

## **Minutes Session 6: Workshop on Special Mortality Registries:**

There are several national SRs which collect considerable information on DRD. Presentations from some countries with comprehensive SR and discussion of issues, proposals for improvement, including possible ways of eventual collaboration

**28<sup>th</sup> November 2008, Lisbon**

**Date of the minutes:** 10 December 2008

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### **Participants**

**AT** Charlotte Wirl; **CY** Byron Gaist; **CZ** Tomas Zabranski; **DK** Henrik Saelan; **DE** Axel Heinemann; **HU** Eszter Nádas; **IE** Ena Lynn; **IT** Teodora Macchia; **NL** Guust Crust; **PL** Artur Malczewski; **SI** Jocica Selb; **TR** Bulent Sam; **UK** John Corkery; **EMCDDA** João Matias, Isabelle Giraudon

### **Background, rationale**

Collection of 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 a Special Register (SR). The EMCDDA recommends that both registries are used, where possible. Sources for Special Registries vary across Europe.

The EMCDDA issued an invitation to tender for an inventory 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 systematic data are available across Europe. It should also give insight on the core data recorded in every DRD case. The Austrian Focal Point applied for the tender and, provided that the contract/paper work is finalised, should be in charge of the project.

To achieve the aim of this inventory project, the Austrian Focal Point would prepare a questionnaire in close cooperation with the EMCDDA and set up an advisory group. The questionnaire should include the issues of which systematic information is available, the core data recorded for each DRD case, the data flow and legal issues. This project would highly benefit and rely on the cooperation of Member States.

Therefore, during the DRD expert meeting, this workshop aimed to introduce this possible project. It was dedicated to a first discussion and exchange of experiences among interested experts of represented countries.

## **Methods proposed for the workshop**

Representatives of the countries were asked to draft a figure of the data flow of DRD information available through their national Special Register(s) and were asked to briefly present it. Discussion followed about the questionnaire to be developed in order to progress with this project of inventory of mortality SR in Europe.

## **Discussions and suggestions of experts**

Denmark suggested as a starting point for the questionnaire the issue of ownership of the data (which may vary - i.e. police, health authorities - and depends on history, legal and funding issues). In the Danish case it's the police that owns the Special Registry. The questionnaire should include questions on "Who is paying" and "Who is enquiring/requiring data". Suggestion for the questionnaire included:

- Statutory regulation - how death is confirmed, and what to do about it (medico-legal death coroner)
- Resources (who pays?)
- Short history – police involvement, forensic institute...
- Detailed flow-chart – who – doctors?, police?, coroners? Does what? For natural deaths, for other deaths, how do the data go to the GMR?
- Data protection problems for monitoring of DRD

Ireland suggested enquiring about the legal basis (e.g. SR included in a national "Drug strategy"), and about the information recorded (e.g. only main cause of death recorded or more)

The UK suggested including questions on how the data is transmitted: by paper, fax, e-mails, or other transfer? Is the data transmitted in systematic ways (forms)? Which substances are included in the Register (e.g. deaths "due" to with over the counter medicine? Illicit substances only? And how are they classified?) Also the UK was willing to send the form used to collect data.

Germany suggested including the timeliness of the information flow, strategy on information chain (mainly liaison with the GMR) and use of data. The issues of resources available for running the SR (e.g. by the police services) was raised, as well as the coverage (national/regional/other).

Poland said the SR has national coverage; that does not work very well but has a similar trend to the GMR although based on different numbers. There was a Police Special Registry that stopped at the year 2000.

Cyprus said data are hold by the NFP, with easy communication between the services in charge (Health Ministry, Statistical services, Forensic services (hospital emergency services mentioned too).

Italy mentioned the role of the police and that is not linked to the GMR (due to legislation concerning confidentiality) and delays in getting the toxicology results.

Slovenia mentioned manual matching of cases across four different sources and suggested including the final report of the Eurostat Task Force on Problems of Data Protection and Method of Data exchange from the GMR.

A flow-chart starting with the death of a person and the following procedures and the consecutive responsibilities as suggested in the Annex of the DRD-Standard protocol seemed a good idea, and some countries could produce a first draft.

### **Perspectives**

As a next step, and provided the project and contract can be confirmed, the Austrian Focal Point could propose to draft a questionnaire. This would be based, in part, on the information and inputs from the workshop and circulated among attendees of this workshop for feedback on a voluntary basis. Contact details for the distribution of the finalised questionnaire would be helpful.