A review of the Inventory of the national Special Mortality Registries in Europe with a focus on information flow to the General Mortality Registries

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Part II

DRAWN UP ON BEHALF OF THE EUROPEAN MONITORING CENTRE FOR DRUGS AND DRUG ADDICTION

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European Monitoring Centre on Drug and Drug Addiction: Isabelle Giraudon & Roland Simon;

National Focal Points and National Experts:

Country	National Expert/s who replied	Institute	National Focal Point	Institute
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Croatia	Tanja Coric, Dragica Katalinic	Croatian National Institute of Public Health	Dijana Jerković	Government of the Republic of Croatia Office for Combating Narcotic Drugs Abuse
Cyprus	Pavlos Pavlou, Ioanna Yiasemi, Kokkinos George, Maria Afxentiou	Ministry of Health, Cyprus Monitoring Centre for Drug and Drug Addiction, Drug Law Enforcement Unit	Ioanna Yiasemi	Cyprus anti-drugs Council ; Cyprus Monitoring Centre for Drug and Drug Addiction
Czech Republic	Blanka Nechanská Frantisek Vorel	Institute for Health information and statistics, Department of forensic medicine, Hospital Ceske Budejovice	Viktor Mravcik	Secretariat of the Council of the Government for Drug Policy Coordination
Denmark	Kari Grasaasen (with help from national experts, Henrik Sælan, Kirsen Wiese Simonsen and Claudia Ranneries)	Danish Health Authority/Danish Focal Point	Kari Grasaasen	National Health Authority
Estonia	Gleb Denissov	National Institute for Health Development	Katri Abel-Ollo	National Institute for Health Development- Infectious diseases and drug monitoring department.
Finland	Pirkko Kriikku	National Institute for Health and Welfare	Martta Forsell	National Institute for Health and Welfare (THL)
France	Anne-Claire Brisacier	French Monitoring Centre on Drugs and Drug Addictions (OFDT)	François Beck	Observatoire Français des drogues et des toxicomanies (French Monitoring Centre for Drugs and Drug Addiction)
Hungary	Gergely Horvath	Reitox Hungarian National Focal Point National Institute for Health Development	Adrienn Nyírády	National Institute for Health Development
Latvia	Inga Martinova	Centre for Forensic Medical Examination	Ieva Pugule	Centre for Disease Prevention and Control of Latvia
Luxembourg	Alain Origer	National Focal Point	Alain Origer	Luxembourg Institute of Health Point Focal OEDT
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Netherlands	Guus Cruts	Netherlands National	Margriet van Laar	Trimbos Institute (Netherlands Institute

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Norway	Thomas Clausen with inputs from; Vigdis Vindenes, Christian Ellingsen, and Gerd Jorunn Delaveris	Norwegian Centre for Addiction Research, University of Oslo	Thomas Anton Sandøy	Norwegian Institute of Public Health
Portugal	Mário Dias	National Institute of Legal Medicine and Forensic Sciences (INMLCF)	Ana Sofia Santos	Serviço de Intervenção nos Comportamentos Aditivos e nas Dependências (SICAD)
Spain	Rosario Sendino, Elena Alvarez. Noelia Llorens, Begoña Brime. Aurora Ruiz-Lizcano. Eva Sanchez-Franco	Spanish Observatory on Drugs Team. Government Delegation for the National Plan on Drugs. Ministry of Health, Social Services and Equality	Francisco de Asís Babín Vich	Government Delegation for National Plan on Drugs (Delegacíon del Gobierno para el Plan Nacional sobre Drogas)
Turkey	Bulent Şam	Ministry of Justice, Council of Forensic Medicine	Bülent Özcan	Turkish Monitoring Centre for Drugs and Drug Addiction (Türkiye Uyuşturucu ve Uyuşturucu Bağımlılığı İzleme Merkezi)

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Glossary

DC	Death Certificate
DRD	Drug related death
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
GMR	General Mortality Register
ICD	International Statistical Classification of Diseases and Related Health Problems
NFP	National Focal Point
SR	Special Register
WHO	World Health Organisation

Executive Summary

- The number of drug related deaths varies widely between countries and also sometimes in the same country in reported numbers from GMR and SR. These differences may be due to 'real' differences and/or differences in methodology, data quality and data completeness.
- The aim of this part of the project is to review the information flow to the General Mortality Registries (GMRs) which often determines the completeness and data quality of mortality statistics.
- The project aims to review, update and expand on the reports done in 2009 on the information flow to the General Mortality Registries (GMRs) as well as identifying examples of good practices as well as pitfalls in the collection of DRD data by the GMRs.
- 19 countries out of 30 answered the questionnaire in 2016.
- Owners of the post mortem reports often lie with the police and judicial system, outside of the departments of health or statistical offices.
- Only 9 out of the 19 reporting countries (47%) reported as having a systematic data collection of post-mortem reports with national coverage.
- Many countries 13/19 (68%) reported that the extraction of data for DRD monitoring either by the focal point or by someone else e.g. by an expert working within the institute which collects the data is possible though sometimes laborious.
- Some countries 9/19 (47%) have a provisional (i.e. death certificate without final cause of death) death certificate in place.
- In 15/19 (79%) countries the GMR is aware that a medico-legal investigation is being carried out.
- The amount of information from the medico-legal investigation reaching the GMRs varies widely between countries. The GMR in a few countries such as the Czech Republic, Denmark and Norway have access to all post-mortem reports using them when issuing the causes of death. Though the amount of information given varies. However in most countries information from the medico-legal investigation is received by the GMR through the 'final' death certificate which may not have enough information to code the cause of death accurately.
- Data protection and sensitivity of data issues are often quoted as reasons for the non transmission of autopsy and toxicology results to the GMRs.
- Countries have resorted to different methodologies to improve the information recorded on the death certificates in order to improve the quality of mortality statistics produced. Some of these methodologies could possibly be adopted in other countries.

1. Introduction and background

Monitoring of drug related deaths (DRDs) is currently based on a European protocol created by the EMCDDA. Countries report data on DRDs through two main sources: the General Mortality Register which report data according to selection B reporting protocol and/or the Special Register which report data according to selection D.
The number of drug related deaths varies widely between countries and also sometimes in the same country in reported numbers from GMR and SR. These differences may be due to 'real' differences and/or differences in methodology, data quality and data completeness.[1]

The GMR and SR use different sources of information to produce statistics on drug related deaths. The main source of information for the GMR is the death certificate which may or may not be supplemented by additional information. It usually has national coverage. The Special Register often obtains information for other specialised sources such as toxicology laboratories and forensic departments. It may or may not have national coverage. The SR and GMR may or may not communicate which each other (figure 1).

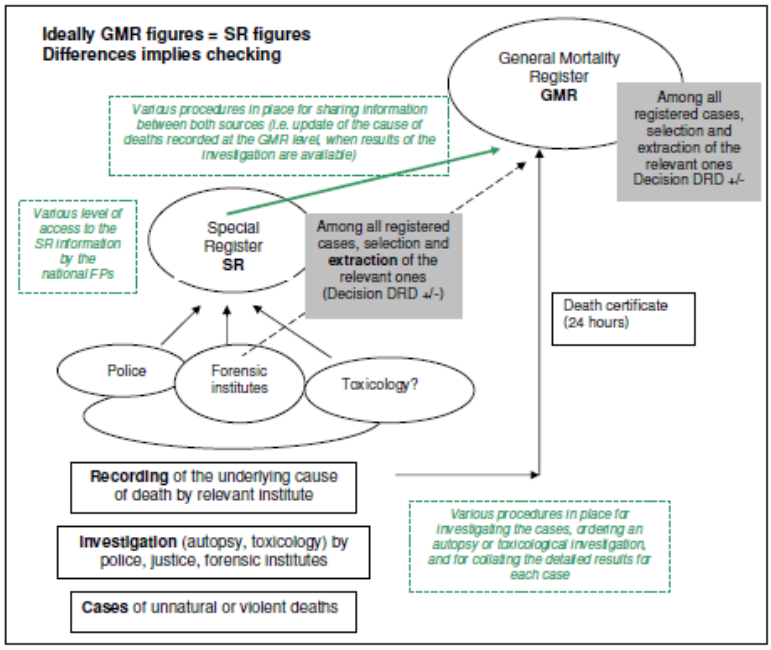


Figure 1: Information flow to GMR and SR[2]

Aim

This report is being carried out to fulfil one of the three tasks in the Project entitled 'To contribute to the EMCDDA review of the drug related death data from the GMR in some countries (including the codification practices of DRD following the WHO revision of ICD coding guidelines)' .[3]

The aim of this part of the project is to review the information flow to the General Mortality Registries (GMRs) which often determines the completeness and data quality of mortality statistics. This project also aims to identify examples of good practices in countries which have facilitated the collection of good quality data, as well as pitfalls which hinder the collection of complete good quality DRD data by the GMRs.
This report will complement two other reports which are also part of the project which will aim to review general trends in DRDs statistics (Part I) as well as look deeper into coding practices in a

number of countries (Part III: Country Reports). The DRDs statistics produced as well as coding used are often determined by what information reaches the general mortality register.

This is a follow up on the project carried out in 2009, and coordinated by Charlotte Klein, at the Austrian Focal point CT.08.EPI.O83.1.0: Inventory of the national Special Mortality Registries in Europe, and description of the core data available.[2]

2. Methodology

The same questionnaire that was created and sent to all members of the European Union as well as Norway and Turkey in 2009 was again sent to these countries in May 2016, followed by a reminder. Countries who had previously replied were asked to review their replies and update as necessary, whilst those who had never answered were asked to complete it.

As the analysis of the questionnaire had been done in great detail in 2009[2], the emphasis in the present report was on information flow to the General Mortality Registry.

The main areas focused on are:

1) Who owns the data of the post-mortem investigation?
2) Is there any location where the information resulting from these post-mortem investigations of unnatural or violent deaths are filed in an organised way ("system")?
3) Is there the possibility of extracting data for DRD monitoring by the national Focal Point (or by somebody on its behalf)?
4) Are death certificates undergoing post-mortem investigation being clearly identified?
5) How is the information generated during the post-mortem investigation used in the death registration process?
6) Is it possible to identify in the outcomes of cause(s) of death produced by the GMR those cases that are/have been under investigation?

The final section will focus on examples of good practice in the information flow to the GMRs as well as pitfalls in the transmission of this data.

3. Results

19 countries out of 30 answered the questionnaire in 2016. Table 1 below, details the countries who contributed in 2009 and 2016, as well as the experts and organisations that replied. This report will focus of those countries which completed the questionnaire in 2016.

Table 1: Country response to the questionnaire in 2009 and/or 2016

Country	Replied in 2009	Replied in 2016	Expert(s) who replied in 2016	Organisation(s)
Austria	Yes	Yes	Judith Anzenberger	Austrian Public Health Institute/Austrian Focal Point
Belgium	No	Yes	Lies Gremeaux	National Focal Point Belgium, Scientific Institute for Public Health
Bulgaria	No	Yes	Georgi Shopov	National Focal Point Bulgaria
Croatia	Yes	Yes	Tanja Coric, Dragica Katalinic	Croatian National Institute of Public Health
Cyprus	Yes	Yes	Pavlos Pavlou, Ioanna Yiasemi, Kokkinos George, Maria Afxentiou	Ministry of Health, Cyprus Monitoring Centre for Drug and Drug Addiction, Drug Law Enforcement Unit
Czech Republic	Yes	Yes	Blanka Nechanská Frantisek Vorel	Institute for Health information and statistics, Department of forensic medicine, Hospital Ceske Budejovice
Denmark	Yes	Yes	Kari Grasaasen (with help from national experts, Henrik Sælan, Kirsen Wiese Simonsen and Claudia Ranneries)	Danish Health Authority/Danish Focal Point
Estonia	No	Yes	Gleb Denissov	National Institute for Health Development
Finland	Yes	Yes	Pirkko Kriikku	National Institute for Health and Welfare
France	Yes	Yes	Anne-Claire Brisacier	French Monitoring Centre on Drugs and Drug Addictions (OFDT)
Germany	Yes	No		
Greece	No	No		
Hungary	Yes	Yes	Gergely Horvath	Reitox Hungarian National Focal Point National Institute of Health Development
Ireland	Yes	No		
Italy	No	No(some feedback was given by email)		
Latvia	Yes	Yes	Inga Martinova	Centre for Forensic Medical Examination
Lithuania	Yes	No		
Luxembourg	No	Yes	Alain Origer	National Focal Point
Malta	Yes	Yes	Kathleen England	Directorate for Health Information and Research
Norway	No	Yes	Thomas Clausen with inputs from; Vigdis Vindenes, Christian Ellingsen, and Gerd Jorunn Delaveris	Norwegian Centre for Addiction Research, University of Oslo
Poland	No	No		
Portugal	No	Yes	Mário Dias	National Institute of Legal Medicine and Forensic Sciences (INMLCF)
Rumania	No	No		

Slovak Republic	No	No		
Slovenia	No	No		
Spain	Yes	Yes	Rosario Sendino, Elena Alvarez. Noelia Llorens, Begoña Brime. Aurora Ruiz-Lizcano. Eva Sanchez-Franco	Spanish Observatory on Drugs Team. Government Delegation for the National Plan on Drugs. Ministry of Health, Social Services and Equality
Sweden	Yes	No		
The Netherlands	No	Yes	Guus Cruts	Netherlands National Focal Point/Netherlands National Drug Monitor (NDM) operated by the Trimbos Institute, Netherlands Institute of Mental Health and Addiction
Turkey	No	Yes	Bulent Şam	Ministry of Justice, Council of Forensic Medicine
United Kingdom	Yes	No		

The information presented in the following results is mainly focused on information flow to the General Mortality Registry and thus does not aim to analyse results related to the Special Register in detail, as this has already been very well accomplished in the previous project in 2009.

3.1 Investigation of unnatural deaths

Investigation of unnatural deaths has been described in the previous report in 2009. Usually when deaths due to 'unnatural causes' happen an investigation is carried out by entities which are outside the health departments or statistical offices where often the GMRs reside. Even though in some countries the health department is involved in the autopsy, further investigation is usually carried out by the police and judicial system. Due to this structure, transmission of information as to the final causes of death may be more difficult to reach the GMRs in some countries. As described in table 2 below, owners of the data often lie with the police and judicial system outside of the departments of health or statistical offices.

Table 2: Who owns the data of the post-mortem investigation?

Country	**Owner of the data**
Austria	Ministry of Justice
Belgium	Possibly Ministry of Justice
Bulgaria	Department of Forensic Medicine/Police
Croatia	The institutes where autopsies are performed own the data
Cyprus	Department of Forensic Medicine under the Direction of the Medical and Public Health Services of the Ministry of Health for autopsy reports. State General Laboratory for toxicology tests
Czech Republic	Forensic Medicine Department
Denmark	Police
Estonia	N/A
Finland	Police/forensic pathologist/Forensic toxicology Unit
France	Forensic Institution
Hungary	Police
Latvia	Latvia State Centre for Forensic Medical Examination (SR) and Centre for Disease Prevention and Control (LSEFME)
Luxembourg	The National Laboratory of Health for toxicological and autopsy reports
Malta	Magistrate
Norway	The Police own the data and the General Attorney of the State regulates it
Portugal	Public Ministry
Spain	Judge and Forensic
The Netherlands	The forensic department of a municipal health service or the Netherlands Forensic Institute (NFI).
Turkey	The Council of Forensic Medicine of Ministry of Justice. (ATK: ADLI TIP KURUMU)

3.2 Systematic data collection on information obtained from post-mortem investigations

Only 9 out of the 19 reporting countries (47%) reported as having a systematic data collection with national coverage, however in some countries this data collection is in a manual form making it difficult to analyse. Other countries report systematic data collection involving toxicology reports only e.g. Finland and Luxembourg.
Also in some countries rather than having a national central system, they have regional services. These may only cover part of the country e.g. in Spain and also accessibility of data to the GMR varies e.g. in France.

Table 3: Is there any location (institute, unit, database) where the information resulting from these post-mortem investigations of unnatural or violent deaths are filed in an organised way ("system")?

Country	Systematic data collection	National Coverage	Place
Austria	No	No	
Belgium	Yes	Yes	The national office (Directorate General Statistics and Economic Information (DGSEI) Statistics Belgium) is responsible for National Health statistics and receives the original death certificate and related document after coding and processing. All information is assembled in the General Mortality Register.
Bulgaria	N/A	N/A	
Croatia	No	No	
Cyprus	Currently manual but the establishment of a documentation system is in progress.	The above database has coverage of the Government controlled area of Cyprus.	Police database.
Czech Republic	Yes	Yes	Every forensic medicine department fill up information about post-mortem investigations into "National register of autopsies and toxicological examinations performed at forensic medicine departments". Institute of Health Information and Statistics of the Czech Republic administer this national register.
Denmark	Yes	Yes	General Mortality Register /Police
Estonia	N/A	N/A	
Finland	No (see comments)	See comments.	The police data is most likely divided in regional databases but - when combined - has a national coverage all in all. The post-mortem toxicology database has a national coverage.
France	No (see comments)	No	The GMR, however some forensic laboratories do not transmit the results

			of their studies to the GMR, arguing medical secrecy. Next, the French National Agency for Medicines and health products Safety (ANSM) signed an agreement with toxicological laboratories to retrieve information on DRD: this is one of the SR. For legal reasons, strong information limitations are set up to prevent any individual recognition. Finally, the police database on DRD should be mentioned, although known for underreporting DRD.
Hungary	No	No	Each institution (N=13) keeps a record of their cases but there is no national database of the results of port-mortem investigations
Latvia	Yes	Yes	Latvia State Centre for Forensic Medical Examination (LSCFME) and by the Centre for Disease Prevention and Control.
Luxembourg	No (see comments)	N/A	The Special Drug Unit of the Judicial Police (SPJ) maintains an inventory on acute drug deaths (which is not a register in the formal sense). The referred inventory indexes all direct overdose cases due to illicit drug use documented by forensic evidence.
Malta	Yes (manual)	Yes	Forms part of the processus verbatim stored in the court of law.
Norway	Yes (manual)	Yes	All the reports are sent to The Norwegian Civil Affairs Authority/Norwegian Board of forensic medicine, in addition to being filed as a case-document in the police file. But the information from the reports is not organized in a "system". The copies of the reports are made available to the GMR.
Portugal	Yes	Yes	Database of the National Institute of Legal Medicine and Forensic Sciences (INMLCF) with information about autopsy including complementary tests (toxicology, genetics etc.)
Spain	Yes	No	Every forensic medicine department has its own database or filing system and sends the data to the autonomous government or it allows an authorized person to access the file. Regional level for some autonomous communities (18 of 19 in 2014) and city level (various big and medium cities). Global geographical coverage about 50% of the Spanish population.
The	Yes	It has national	The Netherlands Forensic Institute

Netherlands		coverage with regard to those selected cases that are investigated at the NFI	(NFI) currently operates an electronic database that has replaced the previous paper archive.
Turkey	Yes	Yes	National Justice Intranet system

3.3 Extraction of data for DRD monitoring by the National Focal Point

Many countries 13/19 (68%) reported that the extraction of data for DRD monitoring either by the focal point or by someone else e.g. by an expert working within the institute which collects the data is possible. However sometimes the process is laborious requiring special permission and may not include individual identifiers.

Table 4: Is there the possibility of extracting data for DRD monitoring by the national Focal Point (or by somebody on its behalf – e.g. an appointed forensic doctor, researcher, etc.-)?

Country	Possibility of extracting data for DRD monitoring	Comments
Austria	Yes	The national Focal Point has full access to the data of SR on drug related deaths and receives additional information from the GMR to be included in the SR. However most of federal states have additional ways of collecting data on drug related deaths e.g. they are receiving the post-mortem investigation files from the forensic institutes (without any legal obligation).
Belgium	Yes	The national focal point is located at the WIV-ISP institute for public health, and data from Statistics Belgium is forwarded to the institute.
Bulgaria	Possible through a study	In recent years NFC Bulgaria performed study through the Centre of Forensic Medicine and deontology to (Alexander's Hospital) in Sofia. Performed under grant agreement with EMCDDA. These cases cover only persons who have died in Sofia-city and region, now NFC unable to retrieve such data from other regional cities in Bulgaria.
Croatia	N/A	In the regular mortality statistics in the process of clarification the unknown (or unclear) causes of death, CNIPH through the network of the IPH (Institutes of Public Health at the County level) try to collect as many post-mortem data as possible in any case of unnatural death.
Cyprus	Yes it is possible	However, access to this information by other authorities is done under special arrangements between the departments.
Czech Republic	Yes	Employee of Institute of Health Information and Statistics of the Czech Republic does the extraction and provides to the National Focal Point
Denmark	Yes	Only as a scientific investigation after special permission.
Estonia	N/A	
Finland	Possible	All research needs to be authorized by an advisory board of the Institute. Within this framework, research on DRD is possible. Data extraction for e.g. the ongoing EMCDDA

		monitoring projects is possible without a separate permission
France	Yes	It is possible and performed each year in case of the GMR on special request.
Hungary	Possibility	There could be a possibility through the National Institute of Forensic Medicine.
Latvia	Yes	
Luxembourg	N/A	
Malta	No	
Norway	Generally no. (see comments)	It is possible, but this requires a lot of manual work and information must be collected from each individual report – since there is no easily available register containing this information.
Portugal	No	
Spain	Yes indirectly	Individual data with an identification code are sent to autonomous government and after to central level (in this last case after removing the identification code). The primary source of information comes from the Forensic Anatomical Institute of Madrid, Coroners, National Toxicology Institute and University Legal Medicine Departments which report this data to their Autonomous Communities, which forward the same to the database of the Spanish Observatory on Drugs of the Government Delegation for the National Plan on Drugs.
The Netherlands	Yes	Yes, each year the Netherlands National Focal Point receives an extraction of all the DRD cases from the Netherlands Forensic Institute (NFI), the statistical findings of which are reported (in Dutch) in the Annual Report of the Netherlands National Drug Monitor (NDM).
Turkey	Yes	Yes but just by the expert working there (member of ATK and national Focal Point).

3.4 Are GMRs aware that a medico-legal investigation has taken place and are post mortem results used in death registration process?

Countries have different procedures in place which allow the GMR to identify that a particular death is undergoing a medico-legal investigation (see table 5). Some countries have a provisional death certificate in place 9/19 (47%) which usually does not contain information on the final cause of death, but is pending further investigation. Other countries have tick boxes on the death certificate which indicates that death is undergoing a medico-legal investigation. 15/19 (79%) countries are aware that a medico-legal investigation is being carried out however in other countries e.g. France this is not possible. However the death certificate in France is being updated.

The amount of information from the medico-legal investigation reaching the GMRs varies widely between countries (see table 6). The GMR in a few countries such as the Czech Republic, Denmark and Norway have access to all post-mortem reports using them when issuing the causes of death. However the content varies quite a bit, from including the full report, also including all toxicology findings, to other cases where only the main findings and codes are given without all the details.
However in most countries information from the medico-legal investigation is received by the GMR through the 'final' death certificate. Staff from the GMR go through great length in trying to improve on the quality of these death certificates which do not always provide exact information as to the

causes of death. They may contact the forensic physician who completed the death certificate or try to link with other sources such as the Special Register. However in some countries forensic institutes do not always provide feedback, citing data protection issues. Only 10 out of 19 (53%) countries can identify if a death in a GMR database has undergone an investigation (Table 7).

Table 5: Are death certificates undergoing post-mortem investigation being clearly identified?

Country	Provisional DC	Awareness by GMR that forensic investigation is being done	Comments
Austria	No	Yes	The death certificate indicates whether the cause of death is based on a post-mortem investigation.
Belgium	No	Yes	The national office (Directorate General Statistics and Economic Information (DGSEI) Statistics Belgium) is responsible for National Health statistics and receives the original death certificate and related document after coding and processing.
Bulgaria	N/A	No	
Croatia	Yes	Yes	
Cyprus	Yes	Indirectly	There is no clear indication on the death certificate on whether there was a post-mortem investigation or not. However, staff of the HMU are able to identify the signatures of the certifiers. When a death certificate is signed by a forensic physician it is assumed that a post-mortem examination was done.
Czech Republic	No	Yes	There is a definitive death certificate only, which can be corrected additionally.
Denmark	Yes	Yes	
Estonia	Yes	Yes	If diagnose is changed in course of investigation an amended medical death certificate may be issued.
Finland	No	Yes	
France	Yes	No	When the causes of death are known, a second certificate is done and data from the first are erased. The doctor who fills in the death certificate has to tick the “medico-legal issue” box so that police and judicial prosecutions are carried on. However, the GMR doesn’t know if the “medico-legal issue” box is ticked or not. This should be changed with the next version of the French death certificates (October 2016).
Hungary	Yes	Yes	Post-mortem investigation is indicated on the death certificate.
Latvia	Yes	Yes	The certificate’s form gives possibility for doctor to choose what kind of certificate it will be – temporary (provisional) or final (definitive).
Luxembourg	N/A	N/A	
Malta	Yes	Yes	Provisional is written on death certificate. Otherwise we identify signature of pathologist.

Norway	No	Yes	The GMR has the responsibility to do the final coding into the GMR coding, based on all available info, and finalizes coding only when the post-mortem report is available if this was performed. The full post-mortem report is scanned and stored, but relevant information for the coding is retrieved manually and punched. Normally the conclusion from the forensic report will be the final cause of death coded by the GMR. Sometimes the GMR receives, all toxicological data, other times, the forensic examiner only includes those substances he/she finds relevant for the cause of death into the autopsy report, and may then not report on all substances identified at toxicology.
Portugal	Yes	Yes	A provisional death certificate is issued with cause of death "under investigation", followed by a definitive death certificate when the forensic doctor establish the cause of death and conclude the autopsy report.
Spain	No	Yes	
The Netherlands	N/A	Yes	This happens in some cases but not systematically in all.
Turkey	N/A	N/A	

Table 6: How is the information generated during the post-mortem investigation used in the death registration process? (e.g. filing the definitive death certificate, or submitting an additional form to be transmitted to the GMR with the final results?)

Country	**Does information from post-mortem reach the GMR?**	**How does the GMR receive the information from the post-mortem investigation**
Austria	Yes	Usually the death certificate is sent to the statistic institute („Statistics Austria“) after an autopsy is conducted (in particular in places of Austria where an autopsy is conducted within days). The Focal Point receives the information to be included in the SR.
Belgium	Yes	The national office (Directorate General Statistics and Economic Information (DGSEI) Statistics Belgium) is responsible for National Health statistics and receives the original death certificate and related document after coding and processing.
Bulgaria	N/A	
Croatia	Yes	In the GMR we use provisional DC without the cause of death (in case of waiting on autopsies and toxicological analyses) and we correct the cause of death after we receive the final cause according to new information in a copy of the DC (from county IPH or forensic doctors). If some data are missing (results of autopsies or toxicological analyses) or quality of data is poor, the GMR collects additional information through the network of County public health institutes, sending the copy of DC with a precise query.
Cyprus	Yes through active seeking of additional	The forensic physicians also complete the **Death Certificate** for submission to the Civil Registration

	information.	Office. These death certificates are not always completed. Usually, they do not contain sufficient information to accurately determine the causes of death. The exact external causes are habitually omitted for reasons of confidentiality. Staff of the Health Monitoring Unit identify these provisional death certificates and seek additional information from the forensic physicians and by reference to their autopsy filing system. Additional information may also be obtained from certifying physicians, police reports and the Department of Labor Inspection filing system.
Czech Republic	Yes	Every forensic medicine department filled up information about post-mortem investigations into "National register of autopsies and toxicological examinations performed at forensic medicine departments". Institute of Health Information and Statistics of the Czech Republic administer this national register.
Denmark	Yes	The Danish Health Data Authority issues the cause of death (by law). As mentioned the forensic data in toto goes to the personnel within the GMR at the Danish Health Data Authoirty (they keep health statistics in Denmark) for possible more precise cause of death diagnosis.
Estonia	Yes	Through final death certificate. Cases diagnosed as poisoning with unknown substance and aspiration are checked annually with forensic toxicologist since 2011 (there is only one such laboratory in the country).
Finland	Yes	Forensic pathologist gives the death certificate (only and final one). Statistics Finland defines the underlying cause of deaths according to ICD-10 for the GMR. If necessary, they ask clarifications from the forensic pathologists and the Forensic Toxicology Unit. This happens often in cases of poly-substance findings.
France	Sometimes	When the causes of death are known and confirmed, a final certificate is delivered. Data of the first certificate are erased and replaced by the causes of the death of this final certificate. But in practice, this final certificate isn't always sent. The GMR is supposed to gather all results of biological analyses performed by any forensic laboratories. In practice, as previously mentioned, some forensic laboratories do not share the information. With the new death certificate, it will be possible to send a complementary form to update the certificate, without doing another. This should permit the forensic laboratories to add information, such as toxicological results that they couldn't wait for to fill in the certificate.
Hungary	Yes	Death certificate is filled in after autopsy was performed and it is sent to the Hungarian Central Statistical Office. If results of examinations (e.g. toxicology) are missing, there is a checkbox on the death certificate to indicate that a modification of the death certificate with the final results will be sent to the Statistical Office.
Latvia		The Death Certificates, what the experts fill in after post

		mortem investigation finally come to the Centre for Disease Prevention and Control (GR). According to the existing information the certificate could be temporary (provisional) or final (definitive). If during the investigation any new information is found the physician submit a new definitive certificate that replaces the provisional information, indicating the death certificate that will be replaced by its unique number. Sometimes information's updates don't follow the primary submitted and only temporary information on cause of death is available.
Luxembourg	N/A	
Malta	Yes	First a provisional and then a final DC is issued with the causes of death. When the GMR wants further information the pathologists are contacted. This is done easily.
Portugal	Yes	Using electronic platform - Information System of Death Certificates (SICO)
Norway	Yes	It receives the post-mortem report including toxicological information
Spain	Sometimes	After having sent death certificate with "provisional" cause of death, forensic "would have to improve or complete the reported provisional cause of death" in a standard form, but there is not legal duty for doing that, at rarely it is done. Some autonomous communities actively search and link SR and GMR to complete and correct cause of death in cases of unnatural deaths
The Netherlands	Sometimes	The GMR may indeed request further information from the SR, but this is not done systematically.
Turkey	N/A	Death certificate is issued often by forensic experts, municipal physicians or physicians from health care clinics; if the death occurs in hospital during treatment, then the related specialist physician issues the certificate.

Table 7: Is it possible to identify in the outcomes of cause(s) of death produced by the GMR those cases that are/have been under investigation?

Country	**Possible to identify cases under investigation**	**Comments**
Austria	Yes	Extra code for death certificates based on post-mortem investigations.
Belgium	No information	
Bulgaria	No	
Croatia	Yes	In the GMR we keep evidence about the DC for which we are sending a query. After our request we can identify cases of legal investigation. Our DC has no special box for point information about the investigation.
Cyprus	Yes	The GMR contains information on whether an autopsy

		was performed (yes/no), whether autopsy findings were available when the death certificate was completed (yes/no) and the manner of death (whether the death was natural, accidental, suicide, homicide, pending investigation or could not be determined after investigation).
Czech Republic	No	
Denmark	Yes	That would be all deaths with a forensic post-mortem, because they will all wait for definitive cause definition until results are present and be preliminary until then.
Estonia	Yes	GMR contains data on profession of certifier (incl. forensic pathologist) and issuing institution (incl. Institute of Forensic Science).
Finland	Yes	Also as all cases involving drugs are investigated.
France	No	Except when stated on the dc.
Hungary	No	Due to data protection.
Latvia	Yes	There is a field in the death certificate that gives information that death case is currently under investigation.
Luxembourg	No	
Malta	Yes	The database includes fields as to whether an autopsy was done and whether it was medical or legal.
Norway	Yes	In the data from the GMR, it is possible to identify which case had undergone a post-mortem and which is based only on a death certificate.
Portugal	Yes	
Spain	No	
The Netherlands	With difficulty	In principle, the contact person at the GMR can look back at the underlying files to check which information has been used to code the cause of death into ICD-10.
Turkey	N/A	

In conclusion, the main problems identified through the process of coding, recording and retrieving the DRD cases are the following:

- Not all unknown or suspicious deaths undergo forensic investigation, sometimes due to budgetary constraints;
- Toxicological and other invesitigation results may not reach the General Mortality Register for varoius reasons but often quoting data protection reasons;
- The GMR may only receive the initial (or provsional) death certificate which would not contain information about the final cause of death. This would result in coding a non specific cause of death and contribute to the undersestimation of DRDs.
- Delays in the transfer of information may result in annual statistics being produced before final death certificate or results of investigation are received by GMR.
- Also when final death certificate is issued it may lack enough detail to properly code the death certificate e.g. death due to ‘overdose‘.

4. Good Practices and pitfalls amongst the various countries

A number of countries have in place measures which could be adopted by other countries to improve the data flow to the GMRs. Some of these practices have also developed in response to lack of information being transmitted to the GMR in the hope that the data quality improves. These include:

- **legal obligation**
- Ad hoc studies or audits
- Formalised national working groups of SMR/GMR experts
- Institute of Health in charge of the GMR data
- Systematic cross-checking of the SMR and GMR sources
- Guidelines or national publication/training
- Information technology

In Austria: Following a **legal obligation**, forensic institutes have to transfer cases involving illegal substances to the Ministry of Health. Usually requests are needed for this transfer.

In Belgium: The law which dates back many years states that 'deaths occurring outside hospital increasingly involve doctors or general practitioners on duty or emergency doctors who have not known the deceased as a patient. In this case the doctor ascertaining death is obliged to fill in the certificate of death immediately and determine the cause of death without being able to wait for the results of any police investigation or judicial inquiry, or being able to consult with the attending doctor.' However the national office (Directorate General Statistics and Economic Information (DGSEI) Statistics Belgium) is responsible for National Health statistics and receives the original death certificate and related document after coding and processing. Also whenever an analytical screening is scheduled for a drug-related death case, the Early Warning System of the National Focal Point (Reitox, EMCDDA), is contacted who will also contribute to the further investigation of the involved substance.
In Belgium the causes of death are transcribed by trained coders who have a medical degree in nursing and had a specific education in coding causes of death. They are supervised by a medical doctor. Also since registration year 2012 in Flanders (and Brussels) and since 2000 in Wallonia, a semi-automatic coding system is used to process the causes of death. In Flanders and Brussels, all external causes are revised and processed manually by the coders in addition.

In Bulgaria: In an effort to improve the quality of data on DRDs, NFC Bulgaria performed studies through the Centre of Forensic Medicine and deontology to (Alexander's Hospital) in Sofia. This study is paid by the (Grant Agreement) Contract for operation between the European Monitoring Centre for Drugs and Drug Addiction and the National Center for Addiction. Delivered data are classified by sex, age, type and amount of detected substances and alcohol in the blood and urine, where they found at autopsy. Also additional information for date of death, cause and place of death was collected. However the study mentioned above only includes cases of persons who have died in Sofia-city and region, now NFC unable to retrieve such data to other regional cities in Bulgaria.

In Croatia: GMR collects additional information through the network of County public health institutes, sending the copy of DC with a precise query.

In Cyprus: These death certificates do not always contain sufficient information to enable the Health Monitoring Unit (HMU) to specify and code the causes of death accurately. Sometimes, they only confirm the fact of death without any reference to the causes of death. This is so, because of difficulties with writing confidential information on a death certificate that is handed over to the relatives. Also in some cases a provisional certificate is issued in order to allow the relatives to proceed with burial, before a definitive report on the causes of death is ready. Such reports do not contain sufficient information to determine the cause of death. In some of these cases, the results of definitive post-mortem investigations and a coroner's final verdict are delayed for many months or years. Since 2007, the **Health Monitoring Unit** of the **Ministry of Health is granted limited, relevant access** to autopsy reports, toxicology reports and information on external circumstances surrounding deaths from the Police and the Department Of Labour Inspection. These arrangements have been agreed between the departments in order to enable the Health Monitoring Unit to accurately determine the causes of death and assign the proper ICD-10 codes. This type of cooperation has proved very useful in meeting the needs of the General Mortality Register. It has greatly improved the quality and reliability of causes of death statistics, particularly, with regard to external causes of death.

In the Czech Republic: Every forensic medicine department fills up information about post-mortem investigations into "National register of autopsies and toxicological examinations performed at forensic medicine departments". Institute of Health Information and Statistics of the Czech Republic administer this national register.

In Denmark: the forensic institutes fill the reports and send them to the police. The police has the ultimate file obligation to keep files, but the post mortem information is also sent to the general mortality register (GMR) for possible more precise cause of death diagnosis. Also the Danish Health Authority has an annual meeting with the forensic institutes, where borderline cases are discussed.

In Estonia: Provisional and final medical death certificate are processed by GMR. Cases diagnosed as poisoning with unknown substance and aspiration are checked annually with forensic toxicologist since 2011 (there is only one such laboratory in the country).

In Finland: The one big change is that our laboratory, formerly the Toxicology lab of the Department of Forensic Medicine at the University, now is part of the National Institute for Health and Welfare (since Jan 2016). In a way, this makes the process smoother since the Institute is the governing body of all medicolegal investigations anyway. Now, all the investigations (autopsies and the laboratory analyses) are under the same roof.

France: Forensic analysis may be canceled for external reason (budget constraints). Also some forensic laboratories do not transmit the results to the GMR, arguing medical secrecy. In that case, the previous temporary "unknown or ill-defined causes of death" code will remain as such. Also some deaths are poorly detailed, since the most frequently seen wording is that of "addiction" or "opioid overdose" without any further specifications.
Sometimes these data only become available two years after they are recorded.
The French National Agency for Medicines and health products Safety (ANSM for its French acronym) signed an agreement with toxicological laboratories to retrieve information on DRD: this is one of the SR. Also with the new death certificate, it will be possible to send a complementary form to update the certificate, without doing another. This should permit the forensic laboratories to add information, such as toxicological results that they couldn't wait for to fill in the certificate.

In Hungary: form for the Modification of the death certificate is actually used by doctors. If they indicated that results are missing, and they do not send the modification on time then they are contacted by the Statistical Office.

At the moment the SR is legally still based on the so called Statistical Data Collection Programme (OSAP).To support the process, National Institution for Forensic Toxicology gives a full (national coverage) list of cases with all drug positive findings with case identifiers. That list contains toxicology findings and helps to identify forensic doctors who have a relevant case. Then the National Institute of Forensic Medicine can contact all the forensic doctors who have a relevant case for the detailed autopsy report. Each institution/forensic doctor sends the autopsy report to the National Institute of Forensic Medicine with detailed data. That report contains name, photos, circumstances as well. Data are processed at the National Institute of Forensic Medicine, institutions/forensic doctors are contacted if clarification is needed.

In Latvia: There is a field in the death certificate that gives information that death case is currently under investigation. Information on death due to drugs are collected by SR. At the same time with the existing information a death certificate is completed and submitted to Centre for Disease Prevention and Control (GMR). According to the existing information the certificate could be temporary (provisional) or final (definitive). If during the investigation any new information is found the physician submits a new definitive certificate that replaces the provisional information. Despite this there are known cases of death certificates for which the information's updates don't follow to the primary submitted temporary information on cause of death.

In Luxembourg: Special software jointly developed by the statistical department and the national focal point allows to extract drug-related death cases from the GMR by the application of a predefined standard (e.g. DRD). A computerised DRD extraction protocol (SPSS ®) conceived by the statistical department of the Directorate of Health (GMR) allows the NFP to compare SR and GMR data.

In Malta: A good system exists whereby when death certificates lack detail, information is sought by the GMR and obtained from the pathologists. Also the GMR had informed the pathologists of the importance of writing all the drugs involved in the death and not just writing 'overdose'.

In Norway: Toxicology is performed with a standard examination program, including more than 100 substances, but this may be extended due to circumstances, and specifically requested additional analyses. A copy of the forensic report is filed by the GMR, in which electronic search functions are available, if required permissions are granted.
Among confirmed cases of overdose deaths, the rate of autopsy is high, however autopsy rate differs between district. In Norway the police has to request an autopsy, and also pay for it, which means the request for an autopsy comes with a financial consequence. This may impact autopsy rates in some police districts. We have no measure of how many of those who do not undergo autopsy in the country are in reality "missed" overdoses.

In Norway the toxicology examination results are sent to the medical forensic examiner only, and not to the GMR. The GMR therefore only receives toxicology codes that the forensic examiner found relevant to include in his/her report.

In Portugal: The National Plan for Reducing Addictive Behaviours and Dependencies 2013-2020 (PNRCAD 2013-2020) was developed. In the context of information and research, the goal is consolidate the knowledge infrastructure and to carry out a timely analysis, holistic and comprehensive of the situation. This has been defined as priority the standardization of data

collection and the development of scientifically proven indicators at the European and international level.

The death certificates, provisional and definitive, are processed on electronic platform - Information System of Death Certificates (SICO).

Spain: After having sent death certificate with "provisional" cause of death, forensic department "would have to improve or complete the reported provisional cause of death" in a standard form, but there is not legal duty for doing that, at rarely it is done. It is estimated that, in Spain, the deaths for drugs taken from the General Mortality Register are underestimated by 40%. Some autonomous communities actively search and link SR and GMR to complete and correct cause of death in cases of unnatural death.

In the Netherlands: the electronic document filing system at the Netherlands Forensic Institute (NFI) allows retrieving information about DRD cases. Currently, special research is being conducted into ecstasy-related cases. Researchers can have selected access to the filing system, within the boundaries of approved research, according to the protocols for approved research.

Each year the Netherlands National Focal Point receives an extraction of all the DRD cases from the Netherlands Forensic Institute (NFI), the statistical findings of which are reported (in Dutch) in the Annual Report of the Netherlands National Drug Monitor (NDM).

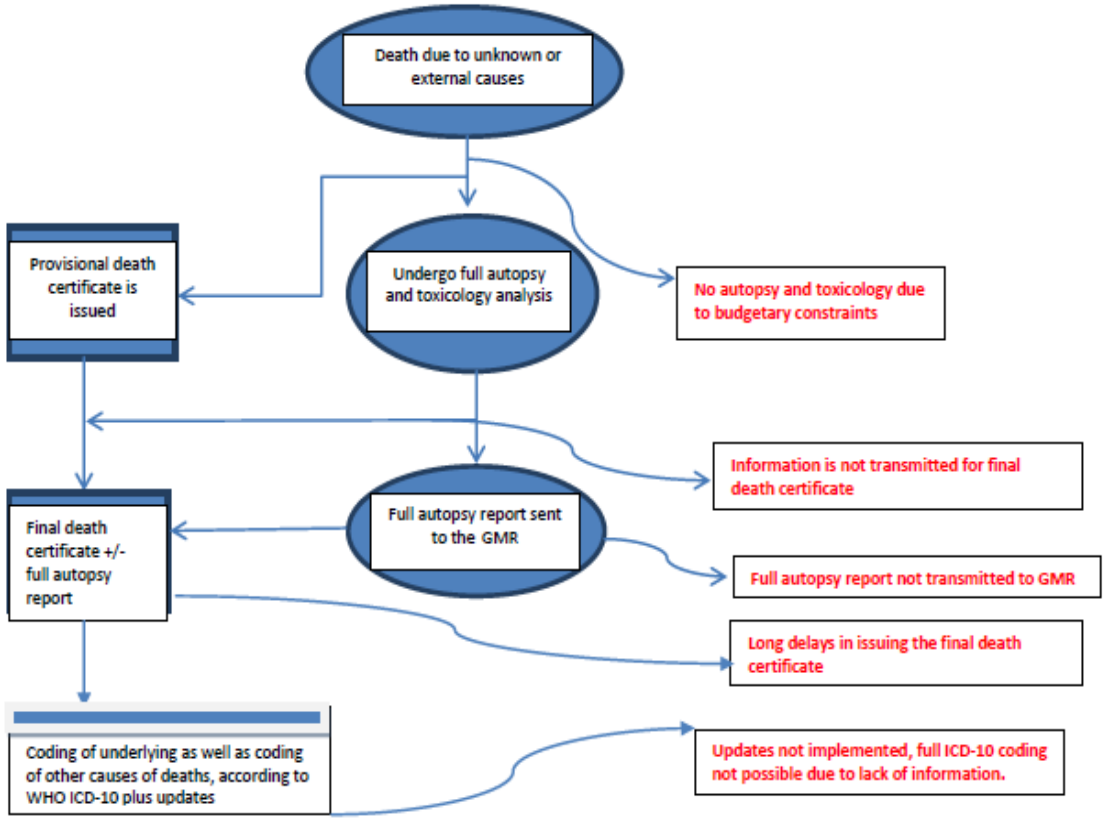
In case a known high-risk drug user has died and there are no other indications of unnatural death, that case may be regarded as a case of natural death, however it is not known how often this happens. There are no strict rules to distinguish between 'natural' and 'unnatural' deaths

Recently, all medical doctors have been reminded about the systematic procedures to be followed by means of the following publication (in Dutch, with abstract in English): Van Meersbergen, D.Y.A. (2015). De huisarts en overlijden [The general practitioner and death]. Huisarts & Wetenschap, 58 (8): 435-437.

Turkey: All autopsy reports are uploaded onto to the National Justice Intranet System (UYAP).

5. Discussion

The aim of this part of the project was to understand what information is reaching the GMRs in the different countries. With the information received, the GMRs produce statistics on causes of death including drug related deaths. Due to the fact that certification of external causes of death often involves a number of entities and always includes the Judicial System, the transmission of data to the GMRs is hampered in some countries. Data protection and sensitivity of data issues are often quoted as reasons for the non transmission of autopsy and toxicology results to the GMRs. Only few countries such as the Czech Republic, Denmark and Norway have access to all post-mortem reports using them when issuing the causes of death. Other countries often have to rely on the death certificate which may or may not contain all the information needed to properly code the causes of death (figure 1).



Countries have resorted to different methodologies to improve the information recorded on the death certificates in order to improve the quality of mortality statistics produced. Some of these methodologies which could possibly be adopted in other countries include:

1. Creating a legal obligation for the transfer of information on autopsies to GMR;
2. Specific studies between GMRs and Forensic Institutes;
3. Querying forensic institutes on cases where the information on the DC is not enough;
4. Access of GMRs to national databases with autopsy and toxicological information;
5. Checking all cases of unknown substances or other ambiguous cases with forensic toxicology;
6. Amendment of death certificate form to allow more detailed information;
7. Creation of electronic databases with information from forensic investigations;
8. Including good quality data collection on DRDs as priorities in national strategies;

9. Linkage of GMR to SR;
10. Training of certifiers in death certification.

Under-reporting of DRDs varies between countries and this not only hampers the accurate monitoring of DRDs by the country and also by EMCDDA but also may underestimate the extent of a problem in a particular country.

6. References

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