GESUNDHEIT ÖSTERREICH GMBH GESCHÄFTSBEREICH ÖBIG



Inventory of the national Special Mortality Registries in Europe, and description of the core data available

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Glossary

DC Death Certificate

DRD Drug Related Death

EMCDDA European Monitoring Centre for Drugs and Drug Addiction

GMR General Mortality Registry

ICD 10 International Statistical Classification of Diseases and Related Health

Problems 10th Revision

n Number of returned questionnaires

NDRDI National Drug-Related Deaths Index in Ireland

NFP National Focal Point

SMR Special Mortality Registry

UK United Kingdom

Executive Summary

The key indicator "Drug-Related Deaths (DRD) and mortality among drug users" has two components. One is the overall and cause-specific mortality among drug users monitored through mortality cohort studies following drug users overtime. A second component is the statistics on deaths directly caused by drugs, also called "overdoses", "poisonings" and more recently "drug-induced deaths". The preferred method of estimating the number of deaths is to extract cases from existing General Mortality Registries (GMR) where a selection of ICD 10 codes are defined as drug-related. An alternative method is to estimate the number of deaths by extracting cases from existing Special Registries (typically forensic or police registries). The method based on the Special Registry will be applied in countries where the preferred method cannot be implemented, but will also be used whenever possible as a backup estimate for the GMR.

The aim of this project was to better understand risk factors and substances involved in druginduced deaths in Europe. It aims to improve the monitoring of drug-induced deaths and to help to assess the feasibility of future work on this domain in Europe. Specific objectives were:

- to conduct a targeted inventory of national Special Mortality Registries
- to describe their overall working procedures and information flows within the Special Mortality Registries
- to describe the core data or information recorded regularly for each case of druginduced deaths.

Potential areas of interest were discussed in a working group. In the follow-up of the working group a draft questionnaire was prepared in close cooperation with the EMCDDA. The questionnaire was send to an advisory group before disseminating to all members of the European Union and Croatia, Norway and Turkey.

16 countries returned the questionnaire on Special Registries (Austria, Czech Republic Croatia, Cyprus, Denmark, Finland, France, Germany, Hungary, Ireland, Latvia, Lithuania, Malta, Spain, Sweden, United Kingdom) on DRD, and 2 countries reported having no Special Registry (Estonia, Poland). This leads to a return rate of 60 percent.

The information flow of data for Special Registry varies across Europe. Most Special Mortality Registries combine various information sources and therefore have different persons in charge. Unlike the information in the GMR the information flow is very complex. Most Special Mortality Registries include a lot of additional (contextual) information which is not found in the GMR and which can be used to describe risk factors for Drug-Related Deaths. This valuable additional information should be focused on by small-scale studies.

1 Introduction and rationale

The key indicator "Drug-Related Deaths (DRD) and mortality among drug users" has two components. One is the overall and cause-specific mortality among drug users monitored through mortality cohort studies following drug users overtime. A second component is the statistics on deaths directly caused by drugs, also called "overdoses", "poisonings" and more recently "drug-induced deaths".

The monitoring of these drug induced deaths aims to provide reliable and comparable information on the number and characteristics of people who die directly due to illicit drug use (e.g. opiates, cocaine, amphetamines and derivates, hallucinogens and cannabis). It is based on the following common definition of DRD developed by the EMCDDA in agreement with a group of national experts: "deaths that are caused directly by the consumption of drugs of abuse. These deaths occur generally shortly after the consumption of the substance(s)".

The preferred method for estimating the number of deaths is to extract cases from existing GMR where a selection of ICD 10 codes are defined as drug-related. An alternative method is to estimate the number of deaths by extracting cases from existing Special Registries (typically forensic or police registry). The method based on the Special Registries will be applied in countries where the preferred method cannot be implemented, but will also be used whenever possible as a backup estimate for the GMR.

The aim of this project was to better understand risk factors and substances involved in druginduced deaths in Europe. It aims to improve the monitoring of drug-induced deaths and to help to assess the feasibility of future work on this domain in Europe. Specific objectives were:

- to conduct a targeted inventory of national Special Mortality Registries (and eventually Registries with substantial and good quality and sub-national coverage) in Europe, both actually used or which could be eventually used for the monitoring of the DRD key indicator
- to describe their overall working procedures and information flows within the Special Mortality Registries and eventually with other institutions (e.g. GMR, police)
- to describe the core data or information recorded regularly for each case of druginduced deaths.

2 Method

Potential areas of interest were discussed in a Workshop on Special Mortality Registries in Lisbon on the 28th of November 2008 (See Annex I for minutes of the Session). In the follow-up of the working group a draft questionnaire was prepared in close cooperation with the EMCDDA. During the construction emphasis lay on a comprehensible and concise questionnaire.

The final questionnaire was divided according to the following sections:

- 1) Investigation of unnatural deaths
- 2) The results (reports, documents) from post-mortem investigations
- 3) Inclusion/Exclusion Criteria
- 4) Information recorded in Special Mortality Registries for DRD
- 5) Information flow(s)
- 6) Procedures and legal background

The questionnaire was send to an advisory group consisting of the members of the EMCDDA meeting. The feed-back of the EMCDDA, John Corkery (UK), Maria Savvidou (Cyprus) and Henrik Saelan (Denmark) were considered and changes made. The questionnaire was sent to all members of the European Union and Croatia, Norway and Turkey. The questionnaire was sent to a known DRD expert in the country and copied to the head of focal point in April 2009. A reminder was sent in May. 16 countries returned the questionnaire (see table below).

Table 2.1: Return of questionnaire

Country	Return	Expert(s)	Organisation(s)
Austria Belgium Bulgaria	X 0 0	Charlotte Wirl, Martin Busch	Austrian Focal Point
Croatia	X	Tanja Coric, Marina Kuzman, Dragica Katalinic	Croatian National Institute of Public Health
Cyprus	X	Pavlou Pavlos, Maria Savvidou, George Kokkinos	Ministry of Health, Cyprus Monitoring Center for drugs and drug addiction, Drug law enforcement unit
Czech Republic	X	Frantisek Vorel, Viktor Mravcik	Society for forensic medicine, Czech Focal Point
Denmark	Х	Kari Grasaasen (with help from national experts, Henrik Saelan, Carsten Hansen)	National Board of Health/Focal Point
Estonia	no SMR		
Finland	X	Sanna Rönkä (in cooperation with Erkki Vuori, Helena Korpi)	National Institute for Health and Welfare (THL)/Focal Point
France	X	Eric Janssen	French Monitoring Centre on Drugs and Drug Addiction (OFDT)
Germany Greece	X 0	Axel Heinemann	Institute for Legal Medicine Hamburg
Hungary	Χ	Eva Keller, Eszter Nádas	Hungarian Focal Point
Ireland	X	Suzi Lyons, Ena Lynn	Health Research Board
Italy	0		
Latvia	Χ	Inga Martionva	State Centre of Forensic Medical Examination
Lithuania	X	Ernestas Jasaitis	Drug control department
Luxembourg	0		

¹ See Annex II

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Country	Return	Expert(s)	Organisation(s)
Malta	Х	Kathleen England	Department of Health Information and Research
Norway	0		
Poland	no SMR		
Portugal	0		
Rumania	0		
Slovak Republic	0		
Slovenia	0		
Spain	Х	Gregorio Barrio Anta	National Office for National Plan on Drugs
Sweden	х	Ingemar Thiblin in collaboration with Lars Age Johansson	Dept. of surgical sciences, division for forensic medicine, Uppsala University
the Netherlands	0	ŭ	, 11
Turkey	0		
United Kingdom	x	John Corkery	International Centre for Drug Policy, St. George's, University of London

X= Questionnaire returned, 0= no response, no SMR = no Special Mortality Registry

Acknowledgments

Special thanks to all the specialist and contact persons from National Focal Points who reported back (see table above).

3 Results

The following analysis seeks to summarise the answers of the 16 returned questionnaires. As the systems' backgrounds vary across countries it is difficult to present quantitative and comparable results. Nevertheless – whenever it makes sense – tables which allow an easy overview over the results by country are included. For detailed information refer to Annex III, where all completed questionnaires are presented. Whenever indicated references to the special situation in the country is presented. However for a thorough analysis of a country please refer to the specialist indicated in the questionnaire.

The analysis usually refers to valid answers only.

3.1 Special Registries country overview

The following country overview gives a first impression of the differences concerning the Special Registries in the participating countries. The focus is on special aspects in the respective country situation. A more systematic overview can be found in the following sections.

In <u>Austria</u> the Special Mortality Registry consists of all cases where illegal substances were found or substitution treatment was terminated due to death (no matter what the cause of death) and is located at the National Focal Point.

Croatian National Institute of Public Health also collects data on DRD. They use as sources of data the GMR, outpatient treatment centre from the Institute of Public Health and the toxicological laboratory of the Ministry of the Interior. During the process of coding causes of death, each death suspected to be related to drug abuse is checked with the Registry (so as to be sure whether this person has already been treated for drug abuse). All data on toxicology performed at the Toxicological Laboratory in the Ministry of the Interior are checked against the Registry as well. The deaths confirmed as deaths from overdoses or intoxication with psychoactive substances (findings from forensic scientists) are registered as DRD and these persons added to the Special Registry as persons whose deaths were connected to drug abuse.

In <u>Cyprus</u> the Special Registry is being coordinated by the focal point and mainly receives information from the police (Drug Law Enforcement Unit), the State General Laboratory and forensic physicians. The Cyprus Health Monitoring Unit (CHMU) and the statistical service are responsible to recode DRD's in the General Mortality Registry. The CHMU receives information regarding the number of drug related deaths from the Special Registry. Additionally, the CHMU codes DRD's according to the relevant year's ICD-10 updates.

The <u>Special Registry</u> in the Czech Republic is based on anonymous data sent from every forensic medicine department to the National Focal Point annually.

The Special Mortality Registry in <u>Denmark</u> kept by the police only has data on DRD positives, personal data, and summary toxicological data, but not diagnoses and ICD codes – they are in the GMR. The police has an annual meeting with the forensic institutes, where borderline cases are discussed. Other cases are sent electronically to the police, with agreed information. The forensic data in toto goes to the staff at the GMR at the National Board of Health (they keep health statistics in Denmark – not the National Bureau of Statistics).

The GMR and the Special Registry provide data on DRD in <u>Finland</u>. Data from the Special Registry are based on forensic toxicological examinations that are conducted in case of an unexpected or sudden death.

The Special Mortality Registry in <u>Germany</u> is defined as being the Registry at the national police department (BKA) in Wiesbaden which gets data only on an aggregated level from the regional police departments in each Bundesland.

In <u>France</u> several data flows exist. The GMR is the main source (generally a 2 year-lag on data). Second (the Special Mortality Registry) the National Agency for Health and Medicine Security (AFSSAPS) signed an agreement with some toxicological laboratories to retrieve information on DRD. This source has never been used by France to report DRD data through the EMCDDA standard. Strong information limitations are set up to prevent any individual recognition. There is also a police database on DRD, which has a strong under-reporting and due to this bias is not published anymore.

At the moment the Special Mortality Registry in <u>Hungary</u> is based on the Statistical Data Collection Program (OSAP). Each institution sends a paper template to the National Institute of Forensic Medicine with aggregated data. The template is in a table format and the data are summarised at the National Institute of Forensic Medicine. The launch of a new system of data collection is in progress.

In <u>Ireland</u> the Special Registry is based on the files and records (including post-mortem analysis) maintained by the 48 coroner districts. Personnel from the Focal Point go through all the files and extract data for DRD.

In <u>Latvia</u> all unnatural and deaths suspected to be unnatural are included in the Special Mortality Registry, which has national coverage. The data is recorded in the death registration system of Latvia and kept at the State Centre of Forensic Examination (SCFME).

<u>Lithuania</u> has no Special Registry set up. However Lithuania returned the questionnaire and filled in information available about the GMR and the transfer of reports.

In <u>Malta</u> the Special Registry is kept by the Police Drug Unit which collects any case of suspected DRD or overdose.

In <u>Spain</u> the Special Registry is based on data send from the forensic and toxicology departments. The information is send with an identification code to the autonomous government and later to the central level (in the last case after removing the identification code). In general the Special Mortality Registry covers about 45% of the Spanish population.

At present <u>Sweden</u> has no comprehensive Special Registry on DRD, covering the whole country. Previously, between 1985 and 1996, there existed a Special Registry that covered the Stockholm region. For some years there has been a cooperative effort to establish a Registry on all forensically examined deaths in Sweden. Participants in this project have been the Forensic Medical Authority, the Swedish National Institute of Public Health and the National Board of Health and Welfare (Epidemiological Centre). As more than 93% of all deaths from violent causes and intoxications among persons below 65 are forensically examined, the Registry will cover the majority of acute deaths related to illicit drugs, prescribed drugs and alcohol. All deaths with presence of illegal drugs at autopsy are classified as drug-related. The main advantage in using toxicological data is that the inclusion criteria are uniform over time and the results are obtainable within a short time-period. On the other

hand, cases with no presence of illegal drugs at death are excluded as well as persons who have died in hospital.

In the <u>United Kingdom</u> information from the police, post-mortem investigation and toxicology reports are collected by the coroner and send to the National Program on Substance Abuse Deaths. The information for each case can include: the np-SAD data collection form, inquest form, toxicology report, post-mortem report and a witness statement.

3.2 Investigation of unnatural deaths

The investigations of unnatural deaths usually start with a general physician or emergency doctor or the police on the scene and a suspected violent (or not natural) death. The investigations are then mostly transferred to the judicial system where a coroner (e.g. Ireland and UK) or the state's attorney or an Investigating judge decides whether to call for an autopsy and further investigations. If the doctor can not establish the cause of death but no violent death is suspected the attending doctor is in some countries obliged to order an autopsy (e. g. in the Czech Republic). The post-mortem investigations are mainly covered by the judicial system. However in some cases, e.g. Croatia and Austria, some autopsies are paid for by the health care system. In the case of Hungary the autopsies and toxicological analyses are paid for by the police. If no further investigation is requested the death certificate can usually be issued by attending physician. In Denmark all deaths where former drug user or any drug abuse, or acute intoxication is suspected a post-mortem (including toxicological analysis) is undertaken. Figure 3.1 gives an impression of the overall flow of procedures in the reporting countries. Table 3.1 gives an overview about who pays for post-mortem analysis. The eligibility criteria for post-mortem examinations is in all cases "Unnatural death or cause of death is unclear".

Figure 3.1: General flow chart concerning the first steps after an unnatural, violent or unclear death case

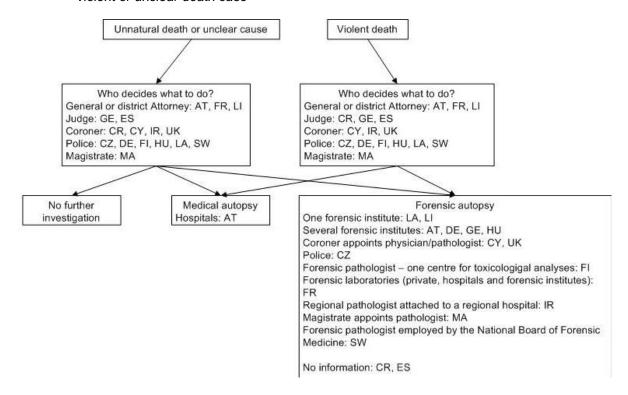


Table 3.1: Who pays for autopsies?

Country	Who pays it?
Austria	Forensic autopsies: Ministry of Justice, non-forensic autopsies: Federal state
Croatia Cyprus	Forensic autopsies: Ministry of Justice, Non-forensic autopsies: Health system State, in some cases relatives
Czech Republic	In case of crime: police, other cases Ministry of Health
Denmark	Ministry of Justice
Finland	State
France	State
Germany	In general Ministry of Justice, some cases university hospital or relatives
Hungary	Police
Ireland	Coroner
Latvia Lithuania	State State
Malta	Ministry of Justice
Spain	State or criminal responsible person
Sweden	National Board of Forensic Medicine, police
United Kingdom	Coroner

3.3 The results (reports, documents) from post-mortem investigations

Despite the fact that most of the forensic investigations are paid for by the judicial system the data and forensic reports are mostly owned and stored at the department of forensic medicine. The reports are sent to the police, coroner or judge for further investigations but are hardly stored or filed in a systematic way in these organisations.

Table 3.2: Owner of the data and access of the NFP

Country	Owner of the data	NFP has access
Austria	Ministry of Justice, Ministry of Health	NFP gets the data from Ministry of Health for analysis
Croatia	Institutes performing autopsies	No data
Cyprus	Department of Forensic Medicine, police, coroner	Yes (limited and relevant information)
Czech Republic	Forensic medicine department	Yes
Denmark	Police	As a scientific investigation after permission
Finland	No overall database ¹	As a scientific investigation after permission
France	Forensic medicine department, Police	No data
Germany	No general owner	Yes as a researcher
Hungary	Police	There could be a possibility via the National Institute of Forensic Medicine
Ireland	Coroner	Yes
Latvia	State Centre of Forensic Medical Examination, Health Statistics and Medical Technologies State Agency	Yes
Lithuania	Institute for Forensic Medicine	Yes
Malta	Magistrate	Not at present
Spain	Ministry of Justice, Forensic institute	No
Sweden	No data	Yes
United Kingdom	Coroner	YNo, but national expert does

¹⁾ The police has almost all information but mostl likely it is not filed in an organised way. There is a database of toxicological investigations

Table 3.3: Flagging of DRD and coverage

Country	Flagging of DRD	Coverage
Austria	Yes	National
Croatia	No data	No data
Cyprus	Yes	Government controlled area of Cyprus
Czech Republic	Yes	National
Denmark	Only DRD	National
Finland	No overall database ¹	Database of toxicological investigations: national
France	Yes	cooperating forensic institutes
Germany	Yes	Majority of forensic institutes participate
Hungary	No data	Regional (no national database)
Ireland	No overall database ²	Regional (no national database)
Latvia	Yes	National
Lithuania	Yes	National
Malta	No	National
Spain	Yes	Regional around 45 % of population
Sweden	Yes	national
United Kingdom	Yes	National (UK, Channel Islands, Isle of Man)

¹⁾ The police has almost all information but mostl likely it is not filed in an organised way. There is a database of toxicological investigations

3.4 Inclusion and Exclusion Criteria and background population of the Special Mortality Registries

3.4.1 Background population

Since Special Registries are set up for different reasons (e.g. police records, forensic backgrounds...) the scope and background population of the registries are different across countries. Most of the Special Mortality Registries have certain pre-selection criteria, so usually not all deaths occurring in a country are the background population.

Table 3.4: Background population of the SMR

Country	Background population
Austria	Residents of Austria dying unnatural deaths, where illicit drugs are suspected
Croatia	Death occurring to people included in the treated Drug Addicts Registry
Cyprus	All direct and indirect drug related deaths ("unusual" deaths of young people connected to illict drugs)
Czech Republic	All unnatural deaths
Denmark	All non-natural deaths or suspicious deaths
Finland	All sudden and unexpected deaths, for which a forensic pathologist has requested a toxicological analysis.
France	Post-mortem analysis where illicit drugs were found from cooperating forensic institutes
Germany	All people dying in Germany
Hungary	All people dying in Hungary
Ireland	All deaths among substances users, all drug-related deaths and all alcohol-related deaths.
Latvia	All unnatural and deaths suspected to be unnatural
Lithuania	Deaths registered by the Institute of Forensic Medicine of the Mykolas Romeris University
Malta	All cases of suspected drug-related deaths or overdose
Spain	Drug-related deaths among people aged 15 to 64.
Sweden	No data
UK	General population resident in or visiting the UK, where the following criteria are met: psychoactive medicine directly implicated in the death, history of dependence, presence of

²⁾ Each coroner files his/her data

3.4.2 Inclusion criteria

The inclusion criteria vary across Europe. All of the valid answers (14 countries) report the inclusion of foreign nationals (if deceased in the respective country). However Sweden and Austria do not include foreign residents in the statistics and Denmark plans to extract foreign nationals and foreign residents in the future. Usually the Registry includes all age groups, in the case of Spain only 15 to 64-year olds are included. Deaths of citizens overseas e.g. on holidays are included in some of the registries and in some not.

The scope of the registries vary, some include all unnatural deaths (40 %).. All include deaths directly related to illegal drugs (see Figure 3.2).

Deaths related to alcohol are collected and registered in six countries, whereas the others only include alcohol deaths if illegal drugs were also detected. The UK is currently considering setting up a separate database for deaths related to alcohol. However 13 registries include deaths related to psychoactive substances, in the case of Germany only deaths due to an opiate substitute or in Denmark only if the deceased was a known drug addict or illegal drugs were involved.

Suicides are included in most of the countries if an illegal substance is found or the deceased was a known drug user. The same is true for homicides.

Most countries (93%) record accidents if substances are involved, some (e.g. DK, AT, UK) also record accidents of known drug abusers. Two-thirds of the countries record all deaths with positive toxicology (whatever the cause of death was). Germany, Latvia and Spain do not include all deaths with positive toxicology unless it was directly drug-induced. A registry of the deaths of all known drug users (whatever the cause of death) only exists in six countries: Croatia, Denmark, Finland, Ireland, Sweden, and UK.

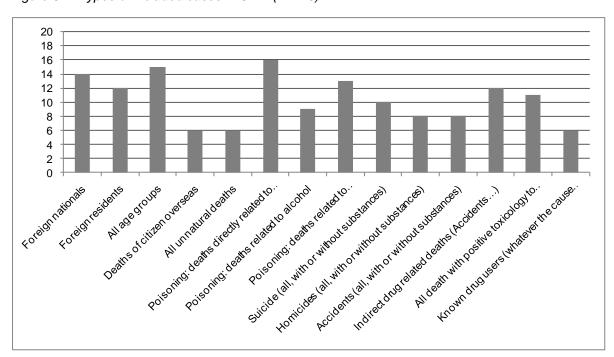


Figure 3.2: Types of included cases in SMR (n = 16)

Table 3.5: Inclusion criteria for the SMR

	1			1		1	1						1			_
Inclusion of	Austria	Croatia	Cyprus	Czech Rep.	Denmark	Finland	France	Germany	Hungary	Ireland	Latvia	Lithuania	Malta	Spain	Sweden	¥
Foreign nationals	Υ	Υ	Υ	Y	Υ	Υ	U	Υ	Υ	Υ	Υ	Υ	N	Υ	Υ	Υ
Foreign residents	N	Υ	Υ	Y	Υ	Υ	U	Υ	Υ	Υ	Υ	Υ	N	Υ	N	Υ
All age groups	Υ	Υ	Y	Y	Y	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	N ⁹	Υ	Υ
Deaths of citizen overseas	N	Υ	N	Y	N	Υ	N	N	N	Υ	N	Υ	N	N	Υ	N
All unnatural deaths	N	N	N ¹²	Υ	Y ¹	Y ²	N	N	N	Y ⁸	Υ	Υ	N	N	N ¹¹	U ¹²
Poisoning: deaths directly related to illegal drugs	Υ	Υ	Υ	Y	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
Poisoning: deaths related to alcohol	N	N	N ⁵	Y	Y ¹	Υ	U	N	Υ	Υ	Υ	Υ	N	N	Υ	Y ¹⁰
Poisoning: deaths related to psychoactive substances	N	Υ	N ⁵	Y	Y ¹	Υ	Υ	Y ³	Υ	Υ	Υ	Υ	Υ	N	Υ	Υ
Suicide (all, with or without substances)	N	Υ	N ⁵	Y	Y ¹	Υ	N	Y ⁴	Y ⁵	Y ⁸	Υ	U	N	N ¹⁰	Υ	Y ¹³
Homicides (all, with or without substances)	N	N	N ⁵	Υ	Y ¹	Υ	N	N	Y ⁵	Y ⁸	Υ	U	N	N ¹⁰	Υ	Y ¹³
Accidents (all, with or without substances)	N	N	N ⁵	Υ	Y ¹	Υ	N	Y ⁵	Y ⁵	Y ⁸	Υ	U	N	N ¹⁰	N	Y ¹³
Indirect drug related deaths (Accidents)	Υ	Υ	Υ	Υ	Y ¹	Υ	Υ	Y ⁶	Y ⁷	Υ	Υ	U	N	N	Υ	Υ
All death with positive toxicology to illegal drugs (whatever the cause of death)	Υ	N	Y	Υ	Y	Υ	Υ	N	Υ	Υ	N	Υ	N	N	Υ	Υ
Known drug users (whatever the cause of death)	N	Υ	N	N	Υ	Υ	N	N	N	Υ	N	N	N	N	Υ	Υ

Y = Yes, N = No, U = Unclear

- 1) If the deceased was known to be an addict or if illegal drugs were detected
- 2) If toxicology was asked for
- 3) If the substance is a substitute for illegal drugs
- 4) If related to drug use/ despair on personal situation which should be dominated by drug use problem
- 5) Only with substances
- 6) Long-term disease following drug use
- 7) Only in Budapest
- 8) Only when inclusion criteria "deaths among drug users, drug related deaths and alcohol related deaths" DRD due to medical errors are excluded
- 9) 15 to 64 years
- 10) Only when illegal drugs are involved
- 11) Some deaths in older persons and many deaths from late complication of trauma are missing
- 12) Only DRD cases
- 13) without substances only when the person is a known drug user

3.5 Information recorded in Special Mortality Registries for DRD cases

In Section 4 we tried to summarise the included variables and what information is collected for each case of DRD. All Special Mortality Registries collect information on the date of birth (or the age at the time of death) and the date of death as well as the sex. The name of deceased is only collected in two-thirds of the countries, due to data protection issues some countries do not collect this information. None of the Special Mortality Registries collects information on whether witness statemens are supplied. The Special Mortality Registries offer a great information source on substances involved and the most common using patterns as almost all include information on the substances found in deaths.

Hungary is currently setting up a new system of data collection that will include more of the information available from autopsy records This new system will also include information on: place of residence (Budapest, town, village, homeless, etc.), tattoo, piercing, sign of intravenous use, level of blood alcohol, level of urine alcohol and histology.

Suggestions for which variables could be included in the Special Mortality Registries are: How many children did the deceased have? If previously treated for dependency what treatment they received? Where the substances found on toxicology implicated in the death? Type of accomodation at time of death? Use of substance in month prior to death? Was deceased in hospital at time of death? Antemortem toxicology? Does the case fulfill EMCDDA requirements? HIV serology?

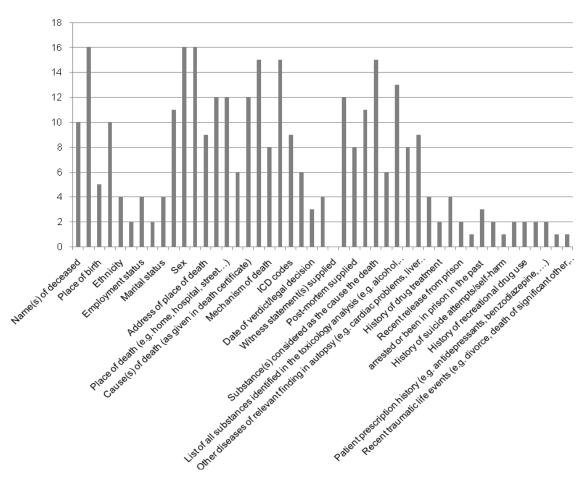


Figure 3.3: Data items recorded for DRD cases (n = 16)

Hungary is currently setting up a new programme. Table 3.6 indicates what information is recorded in autopsy records.

Table 3.6: Information collected and recorded for each DRD case going for autopsy

Variables included	Austria	Croatia	Cyprus	Czech Rep.	Denmark	Finland	France	Germany	Hungary ¹⁰	Ireland	Latvia	Lithuania	Malta	Spain	Sweden	UK
Name(s) of deceased	Υ	Υ	Υ	N	N	Υ	U	N	N ¹¹	Υ	Υ	Υ	Υ	Ν	Υ	Υ
Date of birth (or age at the time of death)	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Y^7	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
Place of birth	Ν	Υ	N	N	N	Ν	Ν	N	N	Υ	Υ	N	Ν	Υ	N	Υ
Nationality	N	Υ	N	N	Υ	Υ	N	Υ	Υ	Υ	Υ	N	Υ	Υ	Υ	Υ
Ethnicity	Ν	Υ	Υ	N	N	Ν	Ν	Ν	N	Υ	Υ	N	Ν	N	Ν	Υ
Educational level	Ν	Υ	N	N	N	Ν	Ν	Ν	N	Ν	Ν	N	Ν	N	Ν	N
Employment status	Ν	Υ	N	N	N	Υ	Ν	Ν	N	Υ	Ν	N	Ν	N	Ν	Υ
Living arrangements	Ν	Υ	N	N	N	Ν	Ν	Ν	N	Υ	Ν	N	Ν	N	Ν	Υ
Marital status	N	Υ	N	Υ	N	Ν	Ν	N	N	Ν	Ν	N	Ν	Υ	Ν	N
Usual address, including post code	Υ	Υ	Υ	N	N	Υ	Ν	N	N	Υ	Ν	Υ	Υ	Y ¹⁴	Υ	Υ
Sex	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
Date of death	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
Address of place of death	Υ	Υ	N	N	Υ	Υ	N	N	N	Ν	Υ	N	Υ	Y ¹⁴	Υ	Υ
Place of death (e.g. urban, rural)	Υ	Υ	Υ	N	N	Υ	Υ	Y ⁸	N	Ν	Υ	Υ	Υ	Υ	N	Υ
Place of death (e.g. home, hospital, street)	Υ	Υ	N	Υ	Υ	N	Υ	N	Υ	Υ	Υ	Υ	N	Υ	N	Υ
Location of incident leading up to death	Υ	Υ	N	N	N	U	N	N	N	Ν	Υ	Υ	Ν	Ν	N	Υ
Cause(s) of death (as given in death certificate)	N	Υ	Υ	Υ	Υ	Υ	Υ	N	Υ	Υ	Υ	Υ	Υ	N	Υ	Υ
Intentionality (e.g. accidental, suicide, homicide, undetermined)	Υ	Υ	Y ²	Υ	N	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Y ¹⁵	Υ	Υ
Mechanism of death	Υ	N	N	N	N	Υ	Υ	N	N	Υ	Υ	Υ	Ν	N	Ν	Υ
Manner of death (e.g. poisoning, injury, traffic accident, disease)	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	N	Υ	Υ	Υ	Υ	N	Υ	Υ
ICD codes	N	Υ	N	Υ	N	Υ	Υ	N	Υ	Υ	Υ	Υ	Ν	N	Υ	Υ
Verdict/legal decision as to cause of death	Υ	U	N	N	N	Ν	Ν	Ν	N	Υ	Υ	Υ	Ν	N	Ν	Υ
Date of verdict/legal decision	N	U	N	N	N	Ν	Ν	N	N	Ν	Υ	Υ	Ν	N	Ν	Υ
Circumstances (e.g. death alone, with witnesses)	N	N	N	N	N	Υ	N	N	N	Υ	N	Υ	N	N	Ν	Υ
Witness statement(s) supplied	N	N	N	N	N	Ν	N	N	N	Ν	N	N	Ν	N	Ν	N
Whether an autopsy was done	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	N	Ν	N	Υ	Ν	Υ	Υ	N
Post-mortem supplied	Υ	Υ	N	N	N	Υ	Ν	N	N	Ν	Υ	Υ	N	Υ	N	Υ
Toxicology report(s) supplied	Υ	Υ	N^3	Υ	N	Υ	Υ	Ν	N	Υ	Υ	Υ	Ν	Υ	Ν	Υ
Substance(s) considered as the cause the death	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	N	Υ	Υ	Υ	Υ	Υ	N	Υ
Route of administration (Injection or others) of the substance in cause	Υ	N	N	N	Y ⁶	N	Υ	N	N	Υ	Z	N	N	Y ⁶	N	Υ
List of all substances identified in the toxicology analysis (e.g. alcohol, prescription drugs, illicit psychoactive substances)	Υ	N	Υ	Υ	Υ	Υ	Υ	N	Υ	Υ	Υ	Υ	N	Υ	Υ	Υ
Level(s) of the substances found	N	N	N	Y ⁴	N	Υ	Υ	N	N	Υ	N	Y ¹³	N	Υ	Υ	Υ

continued

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Variables included	Austria	Croatia	Cyprus	Czech Rep.	Denmark	Finland	France	Germany	Hungary	Ireland	Latvia	Lithuania	Malta	Spain	Sweden	UK
Other diseases of relevant finding in autopsy (e.g. cardiac problems, liver disease, HCV, HIV/AIDS,)	Υ	Y ¹	N	Υ	Ν	Ζ	N	Y ⁹	Y ¹²	Υ	N	Υ	Ν	Υ	Ν	Υ
History of drug abuse	Ν	Y ¹	Ν	Ν	Ν	Ν	Υ	Ν	Υ	Υ	Ν	Ν	Υ	Ν	Ν	Υ
History of drug treatment	N	Y ¹	N	Ν	Ν	Ν	N	N	N	Υ	N	N	Ν	Ν	Ν	Υ
Whether the person was on opiate substitution treatment at the time of death	Υ	Y ¹	N	N	N	N	N	N	N	Υ	N	N	N	N	N	Υ
Recent release from prison	N	Y ¹	N	N	N	Ν	N	N	N	Υ	N	N	N	N	N	Υ
Recent release from detoxification unit	N	Y ¹	N	Ν	Ν	Ν	N	N	N	Ν	N	N	Ν	Ν	Ν	Υ
Whether the person has been arrested or been in prison in the past	N	Y ¹	N	N	N	N	N	N	N	Υ	N	N	N	N	N	Υ
History of overdose(s)	N	Y ¹	Ν	Ν	Ν	N	Ν	N	N	Ν	N	Ν	Υ	Ν	Ν	Υ
History of suicide attempts/self-harm	N	Y ¹	N	Ν	Ν	Ν	N	N	Υ	Ν	N	N	Ν	Ν	Ν	Υ
History of harmful or dependant alcohol drinking	N	Y ¹	N	N	N	N	N	N	N	Υ	N	N	N	N	N	Υ
History of recreational drug use	N	Y ¹	N	N	N	Ν	N	N	N	Υ	N	N	N	N	N	Υ
History of volatile substance abuse	N	Y ¹	N	N	N	Ν	N	N	N	Υ	N	N	N	N	N	Υ
Patient prescription history (e.g. antidepressants, benzodiazepine,)	N	Υ	N	N	Ν	Ν	N	N	N	Υ	N	N	N	N	N	Υ
Patient co-morbidity, including mental health condition and physical	N	Y ¹	N	N	N	N	N	N	N	N	N	N	N	N	N	Υ
Recent traumatic life events (e.g. divorce, death of significant other, redundancy)	N	Υ	N	N	N	N	N	N	N	N	N	N	N	N	N	Υ

Y = Yes, N = No, U = Unclear

- 1) Only if registered earlier in the Registry
- 2) For indirect DRD
- 3) Only toxicology results
- 4) In most cases
- 6) Needle marks
- 7) age
- 8) Bundesland
- 9) HIV rate on aggregated level10) new system of data collection
- 11) TDI codes
- 12) Only if test was performed
- 13) Depends on lab equipment
- 14) Province and municipality
- 15) Suicide only

3.6 Information flows

The information flows provided by the countries are presented in Annex III to this document. Due to vary specific and coherent situations in the countries no generic information flow can be provided. Usually a natural death and non-natural deaths follow different paths of information flow. Table 3.7 gives an overview of which different information sources are combined in the Special Mortality Registries and how the information is stored and who is paying for the data collection. In most countries the data collection in the Special Mortality Registry is part of regular activities of certain institutions (NFPs, Police....) and has no designated budget.

Table 3.7: Information flow of SMR

Country	Who provides Information	Storage of information	Who pays
Austria	Forensic institutes, free-lance doctor conducting autopsies, police	Investigations are sent in PDF – NFP extracts information in EXCEL	Ministry of Health
Croatia	GMR, Treated drug addicts registry	GMR and Treated drug addicts registry	Part of national statistical research
Cyprus	Drug law enforcement unit, national laboratory, statistical sevice, hospital emergency units, forensic pathology services, treatment services	electronically	No extra budget (part pf regular activities of NFP)
Czech Republic	Forensic medicine institute	Database in each forensic institute	Nobody
Denmark	Police, forensic institutes	As a statistic	Forensic institutes, National Board of Health
Finland	Police, forensic medicine	Electronically and paper	State
France	Volunteer forensic practitioners	Database	No extra budget
Germany	Police, forensic institute	Data File	No extra budget
Hungary	Forensic institutes, departments of Forensic Medicine	Paper templates which are summarised in EXCEL	No extra budget (automatic data collection; a person is subcontracted by the NFP to process data.) Department for Health and
Ireland	From coroners by NDRDI-staff	Specific drive of the Health Research Board	Children, Department of Justice, Equality and Law Reform
Latvia	Police, forensic examination, toxicological laboratories	Database in the State Centre of Forensic Medical Examination	State
Lithuania	No SMR	No SMR	No SMR
Malta	Police collects information from relevant sources	Electronical and hardcopy	Court, police
Spain	Forensic medicine, autonomous communities	Databases on level of autonomous communities – files are sent to central level	Autonomous communities
Sweden	No data	No data	No data
United Kingdom	Coroner, police, Drug and Alcohol Action Team, Primary Care Trust, np-SAD staff, General Register Office for Northern Ireland, Northern Ireland Statistics and Research Agency, Scottish Crime & Drug Enforcement Agency	Password protected SPSS datafile	Local authorities, Department of Health

3.7 Procedures and legal background

A couple of countries operate a Special Mortality Registry without a legal basis, solely based on consensus (See Table 3.8), but in some countries the Special Mortality Registry is part of a national strategy on drugs (e.g. in Ireland).

Table 3.8: Legal basis of SMR and link to national strategy

Country	Legal base	Part of national strategy
Austria	Yes "Suchtmittelgesetz"	No national strategy
Croatia	Act on Official Statistics, Health Care Act	No data
Cyprus	Prevention of the use and dissemination of drugs and other substances regulations of 2002	Yes
Czech Republic	No legal basis	Yes
Denmark	The law only regulates how death should be ascertained and the possible reporting to the police	No data
Finland	Decree 169/1948	Yes
France	No data	No
Germany	Internal police codification from 1978	No
Hungary	Governmental degree	No
Ireland	Approval from ethical commitee	Yes
Latvia	No data	Yes
Lithuania	No SMR	The development of future SMR is part
Malta	No data	No data
Spain	Consensus between autonomous communities	Yes
Sweden	No data	No data
United Kingdom	Voluntary basis	Yes

Death Certificates are the basis for GMRs in all countries. The Death Certificate (DC) includes different variables. In some countries it is possible to issue a provisional DC which is at a later stage replaced by a final DC where the final cause of death (after a forensic investigation) is stated (See Table 3.9). The DCs in some countries offer the possibility of indicating whether the Cause of Death is based on a post-mortem investigation. The percentage of DCs based on post-mortem investigations is a well established indicator of the quality of a GMR.

Table 3.9: Identification of post-mortem investitgations in DCs and possibilities of provisional DCs

Country	Post-mortem investigation clearly identified	Provisional DC
Austria	Yes	No
Croatia	Yes	Yes
Cyprus	Not cleary, but can be identified via the signature of forensic physician	Only in some cases
Czech Republic	Yes	No
Denmark	Yes	Yes
Finland	Yes	No
France	No data	Yes
Germany	No	In some regions
Hungary	Yes	Yes
Ireland	Yes	No
Latvia	Yes	Yes
Lithuania	Yes	Yes
Malta	Yes	Yes
Spain	No data	No
Sweden	Yes	No
United Kingdom	Yes	No

4 Discussion

- 16 countries returned the questionnaire on Special Mortality Registries on DRD (Austria, Czech Republic Croatia, Cyprus, Denmark, Finland, France, Germany, Hungary, Ireland, Latvia, Lithuania, Malta, Spain, Sweden, United Kingdom), and 2 countries reported having no Special Mortality Registry (Estonia, Poland). This leads to a return rate of 60 percent.
- The information flow for data for a Special Registry varies across Europe. Most Special Mortality Registries combine various information sources and therefore have different persons in charge. Unlike the information in the GMR the information flow is very complex. Most Special Mortality Registries include a lot of additional (contextual) information which are not found in the GMR and which can be used to describe risk factors for DRD. This valuable additional information should be focused on by small scaled studies (maybe in co-operation between two or three countries).
- In many cases there is a link between GMR and Special Mortality Registries. Often it
 is not completely clear to what extent this link functions. Case-coverage studies
 between GMR and Special Mortality Registry could help to get a more precise
 picture and also to validate information from GMR.
- Some Special Mortality Registries, which seem to include all deaths among known drug users (e. g. Croatia), could function as a basis for mortality cohort studies.
- When the Special Mortality Registry includes in the definition "kown drug users" you can assume, that the data are incomplete (not all drug users are known regardless

which database is used). Nevertheless the data could give a lot of qualitative information about indirect DRD.

5 Summary about the feasibility of future cooperative research project in Europe based on common data

- Since some countries put a lot of effort in putting together various data sources cooperative research seems sensible. The Special Mortality Registries allow more insights into the characheristics of people dying from drugs than the GMR. This project showed the broad additional information collected in the Special Mortality Registries. These information could help to gain further insights on the problem of DRD and detect problematic situations (e.g. after recent prison release) that could be used for prevention of deaths in the future.
- Data protection issues could cause a problem when combining data from different sources.
- Future research on Special Mortality Registries should include general research
 questions and how this could be answered through the Special Mortality Registries
 in the countries, a Standard Table by the EMCDDA seems not feasible at the
 moment as the underlying structures of the Special Mortality Registries are so heterogenous. Interesting research questions that could be answered by a cooperative
 research based on data from the Special Mortality Registries include contextual
 information, substances found, co-morbidity and recent release from detox.
- Additional case coverages studies on linking of GMR to Special Mortality Registries could provide valuable information on the data quality and detect rooms for improvement on data transmission (which is also in the interest of the national statistical institutes).
- A European exchange of knowledge or some data base on models of good practice could lead to more harmonised Special Mortality Registries in the long term. As countries who want to set up a new Special Mortality Registry have models of good practice to draw back on. These could include information on core items and how they are measured as well as information on the technical solution (e.g. data exchange).

6 References

An additional source of information - The National abstracts for the annual meeting on the KI "Drug related death" - 2007.

Drug related deaths Methodology: http://www.emcdda.europa.eu/stats07/DRD/methods

Drug-Related Deaths (DRD) Standard Protocol, version 3.2. by EMCDDA from 2008

Feasibility study of the implementation of the proposals given in the final report of REITOX sub-task 3.3 - to improve the quality and comparability of data on drug-related deaths" from 1998

Methods and Definition: http://stats05.emcdda.europa.eu/en/page032-en.html

Quality and comparability of data on drug-related deaths (feasibility study) by EMCDDA from 1998; http://www.emcdda.europa.eu/html.cfm/index58085EN.html

Test of the draft standards developed by EMCDDA projects on drug-related deaths, and development of proposals to improve data quality and comparability from 1999