WORKING GROUP "PUBLIC HEALTH STATISTICS"

Luxembourg – 18-19 November 2008

Item 9 of the agenda

Statistics on causes of death (COD)

9.1 Activities and work programme

Report on 2008 activities of the COD Core and Technical Group

Aims and draft work programme 2009, 2010 and 2011

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Since the agreement of the Working Group in November 2007, the **Core Group** on Causes of Death statistics (CG COD) has met twice, on 28-29 February 2008 in Vienna and 05-06 June 2008 in Tallinn and had a tele-meeting on 8 September 2008. The annual meeting of the **Technical Group** on Causes of Death statistics (TG COD) was held in Luxembourg on 24-25 September 2008. One new **ad-hoc Task Force** has been set up since in the current PH on coverage and confidentiality; furthermore, the Task Force 'Glossary for Causes of Death Statistics' ended in May 2008 and the final results were adopted during the last TG COD. A quality review of the COD data collections have been made in 2008 on Eurostat's request to assess the process of collecting, processing and disseminating statistical data.

The 'road map on causes of death statistics' developed by the Core Group and first approved at the Technical Group meeting in 2005 was further developed and its implementation is fostered. **The road map provides the overall framework for improving the quality of COD statistics.** It is a list of concrete steps to improve quality of data in this domain in short-, medium- and long-term perspective. **It presents an action plan for both Eurostat and the national COD statistics offices on what to do.** All steps are recommended by experts in the field as a result of ad-hoc Task Forces, methodological studies on the base of contracts or discussions at Core and Technical Group meetings. The road map is regularly reviewed and updated by the Core Group and presented and discussed at the Technical Meeting. **The Technical Meeting COD 2008 gave its approval to the updated version of the road map** (05 June 2008; see Annex I).

In line with the road map, the main focus in the area of COD continues to be on quality improvement by using the several instruments to improve quality that have been developed. Therefore, the COD strand **focus now is on implementation and evaluation of the instruments and on exchange of experiences and best practices.** In order to monitor progress on implementation of available tools, **implementation tables** were developed by the Core Group covering the EU training package, e-death certification and quality control. Information on implementation activities is now collected yearly for all Member States (see Annex II). The results were presented to the Directors of Social Statistics (September 2007), and both discussion and exchange of best practices took place at the Technical Meetings (October 2007 and September 2008).

The work of the different groups centres around three main domains: **certification, coding** and **statistics on causes of death** in the context of the overall goal: ‘to improve the collection, analysis and dissemination of comparable causes of death (COD) statistics at the level of the European Union’.

1. **Certification of causes of death**

In 2001, the project on ‘Comparability and quality improvement in European COD statistics’ funded under the 1998 work programme on Health Monitoring (HMP) resulted in a final

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1 The work under the Partnership Health structure which started in 2003 thus continues and further develops the work carried out by the Task Force COD under the Leadership Group Health Statistics (LEG Health, 1998-2002).
This report contains in particular a set of 39 recommendations that cover different stages of death certification. The representatives of all the Member States agreed these recommendations.

These 39 recommendations and their further development as outlined in the COD road map do now act as an agreed framework, both for each country’s orientation on production of causes of death statistics and as a basis for effective implementation in the context of the future COD work.

In 2004, the Eurostat brainstorming meeting reinforced the 39 recommendations and highlighted in particular the following issues:

- Introduction of a harmonised European e-Death Certificate (long-term objective);
- Definition of minimum requirements for the national mortality file (also in view of a legal basis);
- Continuous training of certifiers.

Accordingly, these main topics in the area of certification were included in the 'road map for COD statistics' and subsequent actions were undertaken to follow the agreed road map. The following tools are agreed and available for national implementation, and its implementation is fostered through exchange of experiences at the Technical Meeting:

- The ad-hoc Task Force on 'European COD statistics, recommendations for items to be collected for the national mortality file' had been established in 2005 and successfully completed its work in early 2006. The final report of the Task Force was adopted by the Technical Group in written procedure in early 2007. The final report 'European COD statistics – Recommendations for items to be collected for the national mortality file' is publicly available in CIRCA³. The recommendations of the final report concern items to be collected for the national mortality file in order to produce good quality COD statistics; depending on the national situation, the information might come from the death certificate or from other sources.

- The 'EU training package on certification of COD' (developed by ISTAT and adopted in 2004 by the TM COD and the Working Group on ‘Public Health Statistics’) is publicly available in CIRCA⁴ and national adaptations and implementations started⁵. 23 Member States implemented or plan to implement a

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⁵ For details see Annex II.
leaflet (based on the EU model: 12 countries; own development: 11 countries), and 19 countries work on the implementation of the training manual (mostly EU manual, some countries own development). Up to now only one country (Czech Republic) tried to nationally adapt and implement the web-based tool but had to stop the activity due to budgetary and technical problems. Turkey has partly adapted the web-based tool deriving from it a manual for trainers of certifiers that includes all the exercises and text. Several countries provide a link to the English reference version of the web-based tool.

During the year 2008, the Core and Technical Group meetings continued the discussions on how to best implement some of these recommendations, and the following activities were carried out:

- the infant death certificate proposal, as accepted by the MRG (Morality Reference Group) as part of the WHO-FIC network (presentation by France);
- current situation of queries, based on the results of ANAMORT project (presentation by Slovenia);
- Coverage for infants and non-residents, based on the results of ANAMORT project (presentation by Estonia);
- Dr. Lars Age Johansson (Sweden) has been invited to present part of his PhD dissertation on “Targeting non obvious errors in death certificates”, with a special focus on the quality of certification;
- an extract of the Terms of Reference for the TF on “coverage and confidentiality” in order to inform the TG and to find volunteers to contribute to the TF.

Activities for 2009-2011

- Implementation of the 'EU training package on certification of COD' for medical certifiers and medical students including the exchange of information on national experiences; review and evaluation of the tool (Recommendations 30 and 33, continuous activity);
- Implementation of the 'Recommendations for items to be collected for the national mortality file' and work towards national implementation (Recommendations 15 to 19, continuous activity);
- Information and preparation work towards the implementation of an e-death certificate (Recommendation 22);
- Continued exploration of possible solutions for the issues related to coverage and completeness of COD (residents dying abroad; Recommendations 1 to 3);
- Investigation of information needs related to queries (best practices, general rules for queries, etc.; Recommendations 23 to 29).
- Information and preparation work towards the implementing EU regulation on Causes of death, in particular for what concerns the exchange of feedbacks and results of the TF on “coverage and confidentiality” in the domain of certification, and possible implementing measures that will be derived as a consequence of the regulation (ongoing);
2. Coding of causes of death

Automated coding

More and more MS are considering or planning to use Automated Coding Systems (ACS) and there is an urgent need of collaboration and expertise in this field.

Following the Workshop on Automated Coding held in Le Vésinet (France) in March 2001, a Technical Meeting on Automated Coding Systems for mortality (ACS) was held in Luxembourg in March 2002. It rallied 30 participants from 15 countries. Decisions were taken on a common effort and on common goals for implementation of ACS, including “to have ACME operational (for all deaths) in all EU MS (and EFTA) by 1 January 2005”. (For the report of the meeting: see Working Group 2003, Doc ESTAT/D6/03/HEA/10-2a).

The Directors of Social Statistics (DSS) agreed in April 2002 that, in the framework of the new Partnership on Health statistics, COD activities should focus, among other priorities, on implementation of Automated Coding (AC). At its meeting of September 2007, the DSS was invited "to support in particular national activities towards the introduction of automated coding systems", and the DSS views on the presented document was overall in favour.

“Training on causes of death manual coding in view of automated coding” is seen to be a crucial element to facilitate the introduction of ACME in Member States. However, both the 2003 and 2004 Eurostat grant actions on that topic failed in finding a suitable application. Another attempt to organise such training through the 2005 work programme of the Community action in the field of public health (2003-2008) also failed, mainly because of the high co-financing required and because of the unavailability of multi-lingual courses. In order to provide some form of support for ACME coding, the Task Force 'ICD-10 updates and ACME implementation in Europe' prepared an 'Introduction to multiple cause coding for ACME' which is publicly available in CIRCA7.

The idea of a new system for automated coding (IRIS) came up in 2001 when France (Inserm CépiDc) and Sweden (National Board of Health and Welfare – Socialstyrelsen) decided to develop such a system in close relationship to ACME. The aim was to create a system which is based on ICD-codes8 and can be used with additional dictionaries and language standardisations for any language.

IRIS is
1. an open (to the user group members) and free (for everybody) coding software that can be adapted for use in any language,
2. developed in accordance with ICD rules and guidelines,

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6 ACME (“Automated Classification of Medical Entities”) is a coding software originally developed by the US National Center for Health Statistics (NCHS) that applies WHO rules for selection of the underlying cause on ICD-10 codes. Today, ACME is the international de-facto standard.


8 International Statistical Classification of Diseases and Related Health Problems, WHO.
3. using MMDS, especially the MICAR and ACME modules, yearly updated and integrated in the package
4. an interactive system.

In 2008, national versions have been implemented in Germany and will be implemented in France and Sweden in 2009. The latest version 3.21 is available since 05 June 2008 for other national implementations. Currently developed dictionaries to be used with IRIS are available for the following languages: English, French, German and Swedish. IRIS updates and modifications are decided by a user group whose members are: France, Sweden, Germany, Hungary; visitors or members states that has performed tests: Italy, Spain, Austria, Switzerland; interested countries: Norway, Belgium, Netherlands, Turkey, South Africa, Brazil and Israel.

The Technical Meeting COD 2008 discussed and exchanged experiences and best practices on:

- overview presentation on the current situation of the IRIS software (presentation by France);
- a workshop organised the day after on how to use IRIS (general presentation following by group-work) in which 22 delegates from 19 countries participated (for details see agenda item 9.2).

ICD related issues

Every change of the ICD (changes of version – ICD-8, ICD-9, ICD-10 as well as updates within ICD-10) are of concern since time series are disrupted. European comparisons are not possible at the 3 or 4 digit level if different versions of the ICD are used. In conclusion, a European harmonised approach for using the same version of ICD-10 is needed and should be implemented as soon as possible. While Member States should follow the ICD-10 update cycle as published on the WHO website, the collection of detailed information on the implementation of ICD-10 updates is showing that major differences still exist between countries.

In 2005, the Core Group COD mandated a Task Force to look into issues related to ICD-10 updates and ACME implementation in Europe and to assist Member States in dealing with these and related matters. The Task Force produced a final report with recommendations as well as the documents 'Background to the ICD-10 updating process and its impact on statistics', 'Guidelines for bridge coding studies', 'Introduction to multiple cause coding for ACME' and overview tables on the 'Use of ICD and coding practices'. All documents prepared by the Task Force were approved by the Technical Meeting in 2006 and 2007 and are publicly available in CIRCA.

An easy way to implement ICD-10 updates is the use of automated coding system as the MMDS/ACME based software handles (most of) the ICD-10 updates. This backs further the

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9  [http://www.cepidc.vesinet.inserm.fr/inserm/html/IRIS/iris_project.htm](http://www.cepidc.vesinet.inserm.fr/inserm/html/IRIS/iris_project.htm)

recommendation that Member States should introduce automated coding, at least ACME decision tables.

The Technical Meeting COD 2008 discussed and exchanged experiences and best practices on:

- views on usefulness of ICD-10 updates (presentations by Germany and the Netherlands);
- a presentation on ICD-11 was made by WHO. This new revision is planned to be implemented from 2015 and should be easy to use, reflect spectrum of needs of multiple cultures and levels of development and ensure compatibility with existing classifications and statistical continuity.

**Standard validation tool for quality control of COD**

In order to harmonise quality control instruments, the Core Group decided to set up an ad-hoc Task Force 'Quality Control on COD statistics' in 2004. The work of the Task Force resulted in the development of a **standard validation tool** (i.e. standard checks to be performed on COD data) and a **set of quality measures** (i.e. actions to ensure the quality as well as quality indicators). The tool aims at ensuring a harmonised use of quality control techniques across countries. The tool is available for use since July 2005, and since then several updates and improvements were introduced. The current version of the tool (31 May 2007) is publicly available in CIRCA\(^\text{11}\). The overall implementation of the tool is monitored through the implementation tables (see Annex II). The tool needs to be further developed based on comments and suggestions received from the Member States and also in view of ICD-10 updates.

Other issues on COD coding

The Technical Meeting COD 2008 discussed and exchanged experiences and best practices on:

- multiple cause coding (short presentations by France, Italy, Cyprus, Sweden, United Kingdom, Latvia and Hungary). Currently 19 countries have (at least partly) multiple causes data available;

- coding of external causes of death, based on the results of ANAMORT project\(^{12}\) (presentation by Estonia). The Project Leader (Mr. François Belanger from InVS) attended the TG meeting. A full consensus could not be reached among MS on all the proposed outcomes, especially on how to code external causes. The CG therefore proposed to forward the recommendations to the Mortality Reference Group (MRG) as part of the WHO-FIC. The MRG has accepted to discuss the topic during their next spring meeting. The MRG chair will contact and make the necessary arrangements with the Project Leader.

Activities for 2009-2011

- Implementation of the recommendations of the Task Force ICD-10 updates and ACME implementation in Europe;
- Implementation of IRIS, assess the feasibility of organizing a training on IRIS in the framework of the EU program on training for Statisticians;
- Implementation of the recommendations of the Task Force on Quality Control on COD: national experiences with the tool and regular up-dating;
- Exchange of information about bridge coding (across classifications; manual vs. automated coding);
- Exchange of information about multiple cause coding and explore the possibility to organize an *ad hoc* workshop;
- Exchange of information about double and ring coding (across countries and regions).

3. Statistics on causes of death

Collection, dissemination and publication of COD statistics

The annual request to MS, CC and EEA/EFTA countries to send COD statistics at national and sub-national level (NUTS 2) has resulted in the majority of countries now having provided data for 2006, and several countries also for 2007. The actual status of data received is given in Annex III.

In line with Eurostat’s dissemination policy, the Eurostat database is available on-line and free of charge since the 1 October 2004. Data for the period 1994\(^{13}\) until latest year available

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\(^{12}\) [http://www.invs.sante.fr/surveillance/anamort/index.htm](http://www.invs.sante.fr/surveillance/anamort/index.htm)

\(^{13}\) 1999 for some new Member States
are disseminated on the Eurostat website (http://europa.eu.int/comm/eurostat, → 'data' → 'health' → 'public health' → 'causes of death'). COD data are shown as total number, crude death rate and standardised death rate for the 65 causes of the 'European Shortlist' for COD, broken down by age, sex and region. To help users in accessing the data, a small document 'Eurostat causes of death statistics - Information on data available on-line' was prepared and disseminated¹⁴. Following the decision taken at the Eurostat Directors' Meeting, endorsed by the Director Generals of the NSIs, to make eDamis compulsory for the transmission of all regular datasets as of 1 July 2008, MS are now requested to use the eDamis Web tool (Portal or Application) as the only communication channel for the data transmission of COD statistics to Eurostat. A presentation on how to use eDamis was made by Eurostat during the Technical Meeting 2008.

In 2007, MS were requested to send meta-data information on their use of ICD updates, automated coding and multiple cause coding. This file is now requested on a yearly basis¹⁵, with the data collection (see Annex IV). Meta-data are available in the SDDS format.¹⁶

On the basis of the COD data, the following publications are available:


Other publications showing COD data are:


- Already in 2004, the 'Atlas on mortality in the European Union' (data 1994-1996) was released together with a Statistics in Focus (data 1997-1999). A Eurostat contract has produced these first detailed descriptive and graphical analyses in the form of a 'Eurostat reporting package on causes of death (COD) statistics'. The publication should serve as a prototype for regular dissemination by Eurostat (i.e. every 5 years) on cause of death data. The atlas concerns a study on general mortality according to age and sex and a study of main causes of death. Data are analysed at the level of NUTS 2. Causes of death selected (based on the 65 Eurostat list) are: circulatory diseases (overall, ischaemic and cerebrovascular diseases), respiratory diseases (influenza and pneumonia, chronic diseases), cancers (lung, stomach, breast, ...), violent death (accidents, suicides), AIDS and alcohol-related causes. Indicators are total number, crude rates, and standardised rates. The next issue of the mortality atlas is to be published by end 2008 or beginning 2009.

¹⁴ Available through the following link:
http://circa.europa.eu/Public/irc/dsis/health/library?l=/statistics_information/information_datapdf_EN_1.0_&a=i

¹⁵ Available through the following link:
http://circa.europa.eu/Members/irc/dsis/health/library?l=/methodologiessandsdata/causessofsdeath/icd-10_updates/countries_24102007.xls_EN_1.0_&a=i

¹⁶ SDDS: Special Data Dissemination Standard, established by the International Monetary Fund (IMF)
- COD data are shown in various cross-cutting publications such as the 'Eurostat Yearbook', 'Key figures on Europe' and 'The social situation in the European Union 2008'.

A point presented during the TG meeting is the new possibility for experts from the MS to contribute as co-authors together with Eurostat staff, to some of the Eurostat publications, such as “Statistics in Focus” and “Data in Focus”.

At the COD brainstorming meeting in 2004, the under-use of COD data was discussed and it was recommended that a new dissemination strategy needs to be developed. The following main elements to consider a better exploitation of COD statistics were mentioned and are now also integrated into the COD road map:

- To provide information beyond pure statistics in order to make the data understandable and meaningful (i.e. metadata and analytical information).
- To “market” the data with attractive topics such as avoidable causes of death, changing mortality patterns through the development of “tool-boxes”\(^\text{17}\) that can be used by all countries.
- To consider different user groups and their different needs (researchers, policy makers, media/the public).

The Technical Meeting COD 2008 discussed and exchanged experiences and best practices on:

- how to use eDamis (presentation by Eurostat);
- best practices in dissemination and how to deal with user demands (presentations by Norway, Malta and Lithuania);
- how to use COD usergroup and CIRCA (presentation by Eurostat);
- Overall improvements of national statistics on COD (presentation by Turkey).

**Glossary for COD statistics**

In order to have a common understanding of COD statistics for international collaboration, A TF on 'Glossary for Causes of Death Statistics' was set up in 2006 and ended in May 2008. The final glossary was adopted during the Technical Meeting 2008 (for details see agenda point 9.2).

**Activities for 2009-2011**

- Continue regular data collection and dissemination of COD statistics, with the aim to improve the timeliness of the data, further development of metadata;
- 'Tool-boxes' for attractive topics such as avoidable causes;

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\(^{17}\) This means the collaboration of a few countries on a specific topic (e.g. alcohol-related deaths) to come up with a proposal (‘tool box’) on best ways to convey a message together with the data to be used as a model by other countries as well.
- Review European shortlist for COD (also through the analyses carried out for the Atlas), European Standard population and indicators provided (premature death, potential years of life lost, etc.).
- Create a historical mortality dataset according to the 65 causes of death European shortlist;
- Maintain and update the glossary.

**Quality review of the COD data collections (rolling review)**

A quality review of the COD data collections was carried out this year through user and partner surveys as well as a questionnaire filled in by Eurostat Unit F5. The preliminary results were presented during the Technical Meeting and the final results will be presented during the Working Group (for details see agenda item 9.2).

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4. **Discussion of the Working Group 'Public Health Statistics'**

The Working Group ‘Public Health Statistics’ is hereby invited to support:

- the implementation and further development of the **road map for COD statistics** which is based on a series of recommendations on **certification** and **coding** which resulted inter alia out of the HMP project on 'Improvement of quality and comparability of European causes of death statistics', the Eurostat brainstorming meeting on COD (2004) and from the discussions at Core Group, Technical Group and Task Force meetings;

- in particular, the implementation through national adaptations and use of the **EU training package on certification on causes of death** (adopted in 2004);

- the consideration and implementation of the **Recommendations for items to be collected for the national mortality file** (adopted in 2007);

- activities on the introduction of an **electronic death certificate** through following existing national activities, and to consider own implementation;

- further actions for a harmonised implementation of **ICD versions and automated coding (AC)** in the Community, following the recommendations of the Task Force 'ICD-10 updates and ACME implementation in Europe';

- national activities towards the introduction of automated coding systems and in particular review the **potential use of the new system for automated coding (IRIS)** which is available since May 2008;

- the use of the **standard validation tool** for COD and its improvement, as well as the **quality measures** recommended by the Task Force on quality control;

- and give suggestions for an improved **dissemination** of COD statistics through analyses and attractive topics;

- the use of the **COD newsgroup** for any questions related to certification and coding (and in particular for questions related to ACS/ACME);

- the adoption of the glossary on COD statistics;
- the use of ICD updates given by WHO;
- the active participation in Task Forces.