I. INTRODUCTION

The project *Quality and comparability improvement of European causes of death statistics* has been undertaken within the context of the European Commission and in a double framework: an agreement of the DG Sanco Health Monitoring Program and the Eurostat Task Force on causes of death.

This project had a duration of two and a half years, from January 1999 to July 2001. It involved experts from the 15 European Union Member States and 2 EFTA countries.

I.1 BACKGROUND

Mortality statistics as a major health indicator

Cause-of-death statistics are widely used as a major source of data for comparing health characteristics between European populations. Results of these comparisons have been used as a starting point to investigate the causes of differences in the level of mortality, or of the health prevention policies, or quality of health care.


It often provides the only data available for comparison of general health status between Member States.

Because causes of death statistics relate to all deaths, the problems of biases and representation due to sampling are avoided. Furthermore, some procedures for the collection of causes of death data are relatively homogeneous between European countries (international forms of death certificates, International Classification of Diseases...). However, in spite of these common features, important quality and comparability issues remain.

The necessity to study comparability biases

The analysis of European mortality rates outlines important differences for various causes of death but before attempting to interpret these inter-country differences in terms of etiological factors, it is essential to assess the possible biases affecting the comparability of the data. Specialists in mortality analysis have often emphasised the importance of such an assessment. This necessity has also been pointed out by the editors of European mortality atlases (Holland WW. *European Community Atlas of Avoidable Death*, Commission of European Communities Health Services Research)
Series N°3, Oxford University Press; Oxford, 1991. World Health Organisation: *Atlas of mortality in Europe*, WHO regional publications, European series, 75; Copenhagen, 1997). One of the questions raised was whether the differences were real or partly the consequence of variations in the process of registering causes of death. Results of a preliminary feasibility study on practices in European Union countries outlined specific procedures that may affect comparability and ended with a general recommendation to analyse more precisely these procedures and to establish proposals for the standardisation of the registration of cause-of-death data (Commission of European Communities Health Services Research. *Evaluation of death certificates quality-report of the feasibility study*, 4th Programme-Project leader: Lagasse R - EC-Report-COMAC-HSR ; 1990).

**The Eurostat Task Force on causes of death**

Since 1994, EUROSTAT decided to address the problem of the comparability of public health statistics between European Union countries. The investigations are located within the larger context of a Working Group on "Public Health Statistics", organised by EUROSTAT, and based on the Statistical Framework Program of the European Commission. Three Task Forces and 'Legs' have been established aiming to address three domains of public health statistics: cause-of-death data, health and health related survey data, and health care data. For each Task Force, an institution from a specific Member State has a co-ordination function beside that of Eurostat. At the moment, CépiDc-SC8 INSERM from France has this role for the Task Force on causes of death.

The main objective of this Task Force is to improve the quality and comparability of cause-of-death data within the European Union, and to define the best way to disseminate the data. For the first issue the specific aims are; (i) to prepare initiatives for data quality improvement and reporting of causes of death, (ii) to examine methodological problems related to specific causes of death (e.g. ill-defined causes, violent death, deaths related to conditions such as alcohol or drug abuse), (iii) to make recommendations to Member States on improvement in quality and comparability.

**The DGSanco (DGV) Health Monitoring programme**

The Task Force on causes of death has divided its work according to three subjects: certification, coding, and statistics. For each item, specific investigations are undertaken. When the objectives of these investigations are too ambitious and need financial aid, they may request the support of specific European programmes. This has been the case with the investigations that CépiDc-SC8 INSERM aimed to initiate on the certification practices and the quality and comparability of statistics. Financial support has been requested from the Health Monitoring Programme, headed by DGV–DG Sanco (Directorate General Sanco). Together with EUROSTAT, the Health
Monitoring Programme has included as one of the primary objectives the selection of health indicators and the assessment and improvement of their quality and comparability. Through regular calls for tenders, DG Sanco select and grants projects that are focused on these items. The study 'Comparability and quality improvement in European causes of death' was submitted for the first time to the European Commission at the Public Health Application for Funding session of October 1997. An administrative obstacle made necessary in order to postpone the proposal until the next session (May 1998) where the project was adopted. The agreement between the Commission of the European Communities and INSERM (Institut National de la Santé et de la Recherche Médicale) was signed in December 1998 for a duration of two years, amended to two and a half years.

I.2 Objectives

Within the general objective of the improvement of the quality and comparability of European causes of death statistics, the project was separated into four specific tasks.

**Certification Practices**

* To complete investigations on causes of death certification practices among Member States.
* To lead towards concrete European recommendations for harmonization.

**Knowledge Base on the 65 Causes of Death (Eurostat Short List)**

* To produce an international database on published studies on the quality and comparability of causes of death statistics.
* To undertake a literature review on specific causes of death.

**To complete investigations on certification practices**

The first objective of the project concerning certification practices has been achieved. The investigations on certification practices have been made by the use of a detailed questionnaire and discussions within the network (meetings, mails and emails).

All 17 countries participating to the project have answered the questionnaire. This representation permitted us to collect complete information on the different practices in use in the European Union and EFTA countries. The information collected is important for the European Commission and for all the professionals working on causes of death statistics. Future work should be focused on more specific analysis and follow-up.

**To outline European recommendations on certification practices**

The production of recommendations to improve and harmonise the certification practices within Member States was considered by DGSanco as a major objective. This objective has been attained.
with the involvement of the network, the completeness of the answers to the questionnaire, and through discussion/validation within the meetings.

The recommendations, which total 39, are scientific suggestions. They have been discussed by experts who have a legitimate scientific point of view on causes of death statistics but who did not act as the official representative of their country.

The remaining task would be to go one step further in the implementation of the recommendations, selecting priorities, analysing in depth their feasibility and studying a methodology to follow-up the implementation.

**To constitute a database on published studies**

The inventory of the international knowledge concerning the quality and comparability of causes of death statistics has been successfully achieved. This inventory has been mainly based on the requests from two databases (Medline and Embase) with keywords such as 'death certificates', 'certification', 'codification', 'accuracy', 'reliability', and 'classification'.

The request outlines 760 papers written from 1980 to 1995 with various significance according to the objectives of the work. 243 papers were issued from specific studies undertaken in different European countries.

This literature review constitutes an extensive database which will be useful for all the professionals implicated in mortality statistics. This amount of information might permit varied types of analysis to be encouraged. Specific attention must be paid to the future methodology for updating the database.

**To investigate specific causes of death**

On the basis of the database on published studies and on a brief questionnaire on the quality and comparability of national statistics sent to each European expert, the aim in this section was to analyse specific causes of death where problems of quality and comparability seemed to be more important.

These first analyses had the objective of setting the framework for a future manual on the 65 causes of death (Eurostat short list) intended for users of mortality statistics.

The framework of the manual has been partly achieved with a direct reference to four groups of pathologies: suicide and controversial cases, cardiovascular diseases, pulmonary diseases (including malignat neoplasm of larynx and trachea/bronchus/lung and breast cancer. Other causes of death originally selected have not been covered by these analyses because of lack of time. They could be the priority of future works intended to achieve the constitution of a European manual on causes of death.
I.3 PARTICIPANTS

A network with experts from 17 European countries

Participants were first contacted during the preparation of the proposal, with the aim of being able to work with at least one causes of death expert in each European Union Member State. The DG Sanco considered this aspect as fundamental. Furthermore good representation was of first importance to insure the quality of the information collected and the validity of the recommendations.

Finally we had established a contact in each European Union Member State and in two EFTA Member States. Most of the time, the experts participated in the meetings. Four countries, (Denmark, Netherlands, Spain, UK-Northern Ireland) only completed the questionnaires, without any direct contact.

EXPERTS FROM EUROPEAN UNION MEMBER STATES
Jeannette Langgasner-Klimont, Richard Gisser
Wim Aelvoet, Peter Hooft
Yvo Pirenne
Marit Karina-Bucarella
Hilkka Ahonen
Eric Jougla, Gérard Pavillon
Matthias Reister, Christiane Rosenow
Chara Zikou
Mary Heanue
Sylvia Bruzzone
Mady Rouleaux
Ferry Oei
Derek Koper
Judite Catarino-Morgado, Humberto Moreira
Margarita Garcia-Ferruelo
Gloria Perèz
Lars A Johansson
Sue Kelly,
Olivia Christopherson,
Cleone Rooney
Stanley Campbell
Susan Cole
EXPERTS FROM EFTA MEMBERS STATES
Sigrun Helgadottir,
Brynjolfur Sigurjonsön
Finn Gjertsen

AUSTRIA
BELGIUM (Flemish Community)
BELGIUM (French Community)
DENMARK
FINLAND
FRANCE
GERMANY
GREECE
IRELAND
ITALY
LUXEMBOURG
NETHERLANDS
PORTUGAL
SPAIN
SPAIN-CATALONIA
SWEDEN
UK-ENGLAND WALES
UK-NORTHERN IRELAND
UK-SCOTLAND
ICELAND
NORWAY
EXPERTS FROM INSTITUTIONS
Henriette Chamouillet EEC / DGSANCO
Marleen Desmedt, EEC / EUROSTAT
Jacques Bonte
Remijius Prokhorskas WHO EUROPE
Rafael Lozano WHO GENEVA

A list with complete names of institutions, functions and addresses is in Annexe A.

In some countries, there was more than one expert because of regional organisation, for example Belgium - Flemish and French speaking communities, United Kingdom with England-Wales, Northern Ireland and Scotland, Spain with Catalonia, or for administrative reasons as in Portugal. In the case of Germany, the expert represented the Land of Hessen. In four countries (Austria, Germany, Iceland, UK-England), participants changed through the duration of the project (all names figure in the list). The participants have been closely involved in the project and we would like to take this opportunity to thank them for their active contribution.

I.4 ORGANISATION

The organisation of the project has been based around a co-ordination team (Centre d'épidémiologie sur les causes médicales de décès–Cepidc-SC8 INSERM), a correspondent network with two working levels (a Steering Group and a Plenary Group), five meetings and specific attention paid to the validation of the decisions made.

The co-ordination team

The co-ordination team was located in SC8-INSERM (called since 2001 the Centre d'épidémiologie sur les causes médicales de décès-CépiDc) which is in charge of the national causes of death statistics in France. This service is incorporated within INSERM (Institut national de la Santé et de la Recherche Médicale) -the national institution of medical research in France.

The co-ordination team was set up with Eric Jougla (head of CépiDc-INSERM) as Project leader, Florence Rossollin as responsible for the co-ordination, Gérard Pavillon (Head of WHO Collaborating Center on ICD in French) as expert, Antoine Niyonsenga and Jean-Loup Chappert as researchers. Lars Age Johannsson, Head of the Coding Service in Statistics Sweden, has been closely associated to the whole project and more particularly on the contents concerning the items of Coverage and Ill-defined conditions.

Six other persons have been regularly involved in the project: Anne-Laure Dottori, Jackie Gharibi and Tanya Vandepoorter as secretaries, Cyrille Suss for the establishment of the European maps Marc Mellah as infographist and Vanessa Renaud for the bibliography.
Some contributors have been implicated at specific stages of the work: Mireille Beaudoin, for the interrogation of the bibliographic databases, Renzo Pace Askias - Malta, for the analysis of published studies and text on breast cancer and Stéphane Rican, for the analysis of published studies and text on pulmonary diseases.

**The correspondent network**

The correspondent network fell into two categories of work.

**The Plenary Group** was constituted from experts from 17 countries, 15 European Union countries and 2 EFTA countries (see above section on participants). The Plenary Group participated in two general meetings (Paris-June 1999 and Barcelona-November 2000) and was involved in all the inquests and recommendations.

**The Steering Group** was organised with experts from eight countries, 6 European Union countries (two regions for UK) and one EFTA country:

- Wim Aelvoet (Belgium-Flanders)
- Eric Jougla (France)
- Matthias Reister (Germany)
- Finn Gjertsen (Norway)
- Judite Catarino-Morgado (Portugal)
- Gloria Perez (Spain-Catalonia)
- Lars A Johansson (Sweden)
- Sue Kelly, Dr Cleone Rooney (UK-England Wales)
- Susan Cole (UK-Scotland)

Suzan Cole and Gloria Perez have joined the Steering Group for the second meeting in Luxembourg

The Steering Group participated in three other specific meetings, apart from the Plenary Group meetings, (Stockholm-March 1999, Luxembourg-December 1999 and Lisbon-April 2000) and was involved in all discussions and decisions.

**The meetings**

The five meetings (two Plenary Group meetings plus three Steering Group meetings) planned in the initial stages of the project all took place. They were located in five different countries (Sweden, France, Luxembourg, Portugal and Spain-Catalonia) and were organised with the help of the expert participant to the Group and his institution for each particular country (Eurostat in Luxembourg).

The organisation of the meetings (all travel and hotel reservations) was managed directly by the co-ordination team. This involved a large amount of work but was the only way to remain within the budget and work via the INSERM administration.

**Stockholm –1st Steering Group meeting – 26 March 99**

The official minutes of the meetings are in the Annexe section of the report.

I. 5 MATERIALS

The investigation used four types of materials related to the different issues of the project:

- A detailed questionnaire on the certification practices (Part 1)
- An international literature review of published papers on quality and comparability on causes of death statistics (1985-1997)
- A questionnaire on the analysis of specific causes of death (Part 2)
- Discussions with the experts (meetings/correspondence).

The questionnaire on the certification practices (Part 1)

The questionnaire on certification practices totalled 182 questions on six items: the death certificate (medical part), the infant death certificate, training practices, query practices, confidentiality practices, and coverage and ill-defined conditions.

The contents of the questionnaire were discussed and validated with the participants from the first Steering Group (Stockholm) and the Plenary Group (Paris). 20 out of 21 experts completed this part of the questionnaire.

The database of published studies
The constitution of the database of published studies has followed three main steps: i) the online identification based on the requests from the two databases (Medline and Embase), ii) the selection and ordering of articles, iii) the practical organisation and elaboration of the database.

The resulting papers are organised with one file (or more) for each of the 65 causes of death. Each causes of death file comprises two copies of the papers, the résumés of the database when they exist, a table (Excel) that summarises the main features of the articles and permits the easy location of any article, and a scientific bibliography which presents the papers as requested in international revues.

**The questionnaire on the quality and comparability of 14 specific causes of death (Part 2)**

On the basis of maps and tables of European statistics, the methods of this part of the questionnaire consisted of collecting expert's opinions on the quality and comparability of 14 specific causes of death statistics and on possible improvement (within countries and at a European level).

The selection of the causes of death and the contents of the questionnaire were discussed and validated with participants of the Steering Group (Stockholm) and the Plenary Group (Paris). 13 out of 21 experts completed this shorter but more complex part of the questionnaire.

**The discussions with European experts**

Within the five meetings or by email, the discussions with the network have been an essential contribution to the project, in particular for the composition of the recommendations.