Questionnaire on Special Registries on drug related death in Europe

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On behalf of EMCDDA

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Country: …… Date: ……..……..

Questionnaire completed by:

Name:

……..

Title/Position:

……..…

Organization:

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Mailing Address:

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Phone: ……..Fax: …… E-mail: ……..……

Background, rationale

Information for the Key Indicator on drug related death and Mortality among drug users (DRD indicator) of the EMCDDA can be based on data retrieved from the General Mortality Register (GMR) or Special Register(ries) (SR). The EMCDDA recommends that both sources are used, if possible.

The EMCDDA launched a call for tender for an inventory of existing mechanisms and structures of National Special Registries in Europe and a description of the core data available. This project should facilitate learning from different systems and find out which data are available across Europe. It should also give insight on the core data recorded for every DRD case. This inventory aims to

1) describe in details the SR, in order to consider ways to improve the level of information available on the DRD on a "project", or a "research" basis (e.g. characteristics of the victims, circumstances, toxicology,) in countries where SR allow for it, in order to better inform interventions to reduce the number of drug-related deaths.

2) to try, in a broader perspective, to find ways to improve the quality and comparability of DRD information across Europe, by exploring ways to improve the coordination between SRs and GMRs.

The Austrian Focal Point was awarded the contract for the project. To achieve the aim of this project, the Austrian Focal Point prepared this questionnaire in close cooperation with the EMCDDA and an advisory group. Special thanks to Henrik Saelan, Maria Savvidou, John Corkery and Isabelle Giraudon.The questionnaire includes issues of which systematic information is available, the core data recorded for each DRD case, the data flow and legal issues.

Instructions

- Please go through the entire questionnaire and make sure that all questions are answered as required.

- The success and potential use of the inventory will be determined by the quality of data gathered. We encourage you to consult other colleagues or experts in the field to obtain the relevant information you do not have at hand.

- In addition, please kindly take note that we are interested in information about your country as a whole and not just in obtaining information for one region or state. Therefore, please provide national data, if possible, and whenever possible provide a reference or source of information. If you are unable to obtain data for the whole country, please make sure that you indicate the section of the country to which the data apply. Another option is answering the questionnaire for different regions. We would be grateful to receive copies of any documents which were used as sources of information for completing this questionnaire or, at least, for relevant references and web-links.

- Some generic questions will be for all countries, and some may only be for some specific countries. If there are two or more Special Registries in your country we recommend you fill in two questionnaires, particularly for the sections specific to one register.

- If you have any questions do not hestiate to contact Charlotte Wirl: wirl@goeg.at, phone:+43151561154 fax: :+4315 1 513 84 72

Next steps

Contributors will be acknowledged on the report.

The report will be available to all contributors and on the EMCDDA web pages by the end of 2009 and results presented and discussed during the 2009 DRD expert meeting.

It is hoped that the results of this project will provide a basis for further improvement of the quality and comparability of the information that can be extracted from the Special Registries, fully taking into account national procedures and regulations. In a broader perspective, it is hoped that the results and lessons learnt from this project will help to improve overall DRD information in Europe.

Thank you very much for your help and cooperation!

1. Investigation of unnatural deaths.

1.1. Usually when there is an unnatural or violent death there is a police/forensic/coroner post-mortem investigation. Could you describe briefly how this investigation takes place in your country?

1.2. Who decides what to do (e.g. police, judge, doctor…)?

1.3. Who does what (e.g. confirming the death, post-mortem exams (autopsy, toxicology), inquest into the circumstances of death – with family or witnesses – analyses)?

1.4. Is the post-mortem investigation the overall responsibility of a single person/institute or could there be parallel and independent investigations (e.g. police and forensic)? Please mention any alternative source, even if it is not used in a systematic way or at national level and indicate them in the flow-chart (question 5).

1.5. Who pays for the post-mortem investigations? Is this different for autopsies and toxicological analyses?

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

2.1. Who is in charge of these reports/documents? Where are they filed?

2.2. Who "owns" the data? Is there any legal authority/law relating to this, or is it based on custom/convention?

2.3. 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")?

2.4. Does this unit/database have a national coverage? If not, please specify (e.g regional or city level)?

2.5. How is this document filing organised? Does it receive information from different sources (e.g. police + forensic…) or only from one source?

2.6. Does this document filing system allow flagging/identifying and retrieving information about DRD cases?

2.7. Who has access to the filing system (e.g. only police, only forensic doctors, researchers …)? What are the regulations for accessing and/or sharing the data?

2.8. 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.-)?

3. Inclusion/Exclusion Criteria

3.1. Which kind of population is included in your **Special Register**? All unnatural deaths (or suspected to be unnatural) or only drug-related deaths? What is the background population and which cases are extracted to the SR?

3.2. Please indicate in the inclusion criteria which cases are included in the SR.

	Yes	No	Unknown	Comment
Foreign nationals				
Foreign residents				
All age groups				
Deaths of citizen overseas				
All unnatural deaths				
Poisoning: deaths directly related to illegal drugs				
Poisoning: deaths related to alcohol				
Poisoning: deaths related to psychoactive substances				
Suicide (all, with or without substances)				
Homicides (all, with or without substances)				
Accidents (all, with or without substances)				
Indirect drug related deaths (Accidents…)				
All death with positive with positive toxicology to illegal drugs (whatever the cause of death)				
Known drug users (whatever the cause of death)				

Other inclusion criteria:

Any exclusion criteria:

4. Information recorded in SR as DRD

4.1. What information is collected and recorded for each DRD case? Please complete the table below

	Yes	No	Unknown	Comment
Name(s) of deceased				
Date of birth (or age at the time of death)				
Place of birth				
Nationality				
Ethnicity				
Educational level				
Employment status				
Living arrangements				
Marital status				
Usual address, including post code				
Sex				
Date of death				
Address of place of death				
Place of death (e.g. urban, rural…)				
Place of death (e.g. home, hospital, street…)				
Location of incident leading up to death				
Cause(s) of death (as given in death certificate)				
Intentionality (e.g. accidental, suicide, homicide, undetermined)				
Mechanism of death				
Manner of death (e.g. poisoning, injury, traffic accident, disease…)				
ICD codes				
Verdict/legal decision as to cause of death				
Date of verdict/legal decision				
Circumstances (e.g. death alone, with witnesses…)				
Witness statement(s) supplied				
Whether an autopsy was done				
Post-mortem supplied				
Toxicology report(s) supplied				
Substance(s) considered as the cause the death				
Route of administration (Injection or others) of the substance in cause				

List of all substances identified in the toxicology analysis (e.g. alcohol, prescription drugs, illicit psychoactive substances…)				
Level(s) of the substances found				
Other diseases of relevant finding in autopsy (e.g. cardiac problems, liver disease, HCV, HIV/AIDS,…)				
History of drug abuse				
History of drug treatment				
Whether the person was on opiate substitution treatment at the time of death				
Recent release from prison				
Recent release from detoxification unit				
Whether the person has been arrested or been in prison in the past				
History of overdose(s)				
History of suicide attempts/self-harm				
History of harmful or dependant alcohol drinking				
History of recreational drug use				
History of volatile substance abuse				
Patient prescription history (e.g. antidepressants, benzodiazepine, …)				
Patient co-morbidity, including mental health condition and physical				
Recent traumatic life events (e.g. divorce, death of significant other, redundancy)				
Other variables that you would find of interest for the monitoring of DRD:				

5. Information flow

5.1. How is the information flow regulated between different parties involved in the post-mortem investigation? Please draw a flow chart, indicating timeliness as in example given in the Annex. Show the path for a “natural” and for a “non natural death”.

5.2. Who provides the information to the SR? (e.g. coroner, coroner’s staff, hospital or treatment services, medico-legal institute, collected by SR staff; other researcher, etc.)

5.3. How is the information stored?

5.4. Who pays for the data collection (gathering of information, analysis of data)

5.4. Is the data flow you described above a systematic procedure (all or almost all cases investigated) or are there any substantial exceptions and why?

6. Procedures and legal background

6.1. What is the legal basis of the Special Register on DRD? Are there any issues/problems/solutions concerning data protection?

6.2. If data collection is part of the national strategy? If yes, could you please attach the part of the national strategy referring to the data collection?

6.3. Are death certificates undergoing post-mortem investigation being clearly identified? And how? (e.g. is there a provisional certificate followed by a definitive death certificate?)

6.4. How are these death certificates (under investigation) processed? Is there any legal regulation about them?

6.5. 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?)

6.6. Are there any legal regulations regarding Death Certificates? Is it possible to have a temporary death certificate that can later be updated? In case there is any legal regulation, is it followed in all cases? In case it is not, why?

6.7. 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?