



An overview of the drug-related deaths and mortality among drug users (DRD) key indicator

Summary

Drug-related mortality is a complex phenomenon, which accounts for a considerable percentage of deaths among young people in many European countries. The EMCDDA, in collaboration with national experts, has defined an epidemiological indicator with two components at present: deaths directly caused by illegal drugs (drug-induced deaths) and mortality rates among problem drug users.

These two components can fulfil several public health and methodological objectives, notably as an indicator of the overall health impact of drug use and the components of this impact, identify particularly risky patterns of use, and potentially identify new risks.

The appropriate implementation of the component on deaths directly caused by drugs requires the existence of quality information sources: general mortality registries and/or special mortality registries. An EMCDDA protocol establishes common criteria and procedures to extract and report cases from existing registries. Estimation of mortality rates among drug users requires follow-up studies, for which a working protocol has been developed. The quality of key indicator information depends on the quality of its sources, and will increase with improvement of post-mortem investigations and with full use of this information for death certification and coding.

Considerable progress has been obtained in this indicator over the last 12 years, and in many European Union (EU) countries both General and Special Mortality Registries exist, and cohort studies have been or are being conducted. However, considerable work still has to be done in some countries to improve quality and completeness of drug-related mortality information. This improvement has to be seen in general in the context of improvement of the quality of information on external causes of death and youth mortality.



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Introduction to the indicator

Mortality, directly or indirectly related to drug use, in particular to the more intensive and harmful forms of use, is one of the main causes of death among young people in many European countries. From 1990 to 2006, between 6 500 and 8 500 deaths directly caused by drug use are reported each year in Europe, in most cases, (where information is available), with presence of opiates. In addition, a substantial number of deaths are estimated to be related more indirectly to drug use (e.g. HIV-AIDS related to injection, accidents, suicides, violence and others).

Drug-related mortality is a complex concept that can be understood from different perspectives, which sometimes might lead to divergent conclusions from a policy and public health point of view.

The EMCDDA indicator comprises at present two complementary components. The first and core component is national, population-based statistics on deaths directly attributable to use of drugs of abuse (drug-induced deaths, poisonings or overdoses). The second component is estimations of the overall and cause-specific mortality among problem drug users (through mortality cohort studies).

The first component is often referred to as ‘the drug-related deaths indicator’. It is widely used in policy debates and scientific publications and contains the figures reported by Member States to the EMCDDA on an annual basis. The aim is to provide valid, reliable and comparable information on the number, rates, and characteristics of people who die directly due to use of illicit drugs. The data are extracted from existing

routine statistical systems, such as the General Mortality Registries maintained usually by the national statistical offices, or data are extracted from Special Registries; ad-hoc registries or recording systems of medico-legal institutions. In principle, these registries cover the whole population either at national level or at regional level.

The second component of the key indicator complements routine statistics and provides data on the overall and cause specific mortality rate based on a cohort of drug users, usually in contact with drug treatment services. The mortality rates include deaths directly induced by use of drugs (overdoses) and deaths that may be indirectly related to drug use such as infectious diseases, injuries and violence, suicides, and other causes of death that may be related to other aspects (such as smoking or alcohol-related causes, mental health problems, or social exclusion). However, this component is less readily available in all countries as it is based on specific studies, which are more resource intensive and often limited in time and geographical coverage, compared to the first component of the key indicator.

The development of both components of the indicator has been a difficult area. One of the main difficulties has been conceptual; what typology of deaths should be included in the case definition (deaths directly or indirectly related to use, linked to drug-related crime, deaths with a positive toxicology). In addition, there have been important methodological challenges, such as difficulties in certification and coding of external causes of death (such as overdose, violence, accidents and suicide) and differences in investigations of unnatural deaths across countries. Finally, there are also differences on whether the results of death investigations are used in practice for death certification and coding.

Considerable progress has been made in the last 12 years by Member States and the EMCDDA, although substantial work needs to be continued in many countries, both in General Mortality Registries and Special Registries.

Purpose of the indicator

The general purpose of the indicator is to improve understanding of the health impact of different forms of drug use and its correlates and determinants, with the aim to inform the development and evaluation of policies and interventions aimed at reducing health problems, in particular mortality, related to drug use.

Data on the number, characteristics and circumstances of people dying directly due to drugs can fulfil several complementary purposes, especially when presented and interpreted alongside other drug indicators. Some of the more relevant purposes are:

- to provide information on the health impact of drug use in the community, in particular to highlight and measure the most extreme consequences of drug taking;
- to identify risky patterns of use (e.g. injection or polydrug use) and risk among the most vulnerable groups of problem drug users;

- to identify new risks such as those of new substances or combination of substances, or contaminated or adulterated batches;
- to help to monitor trends in prevalence of specific drug problems with an elevated risk such as injecting heroin use;
- in combination with other information, to estimate prevalence of problem drug use (multiplier estimation);
- to help in hypothesis-generating in relation to reasons why rates or characteristics of drug related deaths differ between and within countries.

Mortality among drug users is an important component of the indicator. Critically, mortality studies among cohorts of problem drug users will provide information that is to some extent independent (the overall mortality) of certification or coding practices.

- Overall mortality is an indicator of the extension of harm associated with different patterns of drug use.
- Cause-specific mortality can give policy relevant insight on the components of harm related to problem drug use, which often is not evident from standard sources.
- Mortality information may also support the interpretation of routine statistics on drug induced deaths (underreporting, codification issues).
- Mortality studies help to make the link between statistics of drug-induced deaths (number of overdoses) and prevalence estimations of population at risk (e.g. number of opiate injectors).

Marked differences in the overall mortality and the patterns of mortality have been observed in the mortality cohorts from different European countries.

Most mortality cohort studies conducted until now in Europe have recruited mainly or exclusively problem opiate users. Given changing patterns of drug use, it would be advisable to establish cohorts of other typologies of users (e.g. cocaine users) as their patterns of health problems can be substantially different to those of opiate users, and more difficult to identify in routine statistics.

Methodology

EMCDDA monitoring standards

The EMCDDA monitoring standards for drug-related deaths (drug-induced deaths) require the collection at national level on the total number of cases of death attributed directly to the use of illegal substances of abuse. In addition, for each reported case, information will be collected on the characteristics of the victim and on the substances that caused the death.

The information should be extracted from existing information systems: General Mortality (GMR) or Special Registries (SR). The ideal situation will be to extract information from both systems if they exist in a country, for assessment of consistency and cross validation.

The application of the EMCDDA standard protocol requires that the existing national death registry, or registries, have sufficient quality and coverage to identify as completely as possible cases of death directly caused by use of drugs.

The EMCDDA standard protocol for DRD (available at <http://www.emcdda.europa.eu/themes/key-indicators/drd>) describes the procedures to extract cases from existing sources (GMR, SR), select the relevant cases for the indicator and condense the information to be reported annually ('key figures'). Key figures should be reported to the EMCDDA by the Member States, in the framework of annual national reporting, through standard forms with breakdowns by gender, age group and very basic information on substances involved (presence or not of opiates).

Information for the second component — estimates of mortality among drug users — requires the conduction of follow up studies of well defined groups or drug users (cohort studies). A working protocol proposes basic requirements for harmonisation of cohort studies in relation to: recruitment settings (drug treatment centres); target population (users admitted at least once to treatment during the recruitment period); set of common variables to be collected per case (largely compatible with the treatment demand indicator, TDI); follow up methods (record linkage with population or mortality registries); analytic methods to calculate the mortality risk.

Data protection and ethical issues should be considered and maintained both in production of population based statistics and also, in particular, in mortality cohorts.

The main factors to help obtain a high level of implementation of the indicator include:

- existence of the GMR of good quality (in particular, for external causes of death including drug-related deaths) where results of post-mortem investigations are taken into account for death certification and coding, and able to provide information according to the DRD protocol;
- complementary (or eventually as alternative), existence of a good quality Special Mortality Registry with a national coverage, and able to provide information according to the DRD protocol;
- ideally, the two registries would provide similar estimations in numbers of cases and trends over time;
- existence of recent or ongoing mortality cohort study among problem drug users, with enough number of participants to provide reliable estimations.

Methodological approach and information domains

Case definition

The EMCDDA definition of drug-related deaths (more precisely, drug-induced deaths) is simple and relatively restrictive. It includes 'people who die directly due to use of illegal substances, although these often occur in combination with other substances such as alcohol or psychoactive medicines. These deaths occur generally shortly after the consumption of the substance.' They are also known as overdoses or poisonings.

Operative criteria

The EMCDDA standard protocol transforms this definition into operative criteria for extracting the relevant deaths from both GMR and SR (types of death) in a way that provides the best possible estimation for the number of cases matching this definition. For the GMR, these operative criteria consist of a list of codes from the WHO International Classification of Diseases (ICD) 10th Edition. For the SR they consist of the classes of deaths that should be extracted (only overdoses out of all possible cases recorded in these registries e.g. traffic accidents, violence).

For GMR, the list of ICD-10 codes are known as 'Selection B'. Basically, they include cases where the underlying cause of death (the condition that initiated the process that lead to the death) is: (1) mental and behavioural disorders due to psychoactive substance use (harmful use, dependence, and other mental and behavioural disorders (F codes) due to opioids, cannabinoids, cocaine, other stimulants, hallucinogens or multiple drug use, or (2) poisonings (X and Y codes) that are accidental, intentional or of undetermined intent due to substances under the heading of narcotics (T40-0 to T40-9) or psychostimulants (T43.6).

For the SR, the EMCDDA operative criteria are known as 'Selection D'. It indicates that cases will be selected when the death was due to poisoning by accident, suicide, homicide, or undetermined intent by a set of illegal drugs of abuse.

In addition to case definition, quality and reliability of routine information sources is particularly important, in order to have a good level of detecting drug deaths. This includes that, in as many cases as possible of unnatural or violent deaths (e.g. accidents, suicides) some form of investigation takes place to establish the cause of death. The form of an investigation can be of different nature and scope, although more detailed investigations will produce higher quality results. Often results of these investigations are filled and maintained in institutes that can be the basis of Special Registries containing rich information for each case, (e.g. toxicology and circumstances of deaths), although the coverage and continuity over long periods of time may not be guaranteed.

The General Mortality Registries contain information on all deaths happening in a country, based on mandatory death certificates. Coverage and continuity is guaranteed and they could be considered, in principle, as a common source of information for all causes of death. However the information contained in death certificates can be very limited, and for different reasons (lack of resources, administrative limitations, etc.), in some countries, the General Mortality data may clearly under-report drug-related deaths when compared with Special Registries.

The exhaustiveness and quality of post-mortem investigations do not guarantee, per se, the quality of the key indicator. In particular, if results from these investigations are not taken into account in the certification and codification process of General Mortality Registries. Information exchange between institutes conducting the post-mortem investigation and other parties will improve the validity and reliability of drug-related deaths

statistics. In this sense, the existence of both GMR and SR will increase the chances of cross comparison and validation of drug-related deaths information.

This key indicator requires a sustained institutional commitment and cooperation to achieve and maintain quality. The strong legal procedures of mortality data requires generally that several official bodies take an active role in the data collection and processing. It is necessary that national focal points identify those relevant partners and convene a national working group with key experts from national statistical offices, forensic and toxicology departments, the relevant police unit, mortality cohort experts and public health officials and epidemiologists (for more about the Reitox network of national focal points see <http://www.emcdda.europa.eu/about/partners/reitox-network>). The group should have a combination of technical expertise and decision-making capacity. In parallel, at international level, the EMCDDA exchanges information and collaborates with other organisations such as Eurostat and WHO, in the areas of interest regarding causes of death statistics, within their respective mandate.

In the case of mortality estimations among drug users, ideally cohort studies (or more properly record-linkage studies) will require sufficiently big samples of users enrolled, and followed during a sufficient period of time. The objective is to obtain reliable mortality estimates, in order to draw useful conclusions (groups with higher risks for different health impacts, possible determinants of the mortality) for well informed and adequate public health responses. These studies will require usually combining the information from different treatment centres/institutions, and collaboration with population and mortality registries.

Further developments

In addition to the two established components of the key indicator, further components (or analytical approaches) will help to increase understanding of health impact of different patterns of drug use. The EMCDDA has considered relevant the assessment of total burden of drug mortality in a community (See CT.00.RTX.22: 'Coordination of the implementation of the EMCDDA standard guidelines on the drug-related deaths indicator in the EU Member States, and the collection and analysis of information on drug related deaths' 2002 — Annex 1). In recent years, work of some national experts has given a new impulse of this topic).

As complementary work, the EMCDDA is considering developing of estimations based on available published data (e.g. by Eurostat), on other aspects of drug-related mortality such as HIV/AIDS or others.

Strengths and limits of the information on drug-related mortality

The number of drug-induced deaths, and the mortality among drug users, can contribute substantially to assess the intensity and the components of the harm associated with drug use. Mortality is generally considered a useful indicator of the population impact of health problems, due to its universal coverage, the existence of international classifications (WHO International Classification of Diseases), existence of long-term series, and the strong legal basis on which information is collected.

However, data on drug-induced deaths has to be interpreted cautiously and ideally combined with other indicators of the drug situation and interventions (e.g. estimations of the prevalence of drug use, treatment availability and uptake, etc.). The routine mortality statistics still have some limitations regarding data quality and comparability:

- the number of recorded overdoses may be influenced by quality and coverage of reporting;
- incomplete investigation of unnatural or violent deaths and limited report of toxicological information in some countries may limit completeness and quality of information;
- there are still problems in the use of ICD (e.g. a few European countries do not use T codes).

The indicator presents some limitations due to its own definition and conceptualisation. It does not cover:

- some drug-related deaths (such as mortality related to psychoactive medicines and alcohol, without illegal drugs);
- role of drug use in fatal injuries (such as road accidents and violence);
- non-fatal morbidity due to overdose;

The indicator was developed mainly to monitor substances with a high risk of acute deaths due to fatal overdose (e.g. injected heroin), but increasingly prevalent substances may have a different mortality pattern more difficult to identify (e.g. cocaine alone or in combination with alcohol, tobacco and other factors).

Regarding data quality and reliability, considerable progress has been obtained. In many countries, estimates obtained from different sources (GMR and SR) appeared to be consistent in terms of numbers and/or trends. Different cohort studies of drug users allow to better assess and understand population-based statistics.

However, there are still clear quality problems in some countries, and simple comparisons should be made with caution. Some of the quality problems in drug-related deaths information seem to affect not only these, but more generally deaths due to external causes of death, including suicides, accidents and violence. A recent European project (Anamort project) funded by DG SANCO and with participation of all EU countries and Eurostat has analysed this issue in detail.

The strengths of mortality follow-up studies (cohorts) have been highlighted in several sections, including the relative independence of mortality recording and codification practices, the assessment of overall mortality

related (directly or indirectly) to drug use, and the possibility of estimations ('standardised mortality ratios') of excess mortality compared to populations of same age and gender.

However, these studies and their comparability across Member States face the following challenges:

- information on drug use patterns is incomplete in many cohorts, limiting the potential to identify a risk factor, and to improve comparability through more stratified analysis (e.g. controlling by secondary drugs, length of use, injection status or other factors);
- there are differences in recruitment settings which limits direct comparability;
- differences in drug treatment provision (types of treatment, treatment policies) and treatment retention rates, which are difficult to assess, may explain differences in mortality rates;
- record-linkage studies require far less resources than active follow-up of cohort participants but information on relevant changes over time (e.g. change in injection status) is very limited.

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