

**Document: EMCDDA/7/01**

**EMCDDA recommendations on the 5 harmonized key indicators**

**Five key epidemiological indicators:  
Recommended draft technical tools and guidelines**

Improvement of data comparison methods is a core task of the EMCDDA defined in Article 2 of its founding Regulation: “.. the Centre shall: ... ensure improved comparability, objectivity and reliability of data at European level by establishing indicators and common criteria of a non-binding nature, compliance with which may be recommended by the Centre, with a view to greater uniformity of the measurement methods used by Member States and the Community”.

The European Union Action Plan on Drugs 2000-2004, endorsed by the Santa Maria de Feira European Council in June 2000, states (chapter 2.1): “**The Member States according to technical tools and guidelines provided by EMCDDA to give reliable information on the five key epidemiological indicators in a comparable form drawn up by the EMCDDA and adopted by the Council:**

- 1 extent and pattern of drug use in the general population
- 2 prevalence of problem drug use
- 3 demand for treatment by drug users
- 4 drug-related deaths and mortality of drug users
- 5 drug-related infectious diseases (HIV, hepatitis)”

The technical tools and guidelines are to be provided by the end of 2000.

As foreseen in its Regulation and as required by the EU Action Plan, this document provides the EMCDDA’s recommended draft technical tools and guidelines (in annex) for Member States to give reliable information on the five key epidemiological indicators in a comparable form. The guidelines were approved by the Scientific Committee in the favourable opinion given at its meeting in Lisbon, 11-12 December 2000.

**Draft decision**

The Management Board of the EMCDDA adopts the draft technical tools and guidelines on the five key epidemiological indicators annexed to this decision as non-binding recommendations from the Centre to the Member States and the Community. In so doing, the Management Board affirms that these recommendations provide the basis for implementing the five key epidemiological indicators in the Member States and for reporting core data to the EMCDDA in comparable form. In line with the EU Action Plan, it also notes that it is important that the Member States and the EMCDDA, within existing financial limits, ensure that the National Focal Points have the necessary political and financial support regarding implementation of the five harmonised indicators.

Adoption of these draft technical tools and guidelines does not commit Member States to specific mechanisms for collecting and reporting data - these will depend on circumstances in Member States and on developments in information exchange systems at EU level. It is also recognised that the draft tools and guidelines may need to be adjusted in the light of experience and in order to take account of changes in the drug phenomenon and of new information requirements arising from the EU Action Plan.

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## Five key epidemiological indicators:

### Recommended draft technical tools and guidelines

#### 1. Context

##### 1.1 Objective and tasks of the EMCDDA

The EMCDDA was established by Council Regulation<sup>1</sup> in 1993 and became operational in 1995. The Centre's objective<sup>2</sup> is to provide the Community and its Member States with objective, reliable and comparable information at European level concerning drugs, drug addiction and their consequences. The information is intended to help provide the Community and the Member States with an overall view of the drug phenomenon when, in their respective areas of competence, they take measures or decide on action.

To achieve this objective, the Centre is required to collect, analyse, compare and disseminate information at EU level, and in particular to:

“ensure improved comparability, objectivity and reliability of data at European level by establishing indicators and common criteria of a non-binding nature, compliance with which may be recommended by the Centre, with a view to greater uniformity of the measurement methods used by the Member States and the Community.”<sup>3</sup>

##### 1.2 European Union Drugs Strategy (2000-2004)

###### *Information role of EMCDDA*

The EU Drugs Strategy (2000-2004)<sup>4</sup> was noted by the Helsinki European Council in December 1999<sup>5</sup>. This provides the framework for EU drug-related activities over the next five years and covers principles, objectives and the main characteristics of actions to be undertaken at all levels. In particular, it defines a set of general aims, including Strategy aim 8:

“To ensure collection, analysis and dissemination of objective, reliable and comparable data on the drugs phenomenon in the EU with the support of EMCDDA and Europol.”<sup>6</sup>

<sup>1</sup> Council Regulation (EEC) No 302/93 of 8 February 1993 on the establishment of a European Monitoring Centre for Drugs and Drug Addiction

<sup>2</sup> op cit. Article 1: Objective

<sup>3</sup> op cit. Article 2, para, B, Improvement of data-comparison methods, point 6.

<sup>4</sup> European Union Drugs Strategy (2000-2004), 12555/3/99 CORDROGUE 64 REV3, 1 December 1999.

<sup>5</sup> Presidency Conclusions, Helsinki European Council, 10 and 11 December 1999, SN 300/99, para 53.

<sup>6</sup> op cit. chapter III, The principles and objectives of the EU Drug Strategy (2000-2004), point 8.

The reason for this is that the strategy “has to be based on a regular assessment of the nature and magnitude of the drugs phenomenon and its consequences ...

“... It is the task of the EMCDDA to collect, analyse, compare and report existing data on the drug phenomenon. It is of the utmost importance to ensure that the highest quality of information flows to it and from it.”

The Strategy goes on to propose a list of actions, including:

1. Improving comparability of data is a central task of the EMCDDA. The national focal points will play a central role in this respect.
2. Progressive harmonisation of key epidemiological indicators on the prevalence and health consequences of drug use is needed.
3. National authorities should reinforce their commitment to this challenge with political and institutional support.”<sup>7</sup>

### *Strategy targets*

The Strategy also identifies six main targets for the next five years<sup>8</sup>.

1. To reduce significantly over five years the prevalence of illicit drug use, as well as recruitment to it, particularly among young people under 18 years of age,
2. To reduce substantially over five years the incidence of drug-related health damage (HIV, hepatitis B and C, TBC, etc.) and the number of drug-related deaths,
3. To increase substantially the number of successfully treated addicts,
4. To reduce substantially over five years the availability of illicit drugs,
5. To reduce substantially over five years the number of drug-related crimes,
6. To reduce substantially over five years money laundering and illicit trafficking of precursors.

Specifying targets implies defining indicators to measure them.

## **1.3 European Union Action Plan on Drugs 2000-2004**

### *Santa Maria da Feira European Council*

The EU Action Plan on Drugs 2000-2004 was adopted by COREPER on 7 June 2000<sup>9</sup> and endorsed by the Santa Maria da Feira European Council.

“The European Council ... endorses the EU Action Plan on Drugs as a crucial instrument for transposing the EU Drugs Strategy 2000-2004 into concrete actions ... Member States, in co-operation with the European Monitoring Centre on Drugs and Drug Addiction are urged to enhance their efforts to provide reliable and comparable information on the key epidemiological indicators in order to better evaluate the impact of drug-related issues.”<sup>10</sup>

<sup>7</sup> op cit. chapter VIII, Information and evaluation

<sup>8</sup> op cit. Chapter III

<sup>9</sup> EU Action Plan on Drugs 2000-2004, 9283/00 CORDROGUE 32, Brussels, 7 June 2000

<sup>10</sup> Presidency Conclusions, Santa Maria da Feira European Council, 19-20 June 2000, SN 200/00, para 51

### *Five key epidemiological indicators*

The roles of the EMCDDA and of the Member States in the field of information and evaluation are elaborated in chapter 2.1 of the Action Plan, and in particular with regard to the five key epidemiological indicators on prevalence and health consequences<sup>11</sup>:

“2.1.1 The Member States according to technical tools and guidelines provided by EMCDDA to give reliable information on the five key epidemiological indicators in a comparable form drawn up by the EMCDDA and adopted by the Council:

- 1 extent and pattern of drug use in the general population
- 2 prevalence of problem drug use
- 3 demand for treatment by drug users
- 4 drug-related deaths and mortality of drug users
- 5 drug-related infectious diseases (HIV, hepatitis)

2.1.2 The EMCDDA to collect and analyse the information at EU level.

.....

2.1.4 The Member States and the EMCDDA, within existing financial limits, to ensure that the National Focal Points have the necessary political and financial support to implement the five harmonised key indicators.

2.1.5 EMCDDA to complete work on the indicators referred to in 2.1.1. ... by the end of 2000 and thereafter to report annually to the Horizontal Working Party on Drugs on the convergence of the key indicators, progress made in this area, and action proposed in the coming year to resolve outstanding problems.”

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<sup>11</sup> op cit., Chapter 2.1, To ensure collection, analysis and dissemination of objective, reliable and comparable data on the drugs phenomenon in the EU with the support of EMCDDA and Europol (Strategy aim 8).

## 2. Broad Strategy for Implementing Key Indicators

### 2.1 Purpose

The underlying purpose of the indicators is to achieve greater uniformity of the measurement methods used by the Member States and the Community in order to monitor and compare the prevalence and major health consequences of drug use and drug addiction in the EU. This is particularly relevant in view of the importance given in the EU Action Plan to ensuring that actions against drugs are evaluated (Strategy aim 2), and in particular the requirement that:

“Work should be taken forward by EMCDDA/Europol drawing on expertise from Member States to underpin the EU drugs strategy with measurable targets so that assessments can be made of progress in achieving objectives.<sup>12</sup>”

Implementation of the five key indicators by the Member States would make a major contribution to this task by obtaining the objective, comparable and reliable core epidemiological data needed to help monitor and evaluate the first three of the six strategy targets listed in the EU Action Plan concerning prevention (reduce drug use<sup>13</sup>), harm-reduction (reduce drug-related health damage<sup>14</sup>) and treatment (increase number of successfully treated addicts<sup>15</sup>). These core data need to be complemented by a wider range of information and research, both quantitative and qualitative, in order to interpret their significance.

Since different drugs are used in different ways in different populations and with different consequences, it follows that a combination of indicators and methods are needed to achieve a valid and balanced picture of the overall situation. It also follows that the limitations as well as the advantages of each individual indicator should be appreciated.

The challenge is not only to collect data and improve comparability, but also to achieve scientific credibility and political acceptance of the results obtained, both by collecting high quality data and by developing strong analytic capacity to fully exploit those data. This requires adequate resources both within Member States, including support for NFPs in order to ensure quality, and also at the EMCDDA in order to enable careful checking and thorough analysis of the data.

### 2.2 Objective and tasks

The broad objective is to define five key epidemiological indicators to recommend for implementation by Member States in order to collect, analyse and disseminate objective, reliable and comparable core epidemiological data on prevalence and health consequences of drug use in the EU.

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<sup>12</sup> op cit., chapter 2.2.2

<sup>13</sup> op cit., chapter 3.1.1

<sup>14</sup> op cit., chapter 3.1.2

<sup>15</sup> op cit., chapter 3.1.3

The five indicators are:

1. Extent and pattern of drug use in the general population
2. Prevalence and patterns of problem drug use
3. Demand for treatment by drug users
4. Drug-related deaths and mortality of drug users
5. Drug-related infectious diseases (HIV, hepatitis)

### ***Roles of the EMCDDA and of the Member States***

Achieving this objective involves three main tasks.

1. Conception and definition of indicators by EMCDDA  
 EMCDDA: *define recommended EU standards (technical tools and guidelines) for each of the 5 key indicators (this task is to be completed by the end of 2000).*
2. Implementation of indicators by Member States  
 Member States: *implement and maintain information systems to give, according to the technical tools and guidelines provided by the EMCDDA, reliable core data on the 5 key indicators in comparable form drawn up by the EMCDDA and adopted by the Council (accompanying measures from EMCDDA to ensure co-ordination, minimum quality standards and monitoring of progress).*
3. Exploitation of indicators at EU level by EMCDDA (data collection and analysis)  
 EMCDDA: *develop and co-ordinate infrastructures and mechanisms for collecting, registering, analysing and disseminating comparable and reliable information on the 5 key indicators at EU level in an efficient, timely and scientific fashion. (in synergy with wider initiatives on information exchange at EU level).*

## **2.3 Conception and definition of indicators by EMCDDA**

The role of the EMCDDA is to provide leadership at EU level by conceiving and defining key indicators and by co-ordinating the overall direction and content of work on the indicators at EU level. Collaboration with other European or international organisations who are working on these indicators is also a task of the EMCDDA..

### ***Development of guidelines***

The development of tools and guidelines for key epidemiological indicators has been a core element of the EMCDDA's first two 3-year work programmes. Since becoming operational in 1995, the EMCDDA has carried out extensive scientific and technical work together with experts and NFPs to develop methods and guidelines for collecting more reliable and comparable data on the five key epidemiological indicators.

The draft guidelines were drawn up by expert working groups and tested in pilot studies in different Member States. Development of the guidelines was based on analysis of existing information systems and data collection instruments, including those of other Community services (e.g. Eurostat) and international organisations (e.g. Pompidou Group, WHO) and took account of the wider scientific literature on indicators and information systems.

The guidelines cover: purpose, definitions, core data set, methods, coverage, data collection, analysis, reporting format. A brief definition of each indicator is given below in chapter 3, and the more detailed guidelines are annexed.

### *Status of current draft guidelines*

On the basis of this work, and as required by its founding Regulation and by the EU Action Plan, the EMCDDA is presenting recommended draft technical tools and guidelines for the five key indicators.

The draft technical tools and guidelines were discussed and approved by the Scientific Committee of the EMCDDA at its meeting on 11-12 December 2000.

These recommendations reflect a broad consensus amongst experts at scientific and technical level about methods and criteria that can serve as pragmatic minimum common standards for collecting and reporting core data. They provide, if implemented systematically, a clear basis for substantially improving the quality and comparability of core data on prevalence and health consequences in the EU.

These draft guidelines should not be seen as products to be set in stone.

- They were developed to measure the drug phenomenon as it was perceived in the 1990s and on the basis of existing technical tools. It will be necessary to adapt and extend them to take account of the changing drug phenomenon and of new information needs arising from the EU Drugs Strategy and Action Plan.
- They are minimum core standards that represent a compromise between the ideal and the feasible. There is room for refinement and improvement of the guidelines, including exploitation of possibilities arising from developments in methodology and the rapid evolution of information technology.
- It will always be necessary to complement core data from indicators with other information (qualitative and quantitative) from research and other sources in order to analyse the situation and evaluate the impact of drug-related issues.

### *Target audience (users) of guidelines*

The main target audience (users) of these guidelines are those institutions and their specialised staff who are responsible in the Member States for managing the information systems and collecting the data for the indicators concerned and who will be responsible for implementing the guidelines. The style and content of the draft tools and guidelines are primarily technical and vary according to the nature of the specialised expertise involved in understanding and implementing them.

## 2.4 Implementation of key indicators by Member States

Adopting the draft guidelines does not determine exactly how they will be implemented in each Member State, nor the precise mechanisms through which data will be collected and reported. This will depend on national circumstances. It will be necessary to find cost-effective solutions through bilateral discussions between the EMCDDA and Member States, and at European level through discussions of possible solutions in the EU Expert Groups for each indicator.

The EMCDDA and NFPS will also need to maximise synergy with existing mechanisms, at national and EU level, through which institutions in Member States collect and report data on related health indicators. Examples include data collection by Eurostat or the Community Programme on Health Monitoring.

### *Tasks for Member States and NFPS*

For each key indicator, implementation in Member States involves the following stages and tasks, initiated through NFPS and supported by other institutions.

1. Development and political commitment to national strategies for implementing the key indicators
  - formulation of national strategies for implementing the 5 key indicators, including definition of the role of NFPS.
  - seeking political commitment from the range of different departments, authorities and key institutions concerned.
2. Progressive implementation of indicators in each Member State:
  - establishment and animation of a national network and expert reference group per key indicator.
  - development of work plans and targets for each indicator.
  - nomination of key institution(s) responsible for collecting data for each indicator.
  - implementation and monitoring of actions foreseen in national work plans.
3. Collaboration at EU-level:
  - participation of experts from or on behalf of all NFPS in annual meetings of an European Expert Group per indicator.
  - periodic reports on progress and problems to EMCDDA, discussion of solutions, feedback to national network.
4. Ensuring quality
  - development of quality assurance measures in Member State
  - meeting national and EU standards on data protection
  - training and technical advice for staff in Member State
5. Infrastructure to support data collection and reporting
  - establishment of infrastructure and technical services for electronic data collection and exchange.
6. Reporting information to the EMCDDA:
  - collection and reporting of core data in comparable form
  - providing complementary information on context, limitations and interpretation of data.

### *Current situation and need for political support for implementation*

In October 1998, the Management Board of the EMCDDA adopted a paper on the role of the national focal points that included facilitating the implementation of the five key epidemiological indicators and collecting and reporting good quality data to the EMCDDA. Since 1999, a core task defined in the NFPs' contracts has been to actively promote the progressive implementation of the five key epidemiological indicators in the Member States.

All NFPs have begun preparatory work for implementation by producing work plans and targets for the indicators and by starting to establish national networks and expert reference groups to help implement them. In most Member States, for most indicators, progress is encouraging, as indicated in progress reports to the Management Board<sup>16</sup>.

In some Member States important obstacles are encountered concerning the implementation of some of the indicators. It is therefore essential that the Management Board not only endorses the recommended tools and guidelines as a basis for implementing the indicators in the Member States, but also underlines the importance of broader political and financial commitment to support the process of implementation and to ensure longer term sustainability.

This includes the need to mobilise high-level support and co-operation across a range of key parties such as other ministries or departments, national research funding bodies, professional associations and national institutes, to motivate regional or local authorities who are involved, and to provide political as well as financial support for NFPs so that the relevant ministries, institutes and other authorities are tied into the implementation process.

### *Accompanying measures from EMCDDA*

Accompanying measures from the EMCDDA are necessary to monitor progress and identify problems and to ensure that implementation is consistent and coherent between different Member States. In particular, these measures involve:

- co-ordination at EU level to encourage compatibility and facilitate information exchange, including an EU Expert Group per indicator
- monitoring progress, identifying problems, giving feedback to MS and discussing solutions.
- developing criteria and practical mechanisms for quality assurance of national information systems and data reported to EMCDDA
- progress reports to Management Board and Horizontal Working Party on Drugs
- technical advice and support (bilateral if necessary) and if possible development of training for key staff in NFPs
- ensuring compatibility between national and EU developments in electronic databases, networking and data collection.

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<sup>16</sup> See previous progress reports on the situation to the Management Board

## 2.5 Exploitation at EU level by EMCDDA (data collection and analysis)

The EMCDDA's tasks cover (a) development of EU mechanisms and tools for data collection, storage and validation, and (b) collection and analysis of the data at EU level and dissemination of the results. These tasks will be carried out taking account of wider initiatives and developments in systems and mechanisms for electronic information exchange at EU level, including projects undertaken for example by Eurostat, IDA, the European Centre for the Epidemiological Monitoring of AIDS, and the Community Programme on Health Monitoring.

The EMCDDA's tasks are:

1. Database and IT development
  - EU epidemiological database structures
  - internet-based applications for electronic data exchange between MS and the EMCDDA
  - ethical and professional guidelines covering data protection, access to databases and utilisation of data
2. Data collection, registration and validation
  - collection of detailed data from MS in common format
  - careful checking of data and confirmation with NFPs and experts
  - registering and regular updating of data in central database
3. Comparative data analysis at EU level, in co-operation with experts and NFPs, focussing on questions of relevance to decision makers:
  - interpretation of indicators in a comparative context
  - evaluation of progress in achieving EU strategy targets
  - assessing emerging problems and their implications
  - forecasting trends
  - integration into a wider framework of interpretation (e.g. social exclusion, social and cultural change)
4. Dissemination
  - presentation of results in policy fora and conferences
  - preparation of position papers
  - dissemination (Annual Report, Statistical Bulletin, special reports, on-line databases, scientific conferences ...)
  - publication in scientific journals

### 3. Definition of the 5 key epidemiological indicators

The five key epidemiological indicators are:

1. extent and pattern of drug use in the general population
2. prevalence of problem drug use
3. demand for treatment by drug users
4. drug-related deaths and mortality of drug users
5. drug-related infectious diseases (HIV, hepatitis)

These are defined in terms of their purpose, methods involved and the nature of the standards. The full guidelines are annexed.

#### 3.1 Extent and pattern of drug use in the general population

*Purpose:* To obtain comparable and reliable measures of the extent and pattern of the consumption of different drugs in the general population, the characteristics and behaviours of users, and the attitudes of different population groups. Regular, repeated surveys give information how drug use is changing. This is basic information for assessing the situation, monitoring trends, identifying priorities, planning and assessing responses.

*Method:* National representative household surveys of the general population

*Standards:* Core questionnaire items for inclusion in national surveys (current, recent and lifetime experience of different drugs, attitudes and perceptions of risk, basic social and demographic characteristics) and guidelines on methods, procedures for extraction of equivalent data from selected existing surveys, data analysis and reporting of results .

#### 3.2 Prevalence of problem drug use

*Purpose:* To provide comparable, reliable estimates of the prevalence and patterns of more severe drug use, for example heroin dependence or drug injecting, that are not reliably measured by surveys. This is useful for assessing treatment needs or measures to reduce health damage, and offers a basis for estimating other social costs such as drug-related crime.

*Method:* Statistical estimates based on existing data (e.g. treatment, police, AIDS, deaths).

*Standards:*

Case definitions, guidelines for 7 statistical techniques for national prevalence estimation (4 multiplier methods based on treatment, police or mortality registers, capture-recapture method, multivariate indicator, back-calculation of injecting drug use from AIDS/HIV data), additional guidelines for local estimates, standard format for data reporting.

### 3.3 Demand for treatment by drug users

*Purpose:* to obtain comparable and reliable information on the number and characteristics of people starting treatment for their drug use. Information on the dimensions and profile of this population and on their patterns of drug use (e.g. injection, multiple drug use) can be used to identify patterns in the use of services, assess resource needs, and plan and evaluate services for drug users. It also provides an indirect indicator of trends in problem drug use and is a rich basis for more in-depth assessments of prevalence.

*Method:* national, routine, anonymous case-reporting system of standard core data on drug users entering treatment.

*Standards:* common EMCDDA-Pompidou Group protocol defining: system requirements, definitions of terms (e.g. treatment, coverage, first treatment demand, case), core data set (19 variables covering treatment contact, socio-demographic characteristics, drug use pattern and injecting behaviour), guidelines for data coding, analysis and reporting of results, plus translation rules for existing national systems and procedures for minimising double-counting.

### 3.4 Drug-related deaths and mortality of drug users

#### (a) Acute (direct) drug-related deaths

*Purpose:* To obtain comparable and reliable information on the number and characteristics of people who die as a direct consequence of their drug use (acute or direct, drug-induced deaths, e.g. 'overdoses') This is an important indicator of the health impact of more severe forms of drug use, and can be useful for monitoring trends in problem drug use;

*Method:* Extraction and reporting of standard core data on acute drug deaths from general mortality registers and from special registers of drug-related deaths (e.g. forensic registers).

*Standards:* Draft guidelines for extracting and reporting codes on underlying cause of death in general mortality registers and special registers, using the International Classification of Diseases (ICD-9) (ICD-10 under development). They do not cover the death certification process – this is a major future step involving considerable work, in particular linking forensic information to certification.

#### (b) Mortality (all causes) in drug users

*Purpose:* to obtain comparable and reliable information on all causes of mortality in defined groups of drug users followed-up over time. This offers more comprehensive and precise estimates of the relative risk of different causes of death in the groups concerned, including indirect deaths (diseases, accidents, suicides).

*Method:* cohort studies (long-term follow-up of defined group of drug users, usually problem drug takers recruited in treatment). Mortality rates and causes of death ascertained by record linkage to mortality registers and other data sources.

*Standards:* Standard research protocol for comparative cohort studies of annual mortality rates and specific causes of death in defined groups of drug users: definitions, sampling and recruitment of subjects, core data, follow-up procedures, data analysis and reporting of results.

### 3.5 Drug-related infectious diseases (HIV, hepatitis)

*Purpose:* to obtain more reliable and comparable measures of the levels of hepatitis B/C and HIV infections in drug using populations, and in particular of trends in prevalence and in the incidence of new infections amongst injecting drug users. This is needed to identify priorities for prevention of further infections, to forecast health care needs and costs, and to monitor the impact of preventive interventions. In addition the data can be useful for indirect estimates of the incidence, prevalence and trends in drug injecting.

*Method:* this indicator is at stage of development and testing. Current method is collection and reporting of standard core data from existing sources (overdose deaths and non-fatal emergencies, drug treatment centres, needle exchanges, prison/arrested populations, STD clinics, screening of pregnant women, public health laboratories, special studies). Proposals are being developed for a European system of sentinel surveillance based on repeated, standardised community-based surveys.

*Standards:* standard tables for reporting prevalence of HIV, hepatitis B and C in drug using and drug injecting populations from specified sources.

## **Annexes: Draft tools and guidelines**

**Annex 1. Extent and pattern of drug use in the general population**

**Annex 2. Prevalence of problem drug use**

**Annex 3. Demand for treatment by drug users**

**Annex 4. Drug-related deaths and mortality of drug users**

**(a) Acute (direct) drug-related deaths**

**(b) Mortality (all causes) in drug users**

**Annex 5. Drug-related infectious diseases (HIV, hepatitis)**