used should always be reported to help interpretation. Whilst well-designed surveys of IDUs will provide the most robust data, monitoring of diagnostic testing can also provide reliable data where routine annual testing is widely offered. Diagnostic testing data can underestimate prevalence as those with a known previous diagnosis are usually not re-tested, however, trends over time may still be valid indicators for trends in true infection rates (incidence).

The EMCDDA recommends that the DRID data should at least include samples from both drug treatment and other settings, where the other settings should minimally include data from low-threshold services (see the DRID template in Fonte).

As the representativeness of these sampling approaches is uncertain, results should be interpreted cautiously, and inter-study comparisons made with great care. However, even though there may be concerns about representativeness, repeated surveys which consistently use the same sampling approach can produce informative data on trends. The interpretation of trends may be improved if data are available from different settings in the same geographic area.

The size of the sample recruited is also important. For example, small samples my not detect relatively rare events, such as HIV infections in low prevalence settings, and will result in wide confidence intervals around prevalence which may make trends difficult to see.

Protocol

A draft protocol was produced in late 2006 (protocol for the implementation of the EMCDDA key indicator: drug-related infectious diseases (DRID)). The main purpose of the protocol is setting out objectives and detailed processes for the monitoring of infectious diseases and risk and protective behaviours among drug users focusing on those who inject.

The protocol aims to improve data quality and comparability from existing routine sources and from studies by setting out a detailed framework for these so as to permit comparable European-wide data collection. In relation to prevalence studies among IDUs it also provides a core list of data items, plus an additional list of optional data items, which is as far as possible compatible with ongoing studies already being undertaken by EU countries. It provides information on appropriate sampling approaches, suitable study designs, and biological sample collection and testing, as well as information on ethical and data protection issues.

Standards

A number of standards have been set for reporting DRID data — these are detailed in the DRID template ('standard table 9', consisting of four parts) in Fonte. These minimum requirements were first formulated at the 2001 EU expert meeting on DRID. Below is a summary of the key issues.

Reporting period

Data should, where possible be reported by calendar year. The main focus of each annual data collection request is the addition of the previous year's data. Previously provided data doesn't need to be resubmitted, unless there are adjustments.

Minimum reporting requirements: 'core implementation'

Prevalence data:

- Data on samples of injecting drug users ('ever' injectors, or — preferably — those injecting in the last 12 months).
- Prevalence of HCV and HIV in the reporting year:
    - survey data from drug treatment and non-treatment settings, and/or
    - monitoring of diagnostic testing data (treatment and other settings).
- National level data, with breakdown by regions or main cities.
- Data on new injectors and young injectors

Data on notified/reported cases:

- national HIV case reports should be reported through the ECDC/WHO-Europe. Notifications/reports of HCV and HBV cases regarding IDUs are still collected by the EMCDDA but they will in the near future be obtained through the ECDC.

Minimum sample thresholds

Overall samples sizes, which should be provided by appropriate sample size calculations, should be 100 or larger. However, if this is not possible, samples of 50 or larger are accepted. Prevalence data will be accepted for sub-groups if the sub-group sample size is 10 or greater, though ideally sub-group sample size should be much larger than this. To overcome small sample sizes, data from adjoining years may be combined by the EMCDDA in its reports. Information on representativeness of the sample should also be provided.

Notification data and laboratory reporting data should be reported, regardless of the total number (unless local ethical issues or data protection rules prevent this). However, breakdowns of this total should not be reported if the total is less than 10 or if any cell is less than five.

Data collection tool

Until 2007, EMCDDA collected data on DRID using ST9 (www.emcdda.europa.eu/?nnodeid=1375). In 2008, ST9 was replaced by a special template within Fonte. This system is a web-application with a linked (centralised) database. The submission of data is done through logging on to a special internet site. A complete data editing process is built into the system and the retrieval of the data is done using standard or ad hoc queries. Validation of data is done inside the application and there will be some automatic validation procedures. The special template ST9 in Fonte has the same structure as the previous Excel form ST9. See www.fonte.emcdda.europa.eu. The ECDC has separate mechanisms for collecting the case reporting and notifications data, through their online application system ‘TESSy’ www.ecdc.europa.eu.

Outputs

EMCCDA publishes DRID data in its Annual report on the state of the drugs problem in Europe, and the associated Statistical bulletin. This publication gives an overview of the key indicator at an EU level and explores variation in the levels of DRID within the EU. There are also ad hoc publications. See www.emcdda.europa.eu.

Implementation of DRID in the EU Member States

The EMCDDA regularly assesses the level of implementation of the DRID indicator in the EU Member States.

Key references:

EMCDDA documents on improving comparability — drug-related infectious diseases:

1. PDF copy of standard table 9 templates

2. EMCDDA DRID protocol draft, October 2006.

3. Draft guidelines key indicator: drug-related infectious diseases (EMCDDA 2001).

To access these resources, see the online DRID toolbox available at www.emcdda.europa.eu/themes/key-indicators/drid.

WHO and UNAIDS documents:

1. Guidelines for second-generation HIV surveillance.

2. Initiating second generation HIV surveillance systems: practical guidelines.