This report was compiled with the aid of financial support from the European Commission.

CONTENTS

COORDINATING TEAM :

Project Leader: Eric Jougla; Project Coordinator: Florence Rossollin; Researchers: Antoine Niyonsenga, Jean-Louis Chappert; Experts: Lars Age Johansson, Gérard Pavillon.

ASSISTED BY :

Administration: Anne-Laure Dottori, Jacqueline Gharibi and Tanya Vandepoorter; Bibliographic databases interrogation: Mireille Beaudoin; Infographist: Marc Mellah; Bibliography composition: Vanessa Renaud.

SPECIFIC CONTRIBUTIONS :
Analysis on Breast Cancer: Renzo Pace Asciak; Analysis on Pulmonary Diseases: Stéphane Rican; European maps: Cyrille Suss.

CORRESPONDENT NETWORK OF EUROPEAN EXPERTS
AUSTRIA: Jeannette Langgasner-Klimont, Richard Gisser; BELGIUM (Flemish Community): Wim Aelvoet, Peter Hooft; BELGIUM: Yvo Pirenne (French Community); DENMARK: Marit Karina Bucarella; FINLAND: Hilkka Ahonen; FRANCE: Eric Jougla, Gérard Pavillon; GERMANY: Matthias Reister, Christiane Rosenow; GREECE: Chara Zikou; IRELAND: Mary Heanue; ITALY: Sylvia Bruzzone; LUXEMBOURG: Mady Roulleaux; NETHERLANDS: Ferry Oei, Derek Koper; PORTUGAL: Judite Catarino-Morgado, Humberto Moreira; SPAIN: Margarita Garcia-Ferruelo; SPAIN-CATALONIA: Gloria Perez; SWEDEN: Lars A Johansson; UK-ENGLAND WALES: Sue Kelly, Olivia Christopherson, Cleone Rooney; UK-NORTHERN IRELAND: Lois Cook; UK-SCOTLAND: Susan Cole, Stanley Campbell, Graham Jackson.

EFTA MEMBER STATES
ICELAND: Sigrun Helgadottir, Brynjolfur Sigurjonsson ; NORWAY: Finn Gjertsen.

INSTITUTIONS
EEC / DGSANCO: Henriette Chamouillet; EEC / EUROSTAT: Marleen Desmedt, Jacques Bonte; WHO EUROPe: Remigijus Prokhorskas; WHO GENEVA: Rafael Lozano.

Population and number of deaths of countries participant to the project

European Union Member States

EFTA Member States

10 000 : Population (source: Eurostat 1994)

10 000 : Number of deaths (source: Eurostat 1994)

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.

The popularity of cause-of-death data as a general indicator for the status of health is readily explained by its availability. International cause-of-death data is published annually by several international agencies such as the Statistical office of the European Communities (EUROSTAT: *Demographic statistics;* Luxembourg 1996 – http://europa.eu.int/ new-cronos) or the World Health Organisation (WHO: *Wld hlth statist annu*; Geneva 1994 – http://) using standardised lists of categories.

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 controversal cases, cardiovascular diseases, pulmonary diseases (including malignat neoplam 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	**AUSTRIA**
Wim Aelvoet, Peter Hooft	**BELGIUM** (Flemish Community)
Yvo Pirenne	**BELGIUM** (French Community)
Marit Karina-Bucarella	**DENMARK**
Hilkka Ahonen	**FINLAND**
Eric Jougla, Gérard Pavillon	**FRANCE**
Matthias Reister, Christiane Rosenow	**GERMANY**
Chara Zikou	**GREECE**
Mary Heanue	**IRELAND**
Sylvia Bruzzone	**ITALY**
Mady Roulleaux	**LUXEMBOURG**
Ferry Oei, Derek Koper	**NETHERLANDS**
Judite Catarino-Morgado, Humberto Moreira	**PORTUGAL**
Margarita Garcia-Ferruelo	**SPAIN**
Gloria Perèz	**SPAIN-CATALONIA**
Lars A Johansson	**SWEDEN**
Sue Kelly, Olivia Christopherson, Cleone Rooney	**UK-ENGLAND WALES**
Stanley Campbell	**UK-NORTHERN IRELAND**
Susan Cole	**UK-SCOTLAND**
EXPERTS FROM EFTA MEMBERS STATES	
Sigrun Helgadottir, Brynjolfur Sigurjonsson	**ICELAND**
Finn Gjertsen	**NORWAY**
EXPERTS FROM INSTITUTIONS	
Henriette Chamouillet	**EEC / DGSANCO**

Marleen Desmedt, **Jacques Bonte**	**EEC / EUROSTAT**
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

Present: Wim Aelvoet, Judite Catarino-Morgado, Finn Gertsen, Lars A Johansson, Eric Jougla, Sue Kelly, Gérard Pavillon, Matthias Reister, Florence Rossollin.

Paris – 1st Plenary Group meeting – 25 June 99

Present: Wim Aelvoet, Hilkka Ahonen, Judite Catarino-Morgado, Suzan Cole, Marleen De Smedt, Finn Gertsen, Mary Heanue, Sigrun Helgadottir, Lars A Johansson, Eric Jougla, Sue Kelly, Jeannette Langgasner, Rafael Lozano,

Humberto Moreira, Renzo Pace Askias, Gérard Pavillon, Yvo Pirenne, Matthias Reister, Florence Rossollin, Mady Roulleaux, Chara Zikou.

Luxembourg – 2nd Steering Group meeting – 10 December 1999

Present: Wim Aelvoet, Judite Catarino-Morgado, Henriette Chamouillet, Lars A Johansson, Eric Jougla, Gérard Pavillon, Gloria Perez, Matthias Reister, Florence Rossollin.

Lisbon – 3rd Steering Group meeting – 27-28 April 2000

Present: Wim Aelvoet, Judite Catarino-Morgado, Henriette Chamouillet, Ms Susan Cole, Ms Marleen De Smedt, Eric Jougla, Antoine Niyonsenga, Gérard Pavillon, Gloria Perez, Cleone Rooney, Florence Rossollin.

Barcelona–2rd Plenary Group meeting – 16-17 November 2000

Present: Hilkka Ahonen, Jacques Bonte, Sylvia Bruzonne, Judite Catarino-Morgado, Susan Cole, Richard Gisser, Finn Gjertsen, Mary Heanue, Peter Hooft, Lars Johannson, Eric Jougla, Antoine Niyonsenga, Renzo Pace Asciak, Gérard Pavillon, Gloria Perez, Gisèle Renaud, Cleone Rooney, Christiane Rosenow, Florence Rossollin, Mady Roulleaux, Tanya Vandepoorter, Chara Zikou.

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 data bases (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.

EUROPEAN COMMISSION

DG SANCO AGREEMENT

N°EDC DGV/F3 SOC 98 20108

"Comparability and Quality Improvement of European Causes of Death Statistics"

FINAL REPORT

July 2001

CépiDc
Centre d'épidémiologie
sur les causes médicales de décès

Inserm

French Institute
of Health and Medical Research

II. CERTIFICATION PRACTICES

In this section of the report the results of questionnaire (Part 1) are presented. These results allowed us to complete the investigations on the certification practices in Europe and define the recommendations for the improvement and harmonization to be proposed by the experts network to the European Commission.

Even if some errors of interpretation,or the need for additional information remains, this work constitutes an important source of progress for the improvement of the quality and comparability of European mortality statistics. Certainly, one of its main features is that each one of the 15 European Union Member States (+ Iceland and Norway) has been involved in it's preparation.

II.1 BACKGROUND

The elaboration of the mortality statistics is based on two main stages - certification and the coding of causes of death. After coding, additional steps permit us to arrive at the publication of statistics at national and international levels.

The certification of causes of death

The certification process begins with the death, and ends at the time when the coding of the cause of death is possible. In all European countries, the medical certification of death is an obligation. The document used to certify a death is the medical death certificate (in addition to the administrative death certificate that permits the notification of the death to the civil register).

There are two models of international medical death certificates recommended by the WHO (see next page). The first one must be used for all deaths except perinatal deaths; the second one must be used for perinatal deaths (0 to 1 week). These forms are recommendations and they are different applications. The main principles of the general form are now adopted by all European countries (with some remaining discrepancies) but the form for perinatal deaths is less frequently applied.

The objective of the medical death certificate is to permit the certifier to enter as clearly and completely as possible the causes of death. Describing the sequence of diseases leading to the death, mentioning other contributing conditions and specifying, for each cause of death entered, the time interval between onset and death. Some additional medical information concerning the deceased person is usually asked for on the death certificate.

Most of the time, physicians perform the certification. In the case of non-natural deaths, the certification could be made by forensic physicians or in some countries by legal professionals, such as coroners in England.

The medical death certificate follows an administrative circuit specific to each country but in all cases they must finally reach the Causes of Death Statistics offices in order to be coded. (8 maps of the circuit of death registration in different countries were sent back by the experts, they are included in the Annexe section of the Final Report)

INTERNATIONAL MEDICAL CERTIFICATE OF CAUSE OF DEATH

Cause of death	**Approximate interval between onset and death**
I	
Disease or condition directly leading to death***** (a).....	.....
due to (as a consequence of)	
Antecedent causes Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last (b).....	.....
due to (as a consequence of)	
(c).....	.....
due to (as a consequence of)	
(d).....	.....
II	
Other significant conditions contributing to the death, but not related to the disease or condition causing it	.....
.....	.....
****** This does not mean the mode of dying, e.g. heart failure, respiratory failure. It means the disease, injury, or complication that caused death.*	

WHO ICD-10 / 1993

INTERNATIONAL FORM OF MEDICAL CERTIFICATE OF CAUSE OF PERINATAL DEATH

To be completed for stillbirth and liveborn infants dying within 168 hours (1week) from birth
Causes of death a – Main disease or condition in fetus or infant b – Other diseases or conditions in fetus or infant
c – Main maternal disease or condition affecting fetus or infant d – Other maternal diseases or conditions affecting fetus or infant
e – Other relevant circumstances
❑ The certified cause of death has been confirmed by autopsy ❑ Autopsy information may be available later ❑ Autopsy not being held I certify..... .... Signature and qualification

WHO ICD-10 / 1993

The coding of causes of death

The purpose of the coding process is to select the underlying cause of death and to translate the literal text of the listed conditions into ICD codes (WHO International Classification of Diseases). All countries use the ICD codes to code the causes of death but they do not apply a new revision. Nowadays, there are two revisions in application in Europe (ICD 9 and ICD 10) that, in spite of common principles, have important differences such as the number of codes (5000 in the ICD 9 and 10 000 in the ICD10).

Differences also exist in the methods of coding that can be either manual or automated. The automated coding that uses computerized programs is already applied some countries, and is a very successful way of limiting coding biases and improving coding comparability.

After these two main stages, the dissemination of mortality statistics depends on the choice of aggregated lists of causes of death and on the choice of indicators. One of the initial tasks for the Eurostat Task Force on causes of death has been to edit a short list of 65 causes (see below) which is now largely in use.

Causes of death Eurostat shortlist (August 1998)

Nr	Disease or external cause	ICD-10 code	ICD-9 code
All causes of death		**A00-Y89**	**001-E999**
01	*Infectious and parasitic diseases*	*A00-B99*	*001-139*
02	Tuberculosis	A15-A19,B90	010-018,137
03	Meningococcal infection	A39	036
04	AIDS (HIV-disease)	B20-B24	042-044
05	Viral hepatitis	B15-B19	070
06	*Neoplasms*	*C00-D48*	*140-239*
07	Malignant neoplasms	C00-C97	140-208
08	of which Malignant neoplasm of lip, oral cavity, pharynx	C00-C14	140-149
09	of which Malignant neoplasm of esophagus	C15	150
10	of which Malignant neoplasm of stomach	C16	151
11	of which Malignant neoplasm of colon	C18	153
12	of which Malignant neoplasm of rectum and anus	C19-C20-C21	154
13	of which Malignant neoplasm liver and the intrahepatic bile ducts	C22	155
14	of which Malignant neoplasm of pancreas	C25	157
15	of which Malignant neoplasm of larynx and trachea/bronchus/lung	C32-C34	161-162
16	of which Malignant melanoma of skin	C43	172
17	of which Malignant neoplasm of breast	C50	174-175
18	of which Malignant neoplasm of cervix uteri	C53	180
19	of which Malignant neoplasm of other parts of uterus	C54-55	179,182
20	of which Malignant neoplasm of ovary	C56	183.0
21	of which Malignant neoplasm of prostate	C61	185
22	of which Malignant neoplasm of kidney	C64	189.0
23	of which Malignant neoplasm of bladder	C67	188
24	of which Malignant neoplasm of lymph./haematopoietic tissue	C81-C96	200-208
25	*Diseases of the blood(-forming organs), immunol.disorders*	*D50-D89*	*279-289*
26	*Endocrine, nutritional and metabolic diseases*	*E00-E90*	*240-278*
27	Diabetes mellitus	E10-E14	250
28	*Mental and behavioural disorders*	*F00-F99*	*290-319*
29	Alcohol abuse (including alcoholic psychosis)	F10	291,303
30	Drug dependence, toxicomania	F11-F16, F18-F19	304-305
31	Diseases of the nervous system and the sense organs	G00-H95	320-389
32	Meningitis (other than 03)	G00-G03	320-322
33	*Diseases of the circulatory system*	*I00-I99*	*390-459*
34	Ischaemic heart diseases	I20-I25	410-414
35	Other heart diseases	I30-I33, I39-I52	420-423, 425-429
36	Cerebrovascular diseases	I60-I69	430-438
37	*Diseases of the respiratory system*	*J00-J99*	*460-519*
38	Influenza	J10-J11	487
39	Pneumonia	J12-J18	480-486
40	Chronic lower respiratory diseases	J40-J47	490-494,496
41	of which asthma	J45-J46	493
42	*Diseases of the digestive system*	*K00-K93*	*520-579*
43	Ulcer of stomach, duodenum and jejunum	K25-K28	531-534
44	Chronic liver disease	K70,K73-K74	571.0-571.9
45	Diseases of the skin and subcutaneous tissue	L00-L99	680-709
46	*Diseases of the musculoskeletal system/connective tissue*	*M00-M99*	*710-739*
47	Rheumatoid arthritis and osteoarthrosis	M05-M06, M15-M19	714-715
48	*Diseases of the genitourinary system*	*N00-N99*	*580-629*
49	Diseases of kidney and ureter	N00-N29	580-594
50	Complications of pregnancy, childbirth and puerperium	O00-O99	630-676
51	Certain conditions originating in the perinatal period	P00-P96	760-779
52	*Congenital malformations and chromosomal abnormalities*	*Q00-Q99*	*740-759*
53	Congenital malformations of the nervous sytem	Q00-Q07	740-742
54	Congenital malformations of the circulatory system	Q20-Q28	745-747
55	*Symptoms, signs, abnormal findings, ill-defined causes*	*R00-R99*	*780-799*
56	Sudden infant death syndrome	R95	798.0
57	Unknown and unspecified causes	R96-R99	798.1-9,799
58	*External causes of injury and poisoning*	*V01-Y89*	*E800-E999*
59	Accidents	V01-X59	E800-E929

60	of which Transport accidents	V01-V99	E800-E848
61	of which Accidental falls	W00-W19	E880-E888
62	of which Accidental poisoning	X40-X49	E850-E869
63	Suicide and intentional self-harm	X60-X84	E950-E959
64	Homicide, assault	X85-Y09	E960-E969
65	Events of undetermined intent	Y10-Y34	E980-E989

II. 2 QUESTIONNAIRE (PART 1)

The main material used in this section was the collection of information via a detailed questionnaire. The objective of this was to achieve knowledge on certification practices among different European countries, to measure the influence of differences in certification practices on quality and comparability of causes of death statistics, to outline European recommendations for improvement, and to appreciate possible difficulties in the implementation of these recommendations. The questionnaire was composed of six sections covering the different stages of the certification:

1. General death certificate (medical part)
2. Infant death certificate
3. Training practices
4. Query practices
5. Confidentiality practices
6. Coverage and ill-defined conditions.

For each item, the methods consisted of questions on practices in each country, opinions on these practices, and opinions on European recommendations (contents and feasibility).

(The section 6 on Coverage and ill-defined conditions has been prepared and analyzed by Lars Johansson from Statistics Sweden).

II.2.1 METHODOLOGY

The questionnaire on European certification practices (Part 1) is the result of a long process beginning with some previous undertakings in the context of the Task Force on Causes of Death. Two meetings from the project were dedicated to its finalization (Steering Group meeting in Stockholm and Plenary Group meeting in Paris).

Responses from all of the 17 countries participating to the project

The questionnaire (Part 1) was sent to one expert in each European Union Member State and in two EFTA Member States (Iceland and Norway). In countries with a regional administration, each region received the questionnaire (Belgium: French and Flemish communities; United-Kingdom: England-Wales, Northern Ireland and Scotland). In Spain, the questionnaire was sent at a national level and

also to Catalonia. In Germany, the questionnaire was sent to an expert from the Land of Hessen who was responsible for collecting information from other regions.

The questionnaire was sent at the end of October 1999. Experts sent back their responses between December 1999 and March 2000.

20 out of 21 questionnaires came back (missing Belgium – French Community). The 17 European countries participant to the project supplied comprehensive answers to the questionnaire. It was a good participation for such a detailed questionnaire with an important contribution from the experts.

Most of the experts have answered alone (14 out of 20). Others asked for information from colleagues or collaborated very closely with the co-ordinating team. 9 experts were the heads of Causes of Death Statistics Offices. The Offices of the 17 European countries concerned by the study are located mainly in the National Statistical Institutes (12). 3 Offices are dependant upon the Ministry of Health and 2 are related to both institutions.

II.2.2 RESULTS

The results of the questionnaire are presented in two formats. For each one of the six main items, there is a 'General overview' and then 'Detailed responses'. The 'General overview' summarizes the results in a few pages, illustrated with maps for particularly important questions. The 'Detailed responses' give the exact answer of each European expert to each question. *(We hesitated before including these detailed responses in order to avoid possible errors, but they represent an important amount of information, too valuable to be left out.)*

The validation of the answers has been arrived at by sending each expert a table where he could control his answer, compare it to others and eventually correct it. At the moment of the final redaction, answers that still seemed incoherent or surprising were checked again via emails.

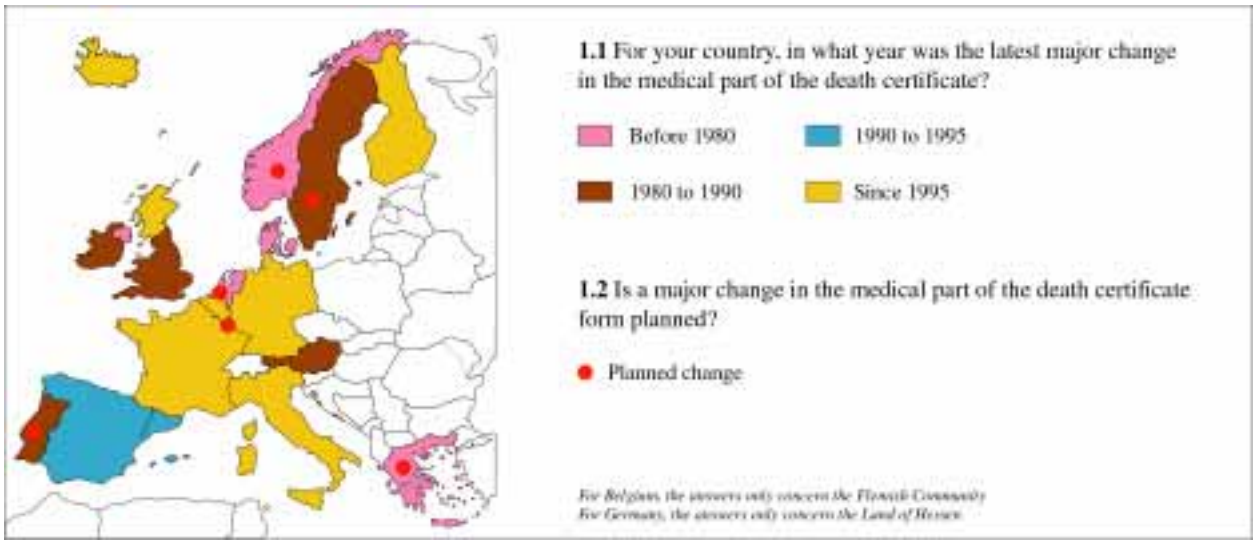
In spite of all these verifications, some errors could remain. If you notice any, can you please take the time to signal these remaining errors to the co-ordination team (jougla@vesinet.inserm.fr).

II.2.2.1 GENERAL DEATH CERTIFICATE

A. GENERAL OVERVIEW

Procedures to change the medical part of the death certificate

Nearly half of the European countries/regions (9/20) have introduced a major change in the form of the death certificate used in their country since 1990 and six countries plan to make a change within the next few years. The reasons for changing are varied: implementation of the 4th line (WHO recommendation) as in Iceland and France, new boxes as in Austria (autopsy) and Sweden (drug abuse/dependence), or technical improvements for digitisation of documents as in Finland or The Netherlands.



The procedure to change the death certificate form is considered a long process, mainly by Scandinavian countries where a wide consensus is required. 6 out of 12 countries concerned by a recent or planned change have undertaken tests before the implementation of a new certificate. In Sweden, the new certificate has been tested for a period of three months to compare certification practices between the old and new and to collect related opinions from certifiers.

Presentation of the causes of death in the death certificates

The logical sequence from the originating cause to the direct cause (WHO international form) is considered as an efficient concept by 17 countries out of 20. However, some experts (Catalonia, Belgium, Sweden) think that it is not well adapted for elderly people with multiple chronic diseases.

The overall implementation of the WHO international form with 4 lines to describe the causes of death in death certificates is on-going (Table 1). Six countries have already adopted it and five countries plan to before 2002. Four lines to describe the cause of death process is considered as

'sufficient' by most experts, but for three of them, it is 'insufficient' and, in contrast, one ticks the box 'too many' because he thinks 'certifiers need space rather than lines'.

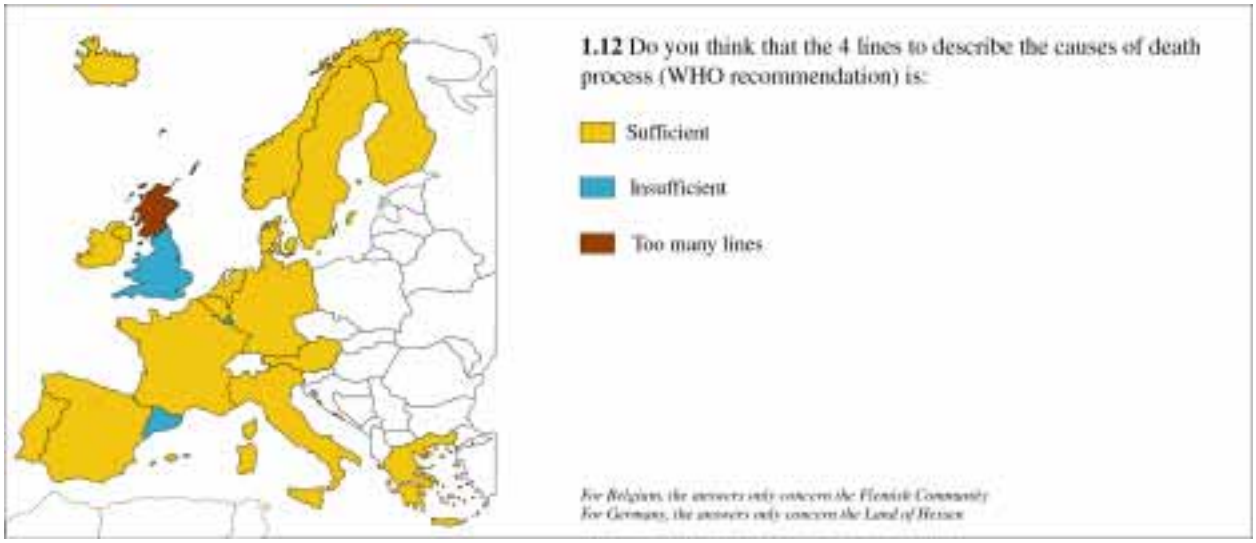
Denmark, Iceland and Sweden have introduced an arrow printed from the originating to the direct cause of death on the death certificate with the aim to help the certifier to understand the sequence concept. Sweden is the only country who found an improvement in certification since this new design was introduced, but the majority of countries who have not yet adopted this arrow would be in favour of it.

Some countries (9/20) think that the role of Part II (Other significant conditions contributing...) is not sufficiently understood by physicians, who may repeat what they have written in the previous sequence.

Table 1 **Number of lines to describe the causes of death**

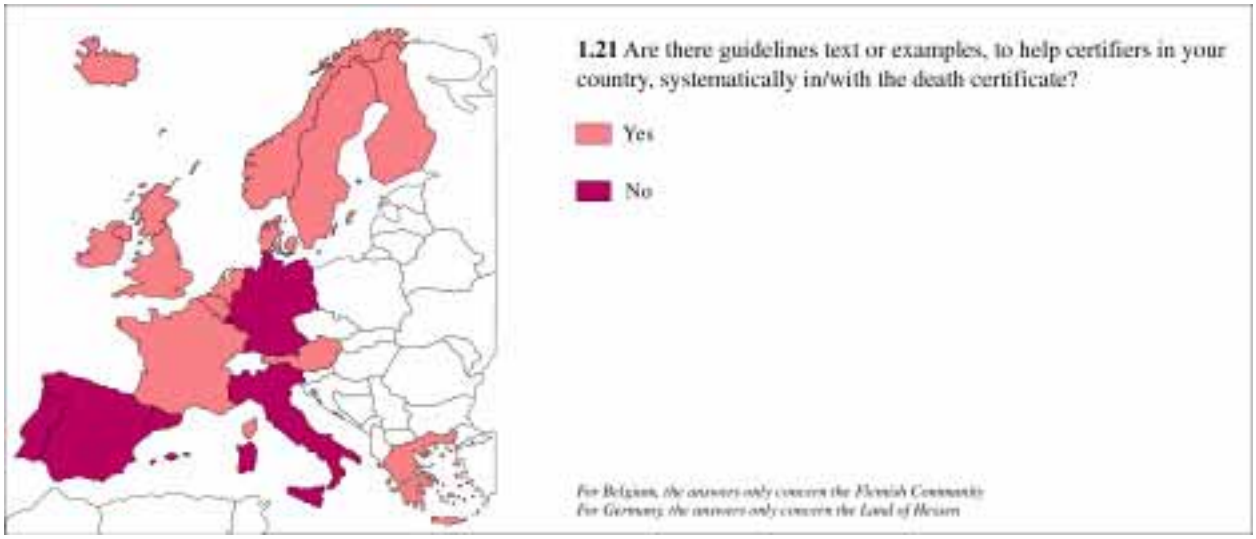
	< 3 LINES	3 LINES	4 LINES	4 LINES PLANNED
AUSTRIA	**X**			
BELGIUM			**X**	
DENMARK			**X**	
FINLAND		**X**		
FRANCE			**X**	
GERMANY		**X**		**2001**
GREECE		**X**		**2002**
ICELAND			**X**	
IRELAND		**X**		
ITALY			**X**	
LUXEMBOURG	**X**			
NETHERLANDS		**X**		
NORWAY		**X**		**2002**
PORTUGAL		**X**		**2002**
SPAIN		**X**		
SWEDEN		**X**		**2002**
UK-ENGLAND-W		**X**		
UK-SCOTLAND			**X**	

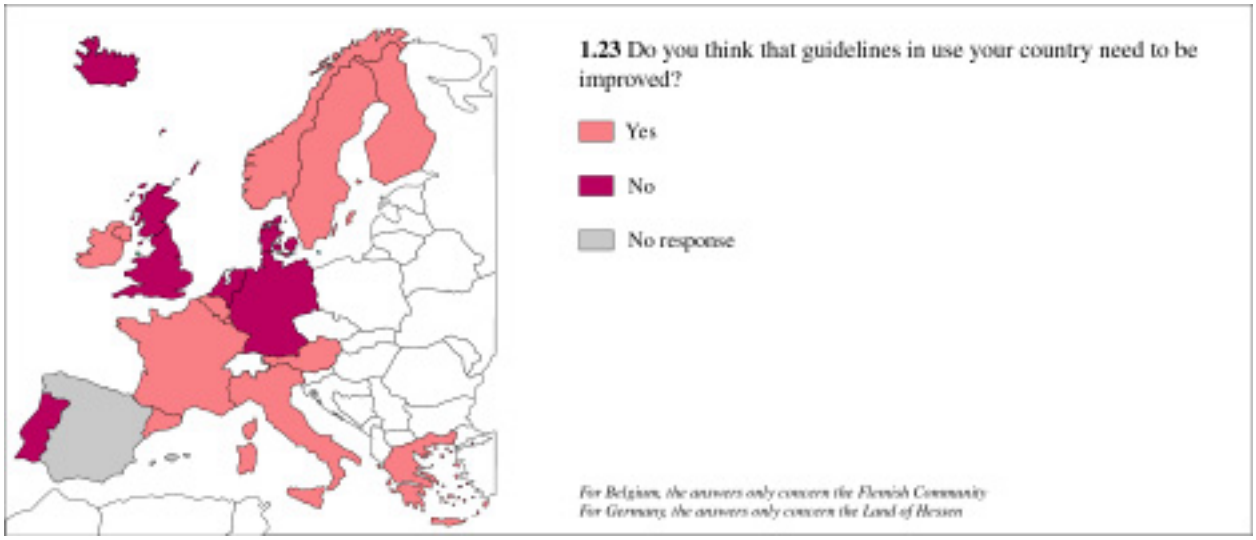
November 2000



Guidelines to help the certifiers

In most countries (14/20), there are guidelines, systematically in/with the death certificate, to help certifiers. They consist in general of a text explaining the certification rules and of concrete examples. The majority of experts think that the guidelines in use in their countries need to be improved (12/20) and nearly all countries find it important to harmonise guidelines within the European Union.





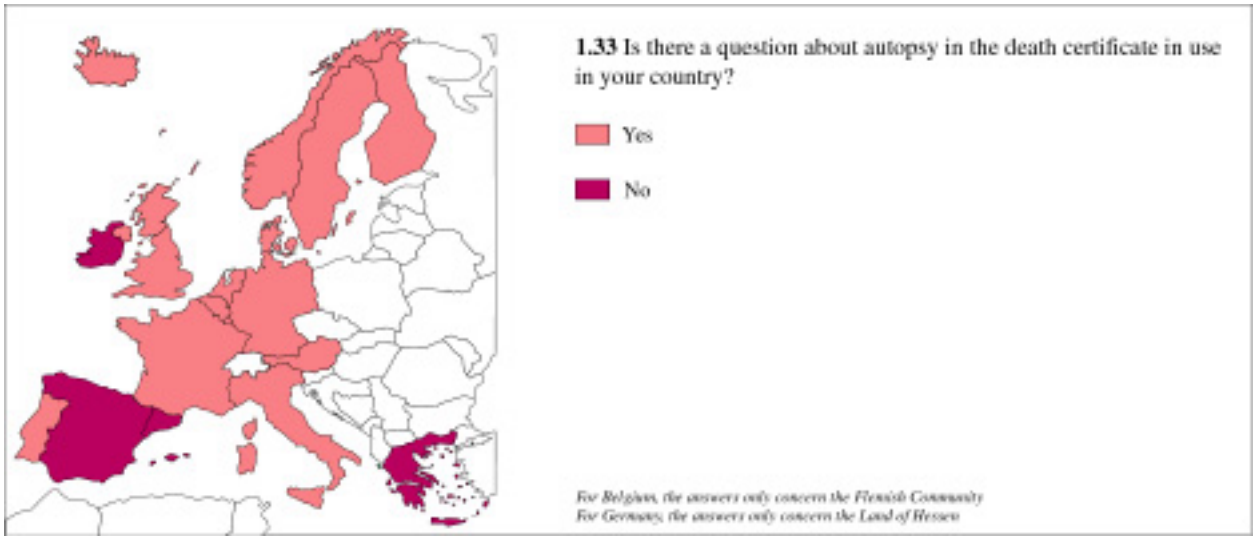
The main reason for European harmonization is that specific examples might introduce biases if they are different: 'Examples should be the same in all countries in order to obtain good comparability'. One major suggestion for harmonization is to use more widely the WHO guidelines and examples (even if it means developing and making them clearer).

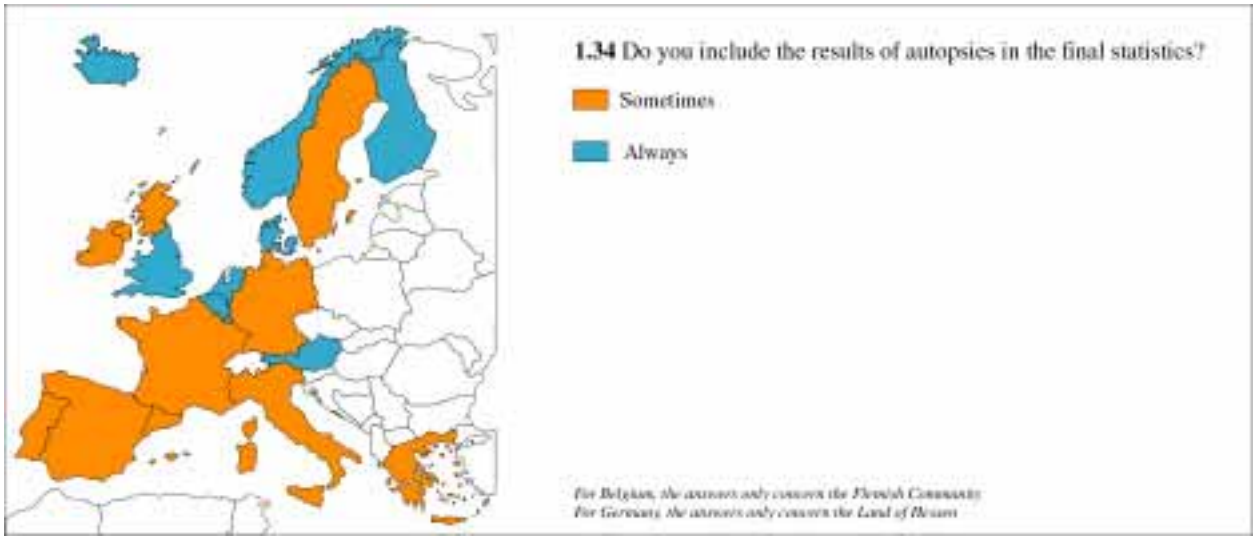
Who are the certifiers?

Usually certifiers are physicians. For violent deaths, the certification is performed in some countries by coroners, judges or police. Within the medical profession, practices vary among countries. In Austria, only the medical health officers are allowed to certify. In The Netherlands, a designated physician can be called in specific occasions. In some countries, the certifier must be the physician in charge of the deceased. In most countries certifiers are young hospital physicians or primary care physicians and pathologists.

Additional medical information

Information on autopsy is often collected on the death certificate (16/20) but the results of autopsy are not systematically included in final statistics. 9 Causes of death Offices include them 'always' and 11 offices 'sometimes'. The main reason why autopsy results are not included is that Causes of death Offices either never get them (Italy, Portugal), or rarely (France, Scotland), or in many cases too late. The opposite situation exists in Finland where it is impossible to certify a death without the results of the autopsy (when an autopsy is undertaken). This situation is considered by all European experts as the most efficient and therefore the one to recommend.





Other medical additional information systematically collected is: accident place, occupational accident/disease, recent surgery and pregnancy. Risk factors such as drug addiction, alcohol abuse or diabetes are rarely systematically collected. Independent of the practices in their countries, experts think that the most useful and feasible/reliable variables to collect systematically are pregnancy state, accident place, occupational accident/disease and recent surgery.

Socio-demographic information

In the final individual mortality file, the socio-demographic variables most often collected are: sex, age, residence, place of death (hospital, home...) and occupation (in a few cases, educational level). This information is mainly directly collected via the death certificate. Six countries collect other items. In Spain-Catalonia, the marital status and the date or place of birth are collected via

the death certificate. In Finland many variables (e.g. family relationships, housing, language, and religion) are collected from the census or from the population register.

Table 2 Additional information in the Mortality Database

	ACCIDENT	WORK ACCIDENT	PREGNANCY	AUTOPSY	SURGERY	OCCUPATION
AUSTRIA	X			X		
BELGIUM	X		X	X		X
DENMARK	X	X		X		
FINLAND	X	X	X*	X	X	X*
FRANCE	X	X	X	X		X
GERMANY	X	X	X			
GREECE	X		X			X
ICELAND	X	X		X	X	X
IRELAND			X		X	
ITALY	X	X		X	X	
LUXEMBOURG	X					X
NETHERLANDS	X			X		
NORWAY	X	X		X	X	
PORTUGAL				X		X
SPAIN	X			X		X
SWEDEN	X	X*	X*	X	X	X*
ENGLAND-W	X	X		X		X
SCOTLAND	X**		X	X		X

* from registers
** by Ecode

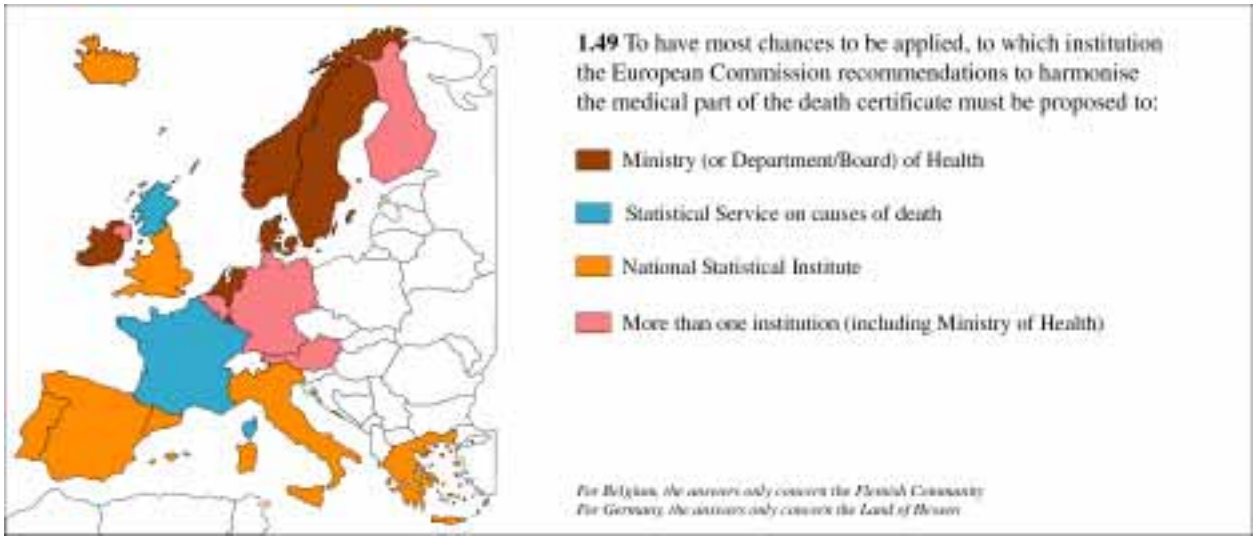
November 2000

All countries find it important to collect information on the socio-economic status of the deceased: education, occupation level, or both. However, they differ on the methods of collection, via the medical part of the death certificate (notified by the certifier), the administrative part of the death certificate (declared by e.g. relatives), or other sources (e.g. registers).

European harmonization of the death certificates

10 countries find it 'necessary' (and 8 'feasible') to harmonise the medical part of the death certificate. The main suggestion for harmonization is to adopt the exact WHO model and to develop a common form that specifies the minimum information to be collected on each death.

Except for four of them, the experts think that harmonization might cause problems in their countries, but naturally it would depend on the level of importance of the change. Main problems could be due to cost (11/20), administrative (11/20) and legal reasons (10/20).



Ministries (Departments or Boards) of Health are the institutions the most implicated in changing the death certificate. Alone or with another institution (including the National Statistical Institute), they would have the responsibility to take the decision for changing the death certificate in 15 countries. In the other 5 countries or regions (Belgium, Greece, Italy, Spain, Spain-Catalonia), the National Statistical Institute would have this responsibility (alone or with an institution other than the Ministry of Health).

B. DETAILED RESPONSES

NB : All questions concern for Belgium : The Flemish Community and for Germany : The Land of Hessen only

1.1 For your country, in what year was the latest major change in the medical part of the general death certificate?

Since 1995	**7 :**	Belgium, Finland, France, Germany, Iceland, Italy, UK-Scotland
1990 to 1995	**2 :**	Spain, Spain-Catalonia
1980 to 1990	**5 :**	Austria, Ireland, Portugal, Sweden, UK-England
Before 1980	**6 :**	Denmark, Greece, Luxembourg, Norway, Netherlands, UK-Northern Ireland

1.2 Is a major change in the medical section of the death certificate form planned?
1.3 If yes, in what year?

Yes	**6 :**	Greece (2002), Luxembourg (no confirmed date), Norway (2001), Netherlands (2001), Portugal (2001), Sweden (2001)
No	**14 :**	Austria, Belgium, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Spain, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland

1.4 Which part of the medical section of the death certificate is concerned by the change (passed planned)?

Section on causes of death	**5 :**	Germany, Italy, Luxembourg, Norway, UK-Scotland
Section on additional medical information	**2 :**	Greece, Netherlands
Both	**6 :**	Belgium, Finland, France, Iceland, Portugal, Sweden

Precise new or changed items:

Previous Changes
Austria : Autopsy yes/no.
Belgium : Interval, part II + additional lines (WHO model).
Finland : More space, boxes for accidents and surgery circumstances, guidelines shortened. Technical improvement (computer readings and to make the death certificate easier to fill out).
France : 4 lines, place of accident, new boxes: pregnancy, autopsy used for certification, accident at work.
Iceland : 4 lines + information on surgical operations.
Italy : Little technical improvement.
UK-Scotland : 4 lines + guidance notes.

Future Changes
Greece : 2002 to add information on live births by birthweight and duration of gestation.
Netherlands : Scanning and Optical Character Recognition.
Norway : Place for text.
Portugal : 4 lines, information on occupational accidents, natural or violent deaths, maternal related causes, autopsies.
Sweden : Part 1 (add Line D). Additional medical information : Tick boxes for drug abuse/dependence. Possibly physician's identification number.

1.5 Reasons for the passed or planned change in the medical death certificate form:

To follow the WHO recommendations on presentation of causes of death	**10 :**	Belgium, France, Germany, Greece, Iceland, Luxembourg, Norway, Portugal, Sweden, UK-Scotland
In connection with the ICD 10	**3 :**	Belgium, Sweden, UK-Scotland
For an improvement in the reliability of the data	**11 :**	Belgium, Finland, France, Greece, Iceland, Italy, Norway, Luxembourg, Portugal, Sweden, UK-Scotland
For an improvement in the international comparability of data	**7 :**	Belgium, France, Greece, Italy, Luxembourg, Norway, UK-Scotland

To collect additional medical information	**10 :**	Belgium, Finland, France, Greece, Iceland, Luxembourg, Norway, Portugal, Sweden, UK-Scotland
For administrative reasons	**7 :**	Finland, France, Germany, Netherlands, Norway, Portugal, Sweden
For legal evolution	**5 :**	Finland, Germany, Iceland, Netherlands, Norway
For other reasons	**4 :**	Finland, Italy, Netherlands, UK-Scotland

1.6 Institutions or groups proposing and finally deciding the contents of the change in the medical section of the death certificate:

PROPOSING

Ministry of Health	**2 :**	Belgium, Luxembourg
Statistical Service on Causes Of Death	**5 :**	Belgium, France, Norway, Portugal, Sweden
National Statistical Institute	**2 :**	Netherlands, Norway
Association of physicians/ epidemiologists	**2 :**	Belgium, Norway
Other institution(s) or group(s)	**2 :**	Belgium, Norway

Belgium : Demographers.
Norway : Forensic institute.

DECIDING

Ministry of Health	**4 :**	Finland, France, Netherlands, Sweden
Statistical Service on Causes Of Death	**0 :**	
National Statistical Institute	**1 :**	Belgium
Association of physicians/ epidemiologists	**0 :**	
Other institution(s) or group(s)	**1 :**	Luxembourg

BOTH

Ministry of Health	**3 :**	Germany, Norway, Portugal
Statistical Service on Causes Of Death	**2 :**	Finland, UK-Scotland
National Statistical Institute	**3 :**	Finland, Greece, Italy
Association of physicians/ epidemiologists	**0 :**	
Other institution(s) or group(s)	**1 :**	Finland

Finland : Population Register Centre, Ministry of Internal Affairs, churches, hospitals.
Sweden : Changes are decided by the National Board of Health, (corresponds in this respect to Ministries of Health in other countries), after consultation with the National Statistical Institute (Statistics Sweden), the National Tax Board (in charge of the population register) and the National Police Board. A number of other interested parties might be consulted as well, although it is not a legal requirement.

1.7 Main problems in proceeding with change:

Change in law needed	**5 :**	Germany, Iceland, Luxembourg, Netherlands, UK-Scotland
Training of certifiers	**1 :**	Italy
Other reasons	**5 :**	Belgium, Finland, France, Norway, Sweden
Both/ more than 2 answers	**2 :**	Greece, Portugal

1.8 Can you briefly explain the problems outlined?

Finland : Long process, careful evaluation, wide consensus, complex linkage to the administrative regulations and practices.
France : Assessing the change in trends passing from 2 to 4 lines.
Norway : Many proposing, suggestions from partners from Cause of Death Statistics Offices.

Sweden : Main problems : Other - wide consultations are extremely time-consuming, and conflicts of interest might be difficult to solve. Any changes that involve new efforts or expenses would be very difficult to carry through.
UK-Scotland : No new legislation but legal formalities.

1.9 Was the new certificate implemented after a practical test? (Will the new certificate be implemented after a practical test?)

Yes	**6 :**	France, Germany, Greece, Norway, Portugal, Sweden

1.10 If yes, can you briefly describe the type of test:

France : Case histories filled out by two samples of physicians with the aim to compare two methods of guidelines (examples versus text).
Greece : With pilot survey to collect data in the regions.
Sweden : The new certificate was tried for three months in three test areas (a part of Stockholm, one middle-sized municipality and one rural district). The certificates issued during the trial period were analysed with regards to mistakes in certification. A similar analysis was made for demographically matching areas in which the old certificate was still in use. Users of the new certificate were encouraged to contact Statistics Sweden and give their opinion, suggest modifications etc.
Portugal : Utilisation of the 2 certificates in a hospital setting.

1.11 If no, why not ?

Belgium : Very difficult to realise a correct sample of physicians.
Finland : Not necessary, wide consensus.
UK-Scotland : Wide consultation, live test not practicable.

1.12 Do you think that the 4 lines to describe the causes of death process (WHO recommendation) is:

Insufficient	**3 :**	Luxembourg, Spain-Catalonia, UK- England
Sufficient	**16 :**	Austria, Belgium, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Netherlands, Norway, Portugal, Spain, Sweden, UK-Northern Ireland, UK-Scotland
Too many lines	**1 :**	Finland

1.13 Why?

Austria : Limits the doctor to relevant information.
Belgium : Enough, even 3 lines seem sufficient.
Finland : The space is more important than the number of lines.
Spain-Catalonia : Insufficient for elderly people.
Sweden : It is very important that there is no doubt whether the physician intended to put a given condition in Part 1 or Part 2. It is very important that there is so much space between Part 1 and Part 2 that conditions belonging to Part 1 are not written in Part 2 because of lack of space.
UK-England : Occasionally, more than four causes of death.
UK-Scotland : 3% of death certificates used the 4 lines in 99.

1.14 Independent of the practice in your country, do you think that the logical process from the originating cause to the direct cause is a good way to describe causes of death?

Yes	**17 :**	Austria, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland
No	**2 :**	Belgium, UK-Scotland
No response	**1 :**	Finland

Sweden: For premature or otherwise avoidable deaths - yes. For deaths in elderly with several independent causes - no.

1.15 Why?

Austria : Good way for observing the development of a disease.
Belgium : Maybe not for older people with multiple pathologies.
Finland : What's the best way to express efficiently, space or lines?
Norway : Yes, but difficult to select sequences and multiple coding.
Spain-Catalonia : Yes but for elderly or terminal diseases, the originating cause can be difficult to establish.
Sweden : If the case history is dominated by one single disease or event, the WHO format allows the physician to present the main stages of the process very succinctly. However, the format presupposes that one single disease or injury had the main responsibility for the death. There is no way to give similar emphasis to two or more different (etiologically independent) conditions.
UK-Scotland : The reverse would be more intuitive but not advocate a change now.

1.16 Is there an arrow printed from the originating to the direct cause on the death certificate in use in your country?

Yes	**3 :**	Denmark, Iceland, Sweden
No	**17 :**	Austria, Belgium, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, UK- England, UK-Northern Ireland, UK-Scotland

1.17 If yes, does it improve the quality of certification?

Yes	**1 :**	Sweden
No	**1 :**	Denmark
No response	**1 :**	Iceland

Sweden: Apparently, there are fewer sequencing errors with the new death certificate (which has the arrow) than with the old (which did not have the arrow).

1.18 If no, do you think that it could be a good way to improve the understanding of certification in your country?

Yes	**12 :**	Finland, France, Greece, Ireland, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
No	**6 :**	Austria, Belgium**,** Germany, Italy, Spain, UK- England
No response	**1 :**	Denmark, Iceland

1.19 Do you think that, in your country, physicians have enough space on the death certificate to enter precisely causes of death?

Yes	**18 :**	Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden, UK- England, UK-Northern Ireland, UK-Scotland
No	**2 :**	Norway, Spain-Catalonia

1.20 Do you think that, in your country, the role of the Part II of the certificate (Other significant conditions contributing...) is well understood by physicians (in some cases, they repeat what they have written in Part I)?

Yes	**9 :**	Austria, France, Greece, Iceland, Ireland, Italy, Spain, Sweden, UK-Scotland,
No	**11 :**	Belgium, Denmark, Finland, Germany, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, UK- England, UK-Northern Ireland

Luxembourg : Might be a source of misunderstanding between the notifying physician and the coder.

Sweden : Mainly, but with many exceptions. It sometimes happens that conditions from Part 1 are entered in Part 2 as well, but not very often. A more common error is to enter serious conditions that belong to the sequence that ended with the patient's death in Part 2.

1.21 Are there guidelines to help certifiers in your country (systematically in/with the death certificate)?

Yes	**14 :**	Austria, Belgium, Denmark, Finland, France, Greece, Iceland, Ireland, Netherlands, Norway, Sweden, UK- England, UK-Northern Ireland, UK-Scotland,
No	**6 :**	Germany, Italy, Luxembourg, Portugal, Spain, Spain-Catalonia

1.22 What do they consist of:

Examples	**1 :**	France
Text without examples	**3 :**	Belgium, Finland, Greece
Text with examples	**10 :**	Austria, Denmark, Iceland, Ireland, Netherlands, Norway, Sweden, UK-England, UK-Northern Ireland, UK-Scotland

Finland : General instructions + instructions in the Finnish classification of diseases.
Sweden : On the back of the certificate - general instructions, no examples. In the leaflet on certification - text and examples.

1.23 Do you think that guidelines in use in your country need to be improved?

Yes	**12 :**	Austria, Belgium, Finland, France, Greece, Ireland, Italy, Luxembourg, Norway, Spain-Catalonia, Sweden, UK-Northern Ireland
No	**7 :**	Denmark, Germany, Iceland, Netherlands, Portugal, UK- England, UK-Scotland
No response	**1 :**	Spain

1.24 Why?

Austria : To harmonize between regions.
Belgium : Insufficient information and badly disseminated.
Denmark : They don't need to be improved, they need to be read!
Finland : Revision in preparation.
Sweden : The leaflet was to a large extent based on the WHO instructions to physicians, and some of the examples are not applicable in Sweden. The part on administrative procedures needs updating in view of changes in legislation
UK-England : Guidelines updated two years ago.
UK-Scotland : Revised in 99.

1.25 Independent of the practice in your country, do you think it is important to harmonize death certificates guidelines within European countries?

Yes	**16 :**	Austria, Belgium, Denmark, Finland, France, Greece, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK- England
No	**4 :**	Germany, Iceland, UK-Northern Ireland, UK-Scotland

1.26 What would you propose as European recommendations?

Austria : To harmonize topics and examples but leave the writing to each country.
Belgium : Official statement on the importance of good vital statistics and on the importance of using the same form to achieve comparability and on training + to establish a European Unity to evaluate 1) The quality of data, 2) The relevance of the forms, and 3) To recommend actualisation of these forms.
Denmark : A WHO recommendation, not necessarily the one in use now.

Finland : Let's take responsibility for the content of the death certificate, EU recommendations - foreign citizens. Death certificate Part II, the expressions of external causes.
Luxembourg : 1) Develop WHO recommendations to make them clearer, 2) Develop recommendations on the Part II.
Portugal : 1) Use the same coding process and rules 2) Using similar training for physicians, and 3) Protecting the confidentiality of causes of death.
Spain : Text with examples.
Spain-Catalonia : Information on the death certificate, how to contact the Causes of Death Office + how to obtain information (leaflets, guidance...).
Sweden : That a common set of instructions is used in all countries, since recommendations (especially examples) might introduce a bias. No examples should be given on the certificate itself (or on the back of the certificate) since the risk that physicians simply copy the examples is quite high.
UK-England : The use of WHO guidelines with clear examples. Legal differences between countries limit the harmonization.
UK-Northern Ireland : The Scottish system.
UK-Scotland : Difficult different working practices (use WHO examples as way of harmonization).

1.27 Who certifies the causes of death in your country's hospitals?

NON MEDICAL PERSONS

Never	**18 :**	Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
Sometimes	**2 :**	Ireland, UK- England
Always	**0 :**	

MEDICAL STUDENTS

Never	**16 :**	Austria, Belgium, Finland, France, Germany, Greece, Iceland, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK- England, UK-Northern Ireland, UK-Scotland,
Sometimes	**4 :**	Denmark, Ireland, Italy, Luxembourg
Always	**0 :**	

YOUNG PHYSICIANS

Never	**2 :**	Austria, Spain
Sometimes	**16 :**	Belgium, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland,
Always	**2 :**	Denmark, UK- England

PHYSICIANS IN CHARGE OF THE DECEASED

Never	**1 :**	Austria,
Sometimes	**13 :**	Belgium, Denmark, France, Germany, Ireland, Italy, Netherlands, Spain, Spain-Catalonia, Sweden, UK- England, UK-Northern Ireland, UK- Scotland
Always	**6 :**	Finland, Greece, Iceland, Luxembourg, Norway, Portugal

PHYSICIANS HEAD OF THE SERVICE

Never	**8 :**	Austria, France, Iceland, Luxembourg, Netherlands, Spain-Catalonia, Sweden, UK- England,
Sometimes	**12 :**	Belgium, Denmark, Finland, Germany, Greece, Ireland, Italy, Norway, Portugal, Spain, UK-Scotland, UK-Northern Ireland
Always	**0 :**	

OTHER PEOPLE

Never	**6 :**	Germany, Iceland, Portugal, Spain, UK-Northern Ireland, UK-Scotland
Sometimes	**13 :**	Belgium, Denmark, Finland, France, Greece, Ireland, Italy, Luxembourg, Netherlands, Norway, Spain-Catalonia, Sweden, UK- England

Always	**1 :**	Austria

Austria : People who are allowed to certify - medical health officers (one year post doctorate training), pathologists, forensic physicians.
Belgium : A specific MD called by the deceased person.
Denmark : Medical officer of forensic medicine.
Finland : Physicians in charge of the deceased should certify except on forensic autopsies.
Luxembourg, Spain- Catalonia : Emergency physicians.
Norway : Forensic physicians.
Sweden : Always physicians. The regulations recommend that the physician in charge of the patient completes the certificate, but it is sometimes done by others (junior physicians under training, chief physicians, primary care physicians who haven't had any previous contact with the deceased, forensic pathologists).
UK-England : Coroners (usually lawyers but sometimes both legally and medically qualified).

1.28 Are physicians directly coding causes of death in your country?

Question not fully understood and therefore responses not exploitable.

1.29 Do you think that a question on the death certificate asking if the certifying physician is the treating physician could be useful?

Yes	**15 :**	Austria, Belgium, France, Germany, Greece, Iceland, Italy Luxembourg, Netherlands, Norway, Portugal, Spain Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
No	**5 :**	Denmark, Finland, Ireland, Spain, UK- England

UK-England: It is legal, the certifying physician has to be the doctor who attended the deceased in his last illness.

1.30 Do you think that to ask the physician to write a sentence as "In my conscience, I certify that..." could be a way to improve the quality of the certification in your country?

Yes	**6 :**	France, Germany, Greece, Sweden, UK- England, UK-Scotland
No	**13 :**	Austria, Belgium, Denmark, Finland, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, UK-Northern Ireland
No response	**1 :**	Spain-Catalonia

Iceland : Already printed in the Icelandic death certificate.
Norway : It is a legal document.

1.31 Do you think that to have the death certificate signed by two physicians (when the death occurs in a hospital) could be a way to improve the quality of the certification in your country?

Yes	**9 :**	Denmark, Finland, France, Germany, Greece, Norway, Spain-Catalonia, UK-Northern Ireland, UK-Scotland
No	**11 :**	Austria, Belgium, Iceland, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden, UK- England

Sweden : Would cause great administrative delay, and increase the attrition rate.

1.32 Do you think that to have the death certificate filled out by a physician head of the service (when the death occurs in a hospital) could be a way to improve the quality of the certification in your country?

Yes	**7 :**	Belgium, Denmark, France, Italy, Norway, UK-Northern Ireland, UK-Scotland
No	**12 :**	Austria, Finland, Germany, Greece, Iceland, Ireland, Netherlands, Portugal, Spain, Spain-Catalonia, Sweden, UK- England
No response	**1 :**	Luxembourg

Finland : Instructions on certifying should include that the head is in charge that the death certificate is correctly processed.
UK-England : Maybe.
Sweden : They do not always know the particulars of the individual case.

1.33 Is there a question about autopsy in the death certificate in use in your country?

Yes	**16 :**	Austria, Belgium, Denmark, Finland, France, Germany, Iceland, Italy, Luxembourg, Netherlands, Norway,

		Portugal, Sweden, UK- England, UK-Northern Ireland, UK-Scotland
No	**4 :**	Greece, Ireland, Spain, Spain-Catalonia

1.34 Do you include the results of autopsies in the final statistics?

Sometimes	**11 :**	France, Germany, Greece, Ireland, Italy, Portugal, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
Always	**9 :**	Austria, Belgium, Denmark, Finland, Iceland, Luxembourg, Netherlands, Norway, UK- England

1.35 If never or sometimes, why?

Italy and Portugal : Reports are too late or addressed to the wrong place.
Spain : The judges (muertes por acussas externas) sometimes use the autopsy results to fill "el impreso estatistico adicional".
Spain-Catalonia : Only upon legal intervention provisional results of the autopsy are included
Sweden : Autopsy reports are not routinely forwarded to Statistics Sweden. If a report is sent to us (for example in response to a query) we will read the report and register significant conditions found at the autopsy as causes of death. The instructions for cause of death certification require the physician to take the autopsy findings in consideration when stating the cause of death.
UK-Scotland : Not always told of the results

1.36 Would you think it important to collect more information about autopsies in the death certificate such as?

AUTOPSY DONE

Yes	**18 :**	Austria, Belgium, Denmark, Finland, France, Greece, Iceland, Ireland, Italy, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK- England, UK-Northern Ireland, UK-Scotland
No	**2 :**	Germany, Luxembourg

LEGAL AUTOPSY

Yes	**15 :**	Belgium, Denmark, Finland, France, Greece, Iceland, Ireland, Italy, Norway, Portugal, Spain-Catalonia, Sweden, UK- England, UK-Northern Ireland, UK-Scotland,
No	**5 :**	Austria, Germany, Luxembourg, Netherlands, Spain

AUTOPSY MADE IN HOSPITAL

Yes	**14 :**	Belgium, Denmark, Finland, France, Greece, Ireland, Italy, Norway, Portugal, Sweden, Spain-Catalonia, UK-England, UK-Northern, UK-Scotland,
No	**6 :**	Austria, Germany, Iceland, Luxembourg, Netherlands, Spain

AUTOPSY USED FOR CERTIFICATION

Yes	**16 :**	Austria, Belgium, Denmark, Finland, France, Greece, Ireland, Italy, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK- England, UK-Northern Ireland, UK-Scotland
No	**4 :**	Germany, Luxembourg, Netherlands, Iceland

Finland: Certification should be impossible if the results of autopsy are not available.
Iceland: 1,2,4 are already existing, 3 does not seem interesting.
UK-Scotland: Age of surviving spouses, number of spouses, occupation of parents.

1.37 What is the socio-demographic information available in the final individual mortality file (additional to the causes of death) and from what source?

SEX

Death certificate	**9 :**	Austria, Italy, Luxembourg, Netherlands, Portugal,

		Spain, Spain-Catalonia, Sweden, UK-Scotland
Census/demographic file/other source	**4 :**	Finland, Norway, UK- England, UK-Northern Ireland
Both or more than 2 answers	**7 :**	Belgium, Denmark, France, Germany, Greece, Iceland, Ireland

AGE

Death certificate	**12 :**	Austria, Denmark, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
Census/demographic file/other source	**2 :**	Finland, UK- England
Both or more than 2 answers	**6 :**	Belgium, France, Germany, Greece, Iceland, Ireland

RESIDENCE OF THE DECEASED

Death certificate	**9 :**	Austria, Italy, Luxembourg, Portugal, Spain, Spain Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
Census/demographic file/other source	**4 :**	Finland, Netherlands, Norway, UK- England
Both or more than 2 answers	**7 :**	Belgium, Denmark, France, Germany, Greece, Iceland, Ireland

LOCATION OF THE DEATH

Death certificate	**14 :**	Austria, Belgium, Denmark, Finland, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain UK-Northern Ireland, UK-Scotland
Census/demographic file/other source	**1 :**	UK- England
Both or more than 2 answers	**3 :**	France, Germany, Greece

PLACE OF THE DEATH (HOSPITAL, HOME)

Death certificate	**13 :**	Austria, Denmark, Finland, France, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, UK-Northern Ireland, UK-Scotland
Census/demographic file/other source	**1 :**	UK- England
Both or more than 2 answers	**2 :**	Belgium, Greece

OCCUPATION

Death certificate	**9 :**	Denmark, Iceland, Italy, Luxembourg, Portugal, Spain, Spain-Catalonia, UK-Northern Ireland, UK-Scotland
Census/demographic file/other source	**4 :**	Finland, France, Sweden, UK- England
Both or more than 2 answers	**3 :**	Belgium, Greece, Ireland

NON MEDICAL PERSONS

Death certificate	**3 :**	Greece, Italy, UK-Northern Ireland
Census/demographic file/other source	**4 :**	Finland, Luxembourg, Sweden, Portugal
Both or more than 2 answers	**1 :**	Belgium

Other socio-demographic items :
Some information can't be collected in countries where laws on privacy are very strong (Italy).
Finland : Many other soci-demographic items from population register or census.
Other systematical medical information:
UK-England : When the patient was last seen by the doctor and whether the doctor saw the body after death.

1.38 What is the additional systematical medical information available in the final individual mortality file (additional to the causes of death) and from what source?

PREGNANCY STATE

Death certificate	**8 :**	Belgium, France, Germany, Ireland, Netherlands, Portugal, UK-Northern Ireland, UK-Scotland
Census/demographic file/other source	**1 :**	Finland

Both or more than 2 answers	**1 :**	Greece

ACCIDENT PLACE

Death certificate	**11 :**	Belgium, Finland, France, Iceland, Italy, Luxembourg, Netherlands, Norway, Portugal, UK- England, UK-Northern Ireland
Census/demographic file/other source	**1 :**	Ireland
Both or more than 2 answers	**1 :**	Spain-Catalonia

OCCUPATIONAL ACCIDENT/DISEASE

Death certificate	**9 :**	Belgium, France, Germany, Italy, Luxembourg, Norway, Portugal, UK- England, UK-Northern Ireland
Census/demographic file/other source	**1 :**	Spain-Catalonia
Both or more than 2 answers	**0 :**	

RECENT SURGERY

Death certificate	**9 :**	Finland, Iceland, Ireland, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-Northern Ireland
Census/demographic file/other source	**1 :**	Belgium
Both or more than 2 answers	**0 :**	

SMOKING

Death certificate	**0 :**	
Census/demographic file/other source	**1 :**	Belgium
Both or more than 2 answers	**0 :**	

DRUG ADDICT

Death certificate	**1 :**	Norway
Census/demographic file/other source	**3 :**	Belgium, Ireland, UK-Scotland
Both or more than 2 answers	**0 :**	

ALCOHOL ABUSE

Death certificate	**1 :**	Luxembourg
Census/demographic file/other source	**2 :**	Belgium, Ireland

DIABETES

Death certificate	**4 :**	Luxembourg, Spain, Spain-Catalonia, UK- England
Census/demographic file/other source	**3 :**	Finland, Belgium, UK-Northern Ireland

1.39 In your opinion, which of this information is the most interesting to have in the final mortality data file?

Education level	**5 :**	Austria, Belgium, Finland, Iceland, Sweden
Occupation	**3 :**	Denmark, Germany, UK-Northern Ireland
Both	**11 :**	France, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Spain-Catalonia, UK- England, UK-Scotland
No response	**1 :**	Norway

Sweden : Educational level rather than occupation. Occupation shifts, might be hard to find out (for example for retired people), some occupations are very hard to classify. Education is more stable and easier to handle statistically.

1.40 In your opinion, how must this information be collected?

In the medical part of the death certificate	**3 :**	Austria, Iceland, Luxembourg
The Registry Office (administrative death certificate)	**8 :**	Belgium, Denmark, Finland, France, Germany, Netherlands, Portugal, UK-Scotland,

The Census	**1 :**	Spain-Catalonia
By other source	**4 :**	Norway, Spain, Sweden, UK- England
Both or more than two answers	**4 :**	Greece, Ireland, Italy, UK-Northern Ireland

Finland : The certifier is unable to give the information, census to ensure the denominator and specific source for the numerator.
Spain, Spain-Catalonia: Linkage with census files.
Sweden : Preferably NOT via the certificate - in many cases the physician will not know the educational level of the deceased.
UK-England : By following back surveys or date linkage.

1.41 Independent of the practices in your country, what would be the five most useful, feasible and reliable pieces of additional information to collect <u>systematically</u>?

Pregnancy state	**11 :**	Austria, Denmark, France, Greece, Ireland, Luxembourg, Portugal, Spain-Catalonia, UK- England, UK-Northern Ireland, UK-Scotland
Accident (place) of death	**8 :**	Belgium, France, Iceland, Ireland, Italy, Norway, Portugal, UK-Northern Ireland
Occupational accident/disease	**8 :**	Belgium, France, Iceland, Italy, Portugal, Spain-Catalonia, UK-Northern Ireland, UK-Scotland, Austria
Recent surgery	**8 :**	Belgium, Denmark, Iceland, Luxembourg, Norway, Portugal, Sweden, UK-Northern Ireland
Smoking	**5 :**	Austria, Denmark, Greece, Iceland, Luxembourg
Drug addict	**4 :**	Belgium, Denmark, Ireland, Luxembourg
Alcohol	**4 :**	Denmark, Greece, Ireland, Luxembourg
Diabetes	**3 :**	Austria, Greece, UK-Northern Ireland

Sweden: In order of precedence: 1) interval between onset of disease and death, 2) recent surgery, 3) intent, 4) place of death, 5) place of occurrence (of accident, suicide etc).

1.42.1 Independent of the practice in your country, do you think it might be necessary feasible to harmonize the medical part of the death certificates in Europe?

NECESSARY

Yes	**11 :**	Austria, Belgium, France, Luxembourg, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No	**5 :**	Denmark, Iceland, Ireland, Italy, Norway
No response	**4 :**	Finland, Germany, Greece, Netherlands

FEASIBLE

Yes	**11 :**	Belgium, Denmark, France, Iceland, Italy, Luxembourg, Norway, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
No	**3 :**	Austria, Ireland, UK-England
No response	**6 :**	Finland, Germany, Greece, The Netherlands, Portugal, Spain

1.42.2 What would you propose to harmonize the medical part of death certificate in Europe (with a view to improving the quality and comparability of European causes of death statistics)?

(Reminder of question 1.26 - What would you propose as European recommendations?)

Austria : Stress the importance of WHO recommendations, harmonize the additional information and possible answers.
Belgium : Question 1.26 + to recommend the WHO model as the form to use with common additional medical items.
Finland : Space in Part II + expressions of external causes.
Portugal : See question 1.26 + same items on the death certificate.
Spain : WHO form.

Spain-Catalonia : 4 lines, arrow, autopsy/pregnancy, linking for education/occupation + risks factors, guidance to the certifier.
Sweden : Develop a common form for the death certificate that specifies the minimum information to be collected on each death. Countries might wish to add to these, but the minimum should be collected by all. I would also like to add a recommendation to item 1.42: include on the certificate something that uniquely identifies the certifier, such as the physician's official licence number, or similar. This could be used to check the certifier's level of training, and indeed if s/he is authorised to issue a death certificate.
UK-Northern Ireland : Better instruction on completing death certificates and clearly defined sequence of conditions.
UK-Scotland, Denmark, Iceland, Spain : Accepting the WHO standards.

1.43 If EC makes recommendations to harmonize the medical part (presentation of causes of death and additional medical information) of the death certificate, do you think that it could cause problems in your country?

Yes	**15 :**	Austria, Belgium, Denmark, Finland, France, Greece, Ireland, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland
No	**4 :**	Iceland, Italy, Luxembourg, Sweden
No response	**1 :**	Germany

1.44 Problems could be due to:

Administrative reasons	**11 :**	Austria, Denmark, Finland, France, Greece, Ireland, Portugal, Spain, Spain-Catalonia, UK-Northern Ireland, UK-Scotland
Legal reasons	**10 :**	Austria, Belgium, Denmark, Greece, Ireland, Netherlands, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland
Epidemiological reasons	**4 :**	Austria, Ireland, UK-England, UK-Northern Ireland
Cost reasons	**11 :**	Austria, Denmark, France, Greece, Ireland, Netherlands, Portugal, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland
Other reasons	**3 :**	Italy, Norway, Spain-Catalonia

1.45 Can you briefly explain these reasons?

Austria: More resources, training, and changes in law, effect on analysis of time series.
Belgium: For additional information such as drug addiction, problems of confidentiality (law on privacy) + the quality of collected information.
Denmark: Aversion to central harmonization, too compacted death certificate formulas but on the other hand good thing to have similar formulas when doctors go abroad they will know how to fill death certificate.
Finland : Tear off useless information, double burden of response on data more reliable in other sources + technical problems + possibly legal reasons.
Greece : Need to change the law.
Netherlands : Strict rules on privacy.
Norway : It is a long process to change the death certificate form.
Spain-Catalonia : Agreement between institutions all involved in the causes of death.
UK-England : Legislation + pilot study.
UK-Northern Ireland : Training, legislation, need to consult doctors, so resource implications.
UK-Scotland : Depends on the scale of changes.

1.46 Do you think that such common recommendations would need for your country a change in the law?

Yes	**10 :**	Austria, Belgium, Germany, Greece, Ireland, Luxembourg, Netherlands, Portugal, Spain-Catalonia, UK-Northern Ireland
No	**7 :**	France, Iceland, Italy, Norway, Spain, Sweden, UK-England

No response	**3 :**	Denmark, Finland, UK-Scotland

1.47 If yes, what type of change?

Belgium : Maybe a change in the law on privacy.
Spain-Catalonia : For autopsy information, for linking, to change death certificate form.
Sweden : Not in the law, but in the regulations issued by the Board of Health and some other authorities. The death certificate form is an integral part of the Board of Health's regulations. If the form is changed, the regulations must be changed accordingly.
UK-England : Primary legislation.

1.48 If EC makes recommendations to harmonize the medical part of the death certificate, what Institution(s) would finally take the decision for the change in your country?

Ministry of Health alone	**7 :**	Denmark, France, Iceland, Luxembourg, Norway, Portugal, Sweden
National Statistical Institute alone	**3 :**	Belgium, Greece, Italy
Ministry of Health and National Statistical Service (with or without another institution)	**5 :**	Austria, Finland, Ireland, Netherlands, UK-England
Ministry of Health with another institution	**3 :**	Germany, UK-Northern Ireland, UK-Scotland
National Statistical Institute with another institution	**2 :**	Spain, Spain-Catalonia

1.49 To have the most chances of being applied, to which institution must these recommendations be proposed?

Ministry of Health alone	**6 :**	Denmark, Ireland, Luxembourg, Netherlands, Norway, Sweden
National Statistical Institute alone	**4 :**	Italy, Portugal, Spain, Spain-Catalonia
Causes of Death Statistical Office alone	**2 :**	France, UK-Scotland
Ministry of Health and National Statistical Service (with or without another institution)	**4 :**	Austria, Belgium, Finland, Greece
Ministry of Health with another institution	**2 :**	Germany, UK-Northern Ireland
National Statistical Institute with another institution	**1 :**	Iceland
No response	**1 :**	UK-England

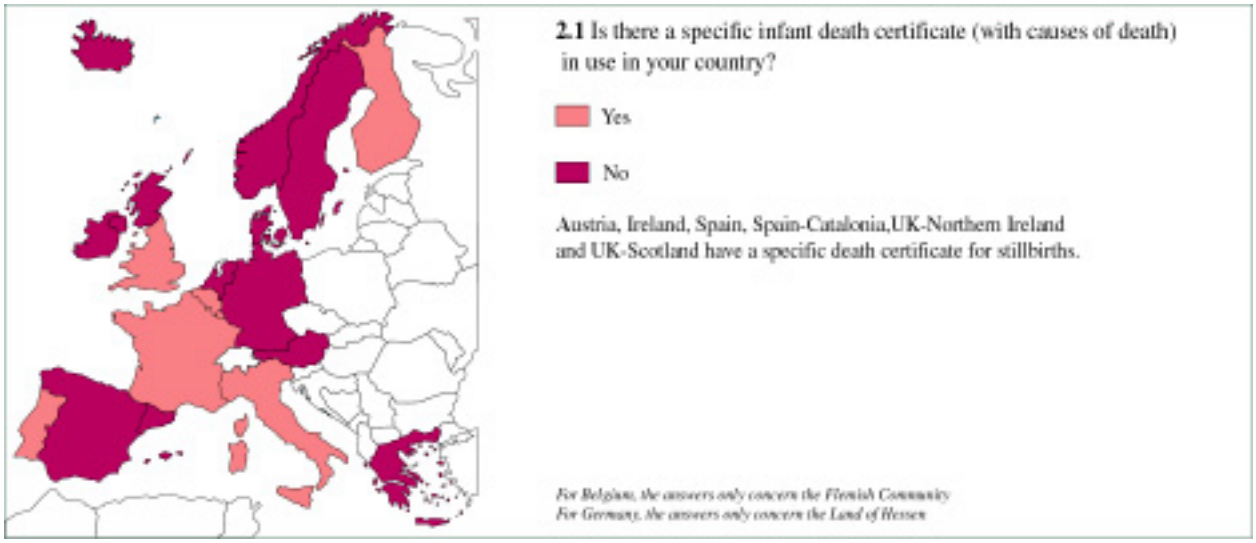
Austria : Ministry of Inner Affairs.
Belgium : Economic Affairs.
Sweden : To the Board of Health and the Ministry of Health and Social Affairs.
UK-Northern Ireland : Department of Health + Register General.

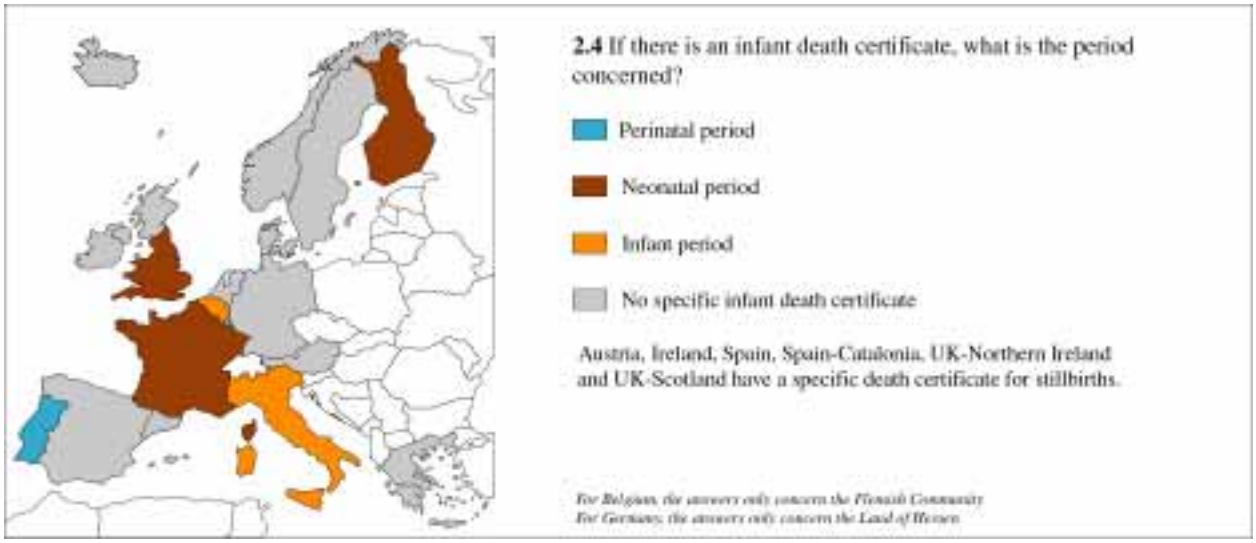
II.2.2.2 INFANT DEATH CERTIFICATE

A. GENERAL OVERVIEW

Specific certificate for infant death

7 out of 20 European countries/regions (Belgium, UK-England, Finland, France, Italy, Luxembourg, Portugal)[1] use a specific causes of death certificate for infant deaths as recommended by the WHO. 6 other countries use a specific death certificate only for stillbirths, not considered in this study as certificates for infant deaths.





The date of implementation for specific infant death certificates varies from 1967 to 1998. In Belgium and France, this introduction is recent (1998 and 1997). In Luxembourg and Italy they were implemented before 1980, and in England, Finland and Portugal during the 80's. In only one

[1] In Germany, the Land of Brandenburg is the only land still using a specific infant death certificate.

country, Denmark, was an infant death certificate used in the past and abolished (1976), preferring specific questions in the general death certificate.

The main reason why countries do not adopt a specific infant death certificate is that they can link information easily from birth registers (or hospital data). This is the case in Scandinavian countries where birth registers give a lot of information and are used as sole source or, as in Finland, in addition to the death certificate. In Germany and Greece, there are no certificates for infant death but specific questions included in the general death certificate. In Iceland and The Netherlands, information such as weight or gestation is collected via the general death certificate and other information via the birth register.

Age periods

The definition of infant age periods is not harmonised in Europe, mainly concerning stillbirths where gestation varies from 154 to 196 days and weight from 500 to 1000 gr. Concerning perinatal, neonatal or infant ages, differences seem to be due more to a language problem. Six countries count ages from zero (6, 27 and 364 days) and 12 countries from one (7, 28 and 365 days). Within these varied limits, differences in ways of counting can lead to errors of interpretation.

The periods concerned by the 7 existing death certificates vary extensively. Only two countries, Portugal and Luxembourg, have adopted the perinatal period (or early neonatal period) which is recommended by the WHO international form. Finland, France and England use the neonatal period and Belgium and Italy select the infant period (until one-year-old).

Independently of the practices in their country, experts' opinions about the most useful period for a death certificate in epidemiological terms are also heterogeneous. The infant death period is considered as the most interesting by 9 experts, mainly located in Central and Northern Europe. The perinatal period is preferred by 6 experts and the neonatal period by 4 of them.

Presentation of the causes of death

Compared to the general death certificate where the WHO recommendation has been adopted by all European countries, the ways to present the causes of death in the infant death certificates remain un-harmonised. The WHO recommendation with two parts, one for the mother and one for the infant, has been adopted by 4 out of 7 countries using a specific death certificate (Finland, France, Portugal and UK-England). Two countries are using the presentation in one part as in the general death certificate (Italy and Luxembourg) and one, Belgium, adopted a combination of the two ways of presentation when changing its infant death certificate two years ago.

The presentation with two parts is considered by half of the countries using it as leading to problems in selecting a unique cause for the infant death and in integrating infant death statistics in the general causes of death statistics. In England, a specific hierarchical classification has been developed to take in account both maternal and infant causes. In France, the Causes of Death Statistics Office thinks that precise guidelines must be edited to facilitate the choice between the causes of death attributed to either mother or child and to integrate maternal causes of death in general statistics by age. Independently of the practice in use in their country, experts opinions are also varied: 8 countries think that the best way to present infant causes of death is in one part as for the general death certificate (which include the 4 English speaking countries/regions). 6 countries would prefer the presentation in two parts, and 4 a combination of the two ways of presentation.

Usefulness of a specific infant death certificate and European harmonization

9 out of 20 experts believe that a specific death certificate is necessary because of the "amount, specificity and complexity of information to collect" for infant death (8 think it is not necessary and 3 did not give a precise answer). In general, expert opinions follow their countries practices, but in a few cases it is different: Ireland does not use an infant death certificate and would like to, and England uses one and is uncertain about its usefulness.

Independent of the practice in their country, 11 experts out of 20 believe it necessary/feasible to harmonise the procedures to collect medical information on infant deaths in Europe. 11 countries find it necessary and 12 feasible but they are not systematically the same. Only 7 countries think it both necessary and feasible to harmonise the procedures to collect medical information about infant deaths in Europe. The possible ways of harmonization would be (i) to create or improve birth registers, (ii) to improve the collection of information on the infant death certificate, (iii) to improve the collection of information on the general death certificate.

In the case of change concerning the infant death certificate, the legal procedures are the same as for the general death certificates in nearly all European countries and harmonization would cause the same constraints as the ones caused by the general death certificate harmonization.

B. DETAILED RESPONSES

NB : All questions concern for Belgium : The Flemish Community and for Germany: The Land of Hessen only

2.1 Is there a specific infant death certificate (with causes of death) in use in your country?

Yes	**7 :**	Belgium, Finland, France, Italy, Luxembourg, Portugal, UK-England
Yes (only for stillbirth)	**6 :**	Austria, Ireland, Spain, Spain-Catalonia, UK-Northern Ireland, UK-Scotland
No	**7 :**	Denmark, Germany, Greece, Iceland, Netherlands, Norway, Sweden

2.2 If yes, when was it implemented?

Before 1945	**1 :**	UK-Scotland (stillbirth)
1945 to 1965	**3 :**	Spain, Spain-Catalonia, UK-Northern Ireland (stillbirth)
1965 to 1980	**2 :**	Italy, Luxembourg
1980 to 1990	**3 :**	Finland, UK-England, Portugal
Since 1990	**3 :**	Ireland (stillbirth), France, Belgium

Scotland: latest version to be introduced in 2000 (stillbirth).

2.3 If no, did one exist in the past, and why is it no longer in use?

Yes	**1 :**	Denmark
No	**19 :**	Others

Denmark: abolished in 1976 .

2.4 If there is an infant death certificate, what is the period concerned?

Stillbirth	**6 :**	Austria, Ireland, Spain, Spain-Catalonia, UK-Northern Ireland, UK-Scotland
Perinatal period	**2 :**	Luxembourg, Portugal
Neonatal period	**3 :**	Finland, France, UK-England
Infant period	**2 :**	Belgium, Italy

Spain: stillbirth + 24 hours

2.5 Independent of the existence of an infant death certificate in your country, what are the definitions of the following periods in use in your country?

STILLBIRTH GESTATION

Days	No of countries
15	3
168	5
180	2
182	2
196	4
No response	4

STILLBIRTH WEIGHT

Weight	No of countries
1000 gr	1
500 gr	6
No response	13

STILLBIRTH SIZE

Size	No of countries
25 cm	1
35 cm	1

No response	13

PERINATAL AGE

Age	No of countries
6 days	6
7 days	12
No response	2

NEONATAL AGE

Age	No of countries
27 days	6
28 days	12
No response	2

INFANT AGE

Age	No of countries
364 days	6
365 days	12
No response	2

2.6 If there is an infant death certificate in your country, how are the causes of death presented? (death certificates for stillbirths are not included).

Two parts : mother and infant causes of death	**4 :**	Finland, France, Portugal, UK-England
One part, as in the general death certificate	**2 :**	Italy, Luxembourg
A combination of the two ways of presentation	**1 :**	Belgium

2.7 If causes of death are presented with two parts (mother and infant causes of death), is it difficult:

To select a unique underlying cause for the infant death?	**2 :**	France, UK-England
To integrate infant death statistics in the general causes of death statistics?	**2 :**	France, UK-England

2.8 Can you summarize these difficulties?

France : No precise guidelines about the choice between mother and child cause of death, difficult to integrate causes of death about the mothers in statistics by age.
UK-England : Have to deliver our own hierarchical classification taking into account both maternal and infant causes.

2.9 If there is not a specific infant death certificate in your country, why not?

Birth register (or hospital data) can be easily linked with the causes of death files	**8 :**	Austria, Denmark, Iceland, Ireland, Netherlands, Norway, Sweden, UK-Scotland
Specific questions about infant death are included in the general death certificate	**4 :**	Germany, Greece, Iceland, Netherlands
Other reasons	**2 :**	Spain-Catalonia, UK-Northern-Ireland
No reponse	**1 :**	Spain

For information :

A specific infant death certificate in use	**7 :**	Belgium, Finland, France, Italy, Luxembourg, Portugal, UK-England

Norway : a) Maternal mortality is a small problem in Norway, b) Since 1967, the Medical Birth Register collects information.
Greece : Specific questions on the DC + birth register.

2.10 If a specific infant death certificate is not considered to be useful enough, can you explain the reasons why?

Scotland : Use hospital in-patient data.

2.11 What is the information (apart from the causes of death) collected in your country at the occasion of an infant death and from what source?

CHARACTERISTICS OF THE CHILD AT BIRTH

Source	No of countries
Death certificate	7
Birth register	6
Death certificate and birth register	4
Other source or other combination of sources	1
No response	2

CHARACTERISTICS OF THE DELIVERY

Source	No of countries
Death certificate	6
Birth register	6
Death certificate and birth register	3
Other source or other combination of sources	2
No response	3

DESCRIPTION OF THE MOTHER'S HEALTH

Source	No of countries
Death certificate	5
Birth register	5
Death certificate and birth register	4
Other source or other combination of sources	2
No response	4

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF MOTHER AND FATHER

Source	No of countries
Death certificate	6
Birth register	6
Death certificate and birth register	1
Other source or other combination of sources	3
No response	4

2.12 Independent of the practice in your country, what do you think would be the most useful information to collect (apart from the causes of death) at the occasion of an infant death and from what source?

Sweden: This is not easy to specify, but the most important additional item to collect is information on miscarriages and abortions following prenatal diagnostic procedures. We would then find a number of malformations that today are not included in the Swedish malformation register. Since malformations that lead to miscarriage and abortion are not included in the present statistics on malformations, our surveillance is incomplete and not comparable with figures from earlier years /when abortions were not freely available.

A further important task for the Board is to enhance the reporting of diseases and other health problems later in life, for example handicaps found later in life.

2.13 Independent of the practice in your country, do you think that a specific infant death certificate is necessary?

Yes	**9 :**	Belgium, France, Iceland, Ireland, Italy, Luxembourg, Portugal, Spain, Spain-Catalonia
No	**8 :**	Austria, Germany, Greece, Netherlands, Norway, Sweden, UK-Northern Ireland, UK-Scotland
No response	**3 :**	Denmark, Finland, UK-England

2.14 Why?

Belgium : Yes. a) The complexity of the causes involving mother and child, b) The amount of information to collect.

Finland : Yes. Too specific variables for small percentage of deaths.
Netherlands : The general death certificate is sufficient.
Norway : Since 1967, the Medical Birth Register collects information.
Portugal, Spain, Spain-Catalonia : Specific information is needed to study and make recommendations for improvement.
UK-England : Uncertain. UK-Scotland : Use of hospital data is more efficient (more information).

2.15 Independent of the practice in your country, what do you think is the most useful period for a specific infant death certificate in epidemiological terms?

Stillbirth	**1 :**	UK-Northern Ireland
Perinatal period	**6 :**	Austria, Denmark, Finland, Netherlands*, Spain, Spain-Catalonia
Neonatal period	**4 :**	France, Italy, Portugal, UK-Scotland
Infant period	**9 :**	Belgium, Germany, Iceland, Ireland, Luxembourg, Netherlands*, Norway, Sweden, UK-England
No response	**1 :**	Greece

*Netherlands two responses.

2.16 Why?

<u>*Perinatal*</u>
Denmark : To collect all major malformations + more 'in born' defects will become registered.
Finland : High risk of dying around the delivery, infant mortality period is more reliable, stillbirths may be underestimated.
Spain : To adopt the WHO recommendation.
Spain-Catalonia : It concentrates nearly all deaths of the first year in developed countries. It is a good indicator about pregnancy problems and deliveries.

<u>*Neonatal*</u>
Portugal : The most specific period (an inquiry should be systematic for post neonatal).

<u>*Infant*</u>
Belgium : Because infant period includes the whole period where prenatal and early neonatal factors have influence.
Norway : Standard period interesting for international comparisons.
Sweden :- Intensive care treatment may keep these children alive for several months. Statistics based on a shorter period (for example the first month only) would underestimate the mortality.
UK-England : Medical certification of all births with information on women's health, pregnancy and delivery and subsequent linkage would be more useful.

2.17 Independent of the practice in your country, what do you think is the best way to present the causes of death?

Two parts : mother and infant (WHO recommendation)	**6 :**	Austria, Finland, France, Portugal, Spain, Spain-Catalonia
One part, as in the general death certificate	**8 :**	Denmark, Germany, Ireland, Netherlands, Norway, UK-England, UK-Northern Ireland, UK-Scotland
A combination of the two ways of presentation	**4 :**	Belgium, Greece, Italy, Sweden
No response	**2 :**	Iceland, Luxembourg

Sweden : Both as ordinary mortality statistics with one underlying cause per person, and as a cross-tabulation between main maternal condition and main infant condition.

2.18 Why?

Belgium : The US certificate allows a smooth transition from maternal to child related deaths in a logical way.
Denmark : One part has sufficient space + information on register.
Finland : In countries with low infant/perinatal mortality, the WHO death certificate seems to be well adapted, but for countries with high infant/perinatal mortality?
Luxembourg : No response because they only experienced a "one part" form which causes problems with coding.
Portugal, Spain-Catalonia : The two parts reflect the reality of mother and child.
Spain : To adopt the WHO recommendation.
Sweden : Most users of mortality statistics expect them to include all deaths, which means that we need traditional underlying causes for the infants as well. Also, traditional tabulation of single causes can be far more detailed than any

cross-tabulation between mother and infant. However, some important relationships between mother and infant will emerge only in cross-tabulation, so that is needed as a complement.
UK-England : Very hard to make sense of multiple cause data alone.

2.19.1 Independent of the practice in your country, do you think it might be necessary/feasible to harmonize the procedures to collect medical information about infant deaths in Europe?

NECESSARY

Yes	**11 :**	Austria, Belgium, France, Ireland, Luxembourg, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Scotland
No	**5 :**	Denmark, Iceland, Italy, Norway, UK-Northern Ireland
No response	**4 :**	Finland, Germany, Greece, Netherlands

FEASIBLE

Yes	**12 :**	Austria, Denmark, Finland, France, Iceland, Ireland, Italy, Luxembourg, Portugal, Sweden, UK-Northern Ireland, UK-Scotland
No	**4 :**	Norway, Spain, Spain-Catalonia, UK-England
No response	**4 :**	Belgium, Germany, Greece, Netherlands

2.19.2 What would you propose to harmonize and improve the infant death statistics in Europe?

To create or improve birth registers	**10 :**	Austria, Belgium, Denmark, France, Iceland, Ireland, Luxembourg, Norway, Sweden, UK-England
To improve the collection of information on :		
The general death certificate	**8 :**	Denmark, Germany, Greece, Italy, Netherlands, Norway Portugal, UK-Northern Ireland
The infant death certificate	**9 :**	Belgium, France, Iceland, Ireland, Italy, Luxembourg, Portugal, Spain, Spain-Catalonia

Denmark : Add some extra questions in the general death certificate instead of having two formulas; the actual WHO specific formula is not collecting enough information.
Finland : To harmonize the definitions according to WHO.
Portugal : Specific death certificate for neonatal period + inquiry for each post neonatal death.
Spain-Catalonia : To account using more information about the pregnancy and delivery, linking information.
UK-England : Medical/midwife certification of birth and linkage to infant and child data.
UK-Scotland : No change advice
Sweden : To improve birth registers - yes, but no to the other alternatives. Other suggestions: co-ordinate the data collection of the European birth registers, to make sure that all of them include data needed for international comparisons.

2.20 In your country, are the legal procedures to change the infant death certificate the same as for the general death certificate?

Yes	**17 :**	Austria, Belgium, Denmark, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No response	**3 :**	Finland, Iceland, Spain

2.22 Would you give the same answers about possible European recommendations for the infant death certificate that you made for the general death certificate?

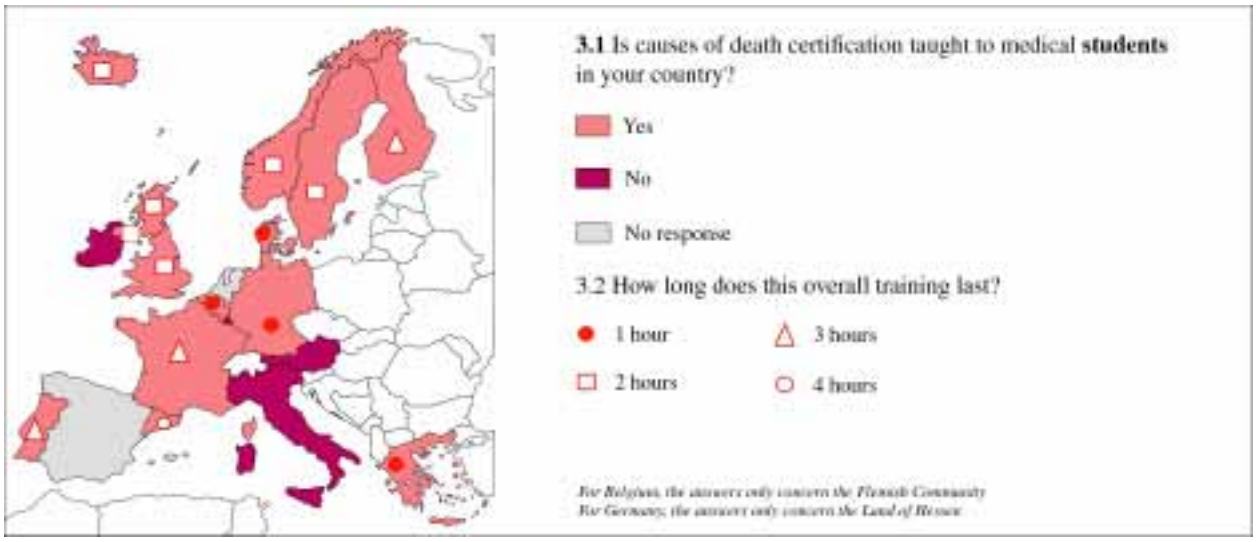
Yes	**18** :	Austria, Belgium, Denmark, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No response	**2 :**	Finland, Iceland

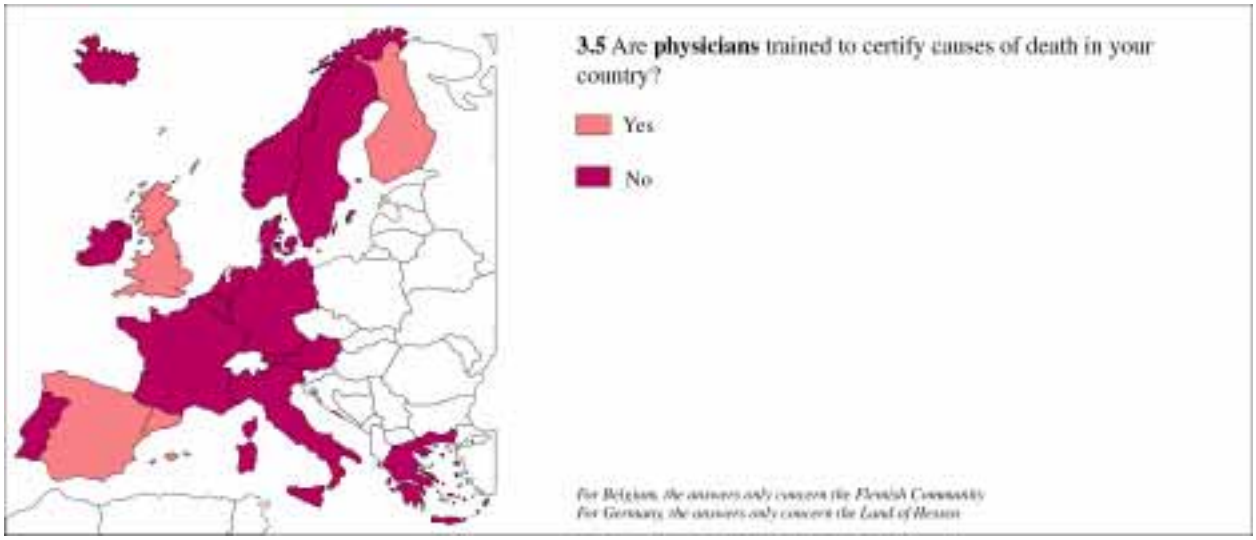
II.2.2.3 TRAINING PRACTICES

A. GENERAL OVERVIEW

Modalities of training for students and physicians

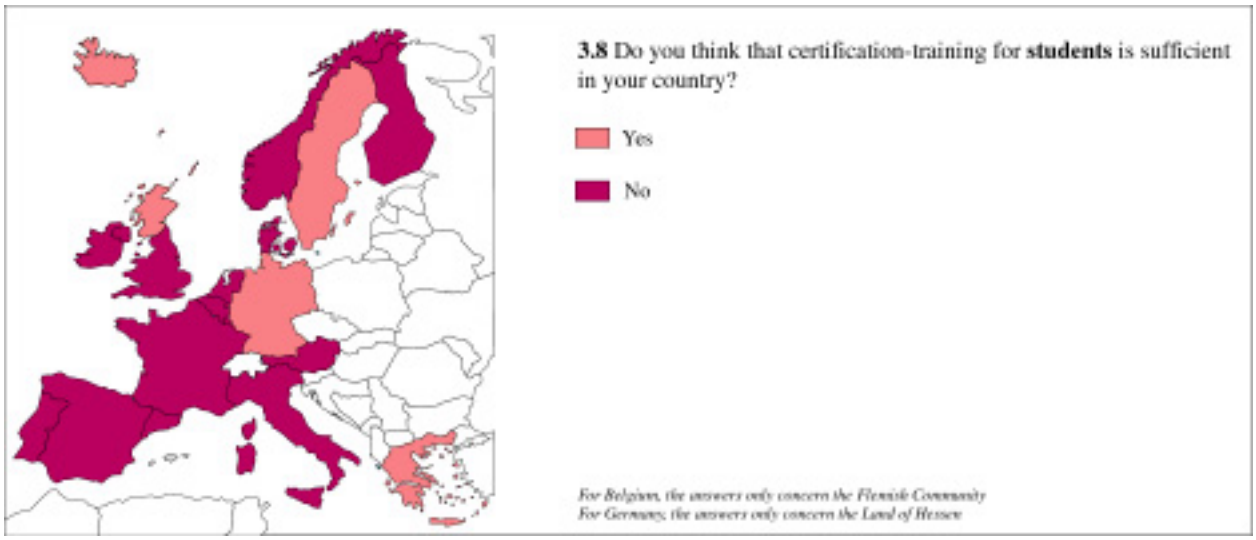
Most of the European medical students learn about death certification in their degree course but training courses are generally quite short (between one and three hours). The only place where training on certification for medical student's reaches up to 4 hours is Catalonia. This region seems to be the only one where the University of Medicine and the Mortality Statistics Office have close links. Professionals of the Mortality Statistics Office teach lectures on causes of death statistics, and questions on certification prepared by them are included in the final exams. In other countries, training on certification is usually taught as part of forensic or legal medicine.





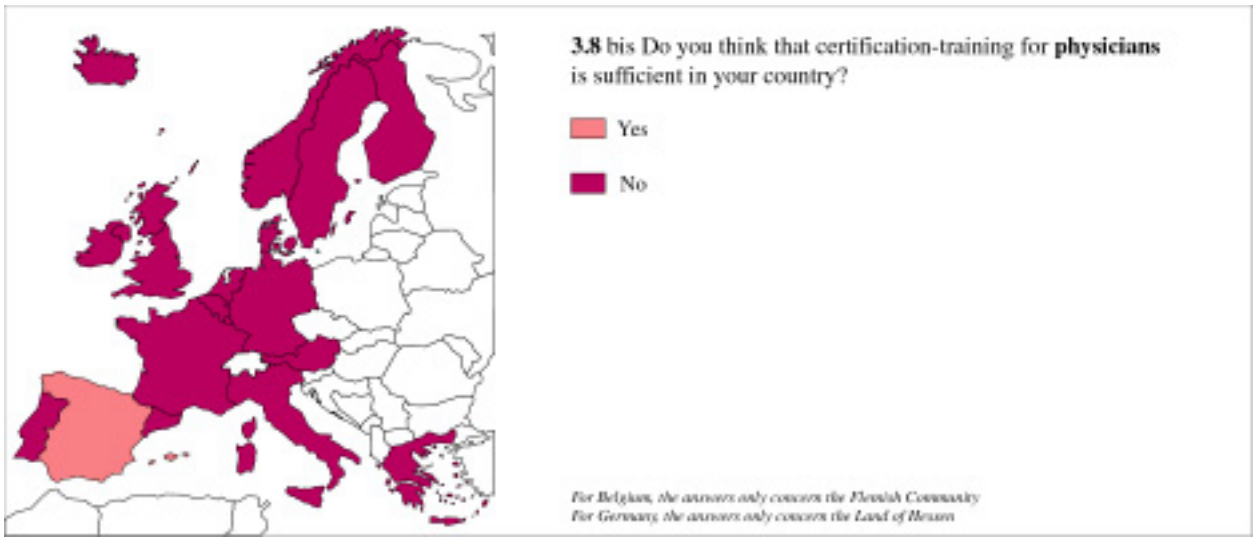
Vocational training on certification is even less frequent. In 15 European countries/regions out of 20, physicians are never trained to certify causes of death. Within the five countries where

vocational training does exist, the modalities are varied. In Finland, continuous training by local forensic doctors has been organised in the context of transfer from one ICD version to another. In Spain, some workshops are organised by the Regional Mortality statistics Offices. In the UK, a training pack of one hour is available (with slides, video and examples on how to complete a death certificate). In Catalonia, training contents (mortality statistics, certifying rules, practical cases...) is the same as for students but it is taught differently.



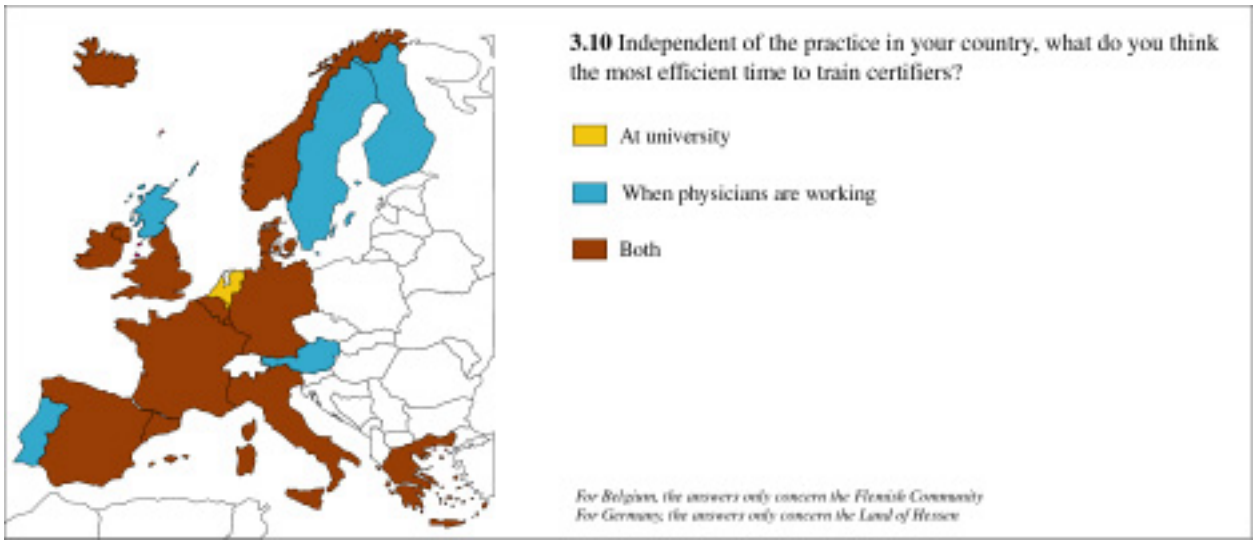
Guidelines exist for certification training in only half of the countries. Generally, the guidance consists of a booklet with text and examples and it is similar for students, teachers and physicians. The UK is the only region where a video has been realised and largely disseminated.

Opinions on training improvement modalities



Generally experts on causes of death statistics find the certification training in their country insufficient, in particular for physicians (19 out of 20). Regarding student training, 15 countries

out of 20 agree that it is insufficient, whereas 5 countries think it is sufficient (Germany, Greece, Iceland, Sweden, UK-England). The major reason given by these 5 countries is the work overload during medical studies: 'The university courses are full of subjects that seem (and in many cases are also) more important than certification of death'.



The majority of experts find it important to train both at university and when physicians are working because perspectives, problems and needs are different. One country (The Netherlands) finds it more efficient to train certifiers only at university and five other countries (Austria, Finland, Portugal, Sweden, UK-Scotland) only when physicians are working (because it is more efficient when they are confronted with specific problems).

Opinions on training contents

Most of the experts think that the training contents for students should conciliate theory and practice and be tested by some sort of examination. Theory must be taught within an epidemiological background in addition to legal medicine. Practice should consist of working on examples and filling out death certificates based on medical case histories. Methods should be as interactive as possible and use modern material and media (computer training packs, web...). One expert suggests developing a national training module for undergraduates with specific sub-modules for postgraduate's specialties.

The contents should be the same for physicians but may be more advanced. Attention must be paid to increase the importance of their contribution and could be thought of as feedback. The best occasions to train physicians are workshops, meetings, queries and medical journals.

Few experts believe that training must not be considered as the solution to all problems because it could be very difficult to control: 'The most efficient way to train is to develop a death certificate form that leaves as little room for misunderstandings as possible'.

European harmonization

Training is the subject where most of the experts think that European common recommendations should be necessary (14 out of 20) and feasible (15 out of 20). A better comparability is the main reason for such an agreement and also the necessity to make WHO guidelines for certification more efficiently applied by all European countries.

The most important recommendations should be to propose a common leaflet on certification (with emphasis on the importance of reliable statistics), and to edit contents for the training course. Countries agree largely on the items to include in this common leaflet or training course, i.e.: concept of the causes of death sequence and selection of the initial cause, presentation of causes of death data as a major public health indicator, and examples.

Concerning the application of such recommendations, experts are fairly positive: 13 answered that they could be (easily) applied in their country but 7 doubt about the possibility of applying common recommendations in their country (Belgium, Denmark, Iceland, Ireland, Norway, UK-England, UK-Scotland).

B. DETAILED RESPONSES

NB : All questions concern for Belgium: The Flemish Community and for Germany : The Land of Hessen only

3.1 Is causes of death certification taught to medical students in your country?

Yes	**14 :**	Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Norway, Portugal, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No	**4 :**	Austria, Ireland, Italy, Luxembourg
No response	**2 :**	Netherlands, Spain

3.2 How long does this overall training last?

1 hour	**4 :**	Belgium, Denmark, Germany, Greece
2 hours	**6 :**	Iceland, Norway, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
3 hours	**3 :**	Finland, France, Portugal
4 hours	**1 :**	Spain-Catalonia

3.3 Can you briefly describe what training consists of?

Denmark : Lectures on legal and forensic medicine + how to fill formulas.
Finland : Orientation towards the death certificate form, question by question, + examples of correctly/wrongly completed certificates.
Greece : Theory and practice for death certificate completion.
Iceland : Mostly about ICD and coding.
Norway : Depends on universities, the form, rules for filling, underlying cause, use of information.
Portugal : Legal medicine and community health discipline (students don't pay too much attention to it).
Spain : Tema of legal medicine at the end of the studies.
Spain-Catalonia : 4 hours, lectures about mortality statistics, certifying rules and practical cases (the same for active physicians but in courses).
Sweden : Lectures from a senior forensic pathologist. Medical certification is usually a part of the training in forensic medicine.
UK-Northern Ireland : Department of pathology.

3.4 Is there any question on causes of death certification in the post graduate examinations for physicians?

Yes	**3 :**	Austria, Greece, Spain-Catalonia
No	**12 :**	Belgium, Denmark, Finland, France, Germany, Ireland, Luxembourg, Norway, Portugal, Sweden, UK-Northern Ireland, UK-Scotland
No response	**5 :**	Italy, Iceland, Netherlands, Spain, UK-England

3.5 Are the physicians trained to certify deaths (causes of death) in your country?

Yes	**5 :**	Finland, Spain, Spain-Catalonia, UK-England, UK-Scotland
No	**15 :**	Austria, Belgium, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway Portugal, Sweden, UK-Northern Ireland

3.6 Can you briefly describe what the training consists of?

Finland : In the context of transfer from one ICD version to another. Local forensic doctors give continuous training for writers who need information.
Spain : Seminars are organised for regional death registry offices.
UK-England : Yes - very little.
UK-Scotland : 1 hour - training pack with slides, examples to complete a death certificate, + video.

3.7 Who are the teachers?

STUDENTS

People from the causes of death office	**1 :**	Spain-Catalonia
Physicians	**11 :**	Austria, Belgium, Denmark, France, Germany, Iceland, Netherlands, Norway, Portugal, UK-England, UK-Scotland
Forensic pathologists	**3 :**	Finland, Sweden, UK-Northern Ireland
No response	**5 :**	Greece, Ireland, Italy, Luxembourg, Spain

PHYSICIANS

People from the causes of death office	**2 :**	Finland, Spain-Catalonia
Physicians	**2 :**	Spain, UK-Scotland
Forensic pathologists	**1 :**	Finland
No response	**16 :**	Belgium, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, UK-England, UK-Northern Ireland

Finland : Forensic doctors + causes of death office (ICD introduction training) + people of the ICD Classification Centre.
Sweden : Mainly forensic pathologists. In rare cases people from Statistics Sweden (for the last time about ten years ago).

3.8 Do you think that training to certify is sufficient in your country?

STUDENTS

Yes	**5 :**	Germany, Greece, Iceland, Sweden, UK-Scotland
No	**14 :**	Austria, Belgium, Denmark, Finland, France, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, UK-England, UK-Northern Ireland
No response	**1 :**	Spain

PHYSICIANS

Yes	**1 :**	Spain
No	**19 :**	Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland

3.9 Why?

Finland : Not a bad level but (could be) more continuous and interactive.
Iceland : Mostly for physicians in activity.
Spain : Training seems sufficient because certification is good except in some regions.
Spain-Catalonia : No because of money, time...
Sweden : For students : Training at this stage is ineffective and should be restricted to the main concepts of "sequence" and "originating cause". For physicians : Given the fact that most physicians issue quite few certificates, it is hard to motivate training in certification for physicians in general. However, there should be training materials and perhaps seminars for physicians with a special interest in the area.
UK-Scotland : More training is needed nearer time of use.
UK- Northern Ireland : Certification is very poor.

3.10 Independent of the practice in your country, what do you think the most efficient time to train certifiers?

At university	**1 :**	Netherlands
When physicians are working	**5 :**	Austria, Finland, Portugal, Sweden, UK-Scotland
Both	**14 :**	Belgium, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Norway, Spain, Spain-Catalonia, UK-England, UK-Northern Ireland

3.11 Why?

Greece : Both because they allow for different perspectives.
Finland : Better motivation to learn when someone is working with the problem.
Spain-Catalonia : Both because they have different problems and needs.
Sweden : The university courses are full of subjects that seem (and in many cases also are) more important than certification of death. The students will hardly remember things that they do not see as important. Therefore training would be more efficient if directed to physicians who have some experience of certifying deaths, and who knows what the difficulties might be.
UK-England : Specific training depending on specialities (neonatal death certification).

3.12 What would you propose as the most efficient way to train students in your country?

Austria : Theory and practice (people who are allowed to certify ; medical officers of health ((one-year post doctorate training)); pathologists, forensic physicians).
Belgium : Theoretical introduction to motivate to fill in the forms properly + concrete case histories and commented, filled in certificates. Examples provided by WHO Europe and worked by the cause of death office.
Denmark, Spain : Only concrete training.
Finland : Group training in small groups with theory and examples.
France : To link the training with an epidemiology course in addition to legal medicine.
Iceland : Filling out death certificates based on medical histories.
Greece : Extend the approach used in The University of Athens Medical School to all medical schools.
Italy : Information on WHO recommendations, practice and theory.
Luxembourg : Theory.
Spain-Catalonia : Lectures.
Sweden : Perhaps a short lecture on mortality statistics from an epidemiologist. The lecture should describe how the statistics are produced, stressing the role of the death certificates and describing "sequence" and "originating cause", and give a few practical examples of cases in which analysis of mortality statistics has led to, for example, changes in health care policy.
UK-England : National training module for undergraduates with specialist sub-modules for postgraduates.
UK-Scotland : Computer assisted training (possibly using WWW, training packs for tutors (both backed up by quality control in practice).
UK-Northern Ireland : Video on death certification.

3.13 Do you think that to question on causes of death certification in the postgraduate examinations for physicians are an efficient way to train students?

Yes	**13 :**	Austria, Belgium, Finland, France, Greece, Italy, Netherlands, Norway, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland
No	**5 :**	Denmark, Germany, Luxembourg, Portugal, UK-Scotland
No response	**2 :**	Iceland, Ireland

3.14 What would you propose as the most efficient occasion to train the physicians?

During workshops, meetings, etc	**15 :**	Austria, Belgium, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Netherlands, Norway, Spain, Sweden, UK-Northern Ireland, UK-Scotland
On demand	**11 :**	Austria, Belgium, Denmark, France, Greece, Iceland, Ireland, Portugal, Spain, Sweden, UK-Scotland
With queries	**8 :**	Denmark, Luxembourg, Germany, Italy, Norway, Spain-Catalonia, Sweden, UK-Northern Ireland
Other occasions :	**7 :**	Austria, France, Luxembourg, Portugal, Spain-Catalonia, UK-England, UK-Scotland

Austria : Advanced training.
Denmark : Only concrete training.
Finland : Exercises and examples of death certificates from the person who is attending the course (queries), repeating the ICD structure and specialities.
France: More widely with a leaflet.
Germany: Obligatory lesson in the first year as assistant physician.
Luxembourg: Plus medical journals.
Spain-Catalonia: Specific courses.
UK-England: Put in the examination syllabus.

3.15 With what contents?

Austria : Determination of a death, the cause of death and the way of death + especially external causes.
France : As a feedback to physicians (on epidemiology and process).
Greece : Several alternative "causes"-multiple choice approach.
Italy : Concrete teaching on the certification (we have noticed some differences in certifying from one region to another).
Portugal : The value of their contribution and the way of doing things- real situations.
Spain-Catalonia : Mortality statistics, death certification rules, and practical exercises.
Sweden : The same as for the students. Since physicians will have actual experience of issuing death certificates, the training could also include common problems in cause-of-death certification.
UK-England : Separate sets for obstetrics, coroners, midwifery, paediatrics, short question (common causes of death + causes of death badly certified).

3.16 Does it exist; books, videos etc. to train to certify?

Yes	**11 :**	Finland, Greece, Iceland, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No	**9 :**	Austria, Belgium, Denmark, France, Germany, Ireland, Italy, Luxembourg, Netherlands

3.17 If yes, what kind of guidance and who is in charge of this?

Greece : Test book Epidemiology Dr Trichopoulos, 1982.
Norway : Guidance from the Ministry of Health (since 1982) + articles in medical books.
Portugal : Small booklets with text and examples.
Spain-Catalonia : The guidance (manual of certification) has two parts : one small one with the mortality statistics in Spain-Catalonia, the second with the death certificate and the rules + medical cases and how to fill them.
Sweden : Yes, a booklet (about 30 pages).
UK-England : Video + booklet with questions to self-test.

3.18 On what occasions is the guidance used?

At university (for students or teachers)	**8 :**	Finland, Greece, Iceland, Norway, Portugal, Spain-Catalonia, UK-England, UK-Northern Ireland
During workshops, meetings, etc. (for physicians)	**4 :**	Portugal, Spain, UK-England, UK-Scotland
With queries (for physicians)	**2 :**	Greece, UK-Northern Ireland
Other occasions	**3 :**	Iceland, Portugal, Sweden

Iceland : Sent to physicians by mail (booklet with text and examples).
Spain-Catalonia : At university + courses + sent by mail to the subscribers of our publication (free).

3.19 Independent of the practice in your country, do you think it useful to provide guidance to the physicians?

Yes	**20 :**	All countries

3.20 If yes, what type of guidance?

Austria : Video, papers.
Belgium : Short and clear.
Denmark : Video, booklets, and web-sites.
Greece : Specific workshops.
Iceland : Booklets, workshops, and articles in journals.
Norway : Good instructions on the death certificate is the best guidance + a special publication and articles in medical journals.
Portugal : Booklets/guidelines.
Spain : Only concrete training.
Spain-Catalonia : Practical cases are good (written by hospital physicians)
Sweden : It is useful to have something to send to physicians who ask for more information, but it is not a very efficient way of improving the quality of cause-of-death certification. Doctors in general are far too busy to take time to read even a booklet of 30 pages. The most efficient way is to develop a death certificate form that leaves as little room for misunderstandings as possible.
UK-England : Short and easy, video, booklet, computer-based program with emphasis on the purpose of data.

3.21 Do you think that it might be necessary/feasible to have European common recommendations for training practices?

NECESSARY

Yes	**16 :**	Austria, Belgium, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland
No	**2 :**	Denmark, Iceland
No response	**2 :**	UK-England, UK-Scotland

FEASIBLE

Yes	**17 :**	Austria, Belgium, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland
No response	**3 :**	Finland, Spain, UK-Scotland

3.22 Why?

Austria, Spain : Comparison of statistics.
Belgium : Helpful to put more importance on public health in training.
France : A common analysis would be interesting.
Greece : Incentives are necessary and funding is required.
Iceland : To follow ICD 10 examples.
Luxembourg : Important when physicians are going to other countries.
Portugal, Spain-Catalonia : For better comparability.
Sweden : I believe the question in the examinations could be useful, but since the curriculum is overloaded already, it would be very difficult to introduce in our country unless there is an EU recommendation to do so.
UK-England/UK-Scotland : Role of the WHO.
UK-Northern Ireland : If we have common certification, we can have common training.

3.23 What could be the most important of these recommendations?:

To propose a leaflet about certification and importance of reliable statistics	**18 :**	Austria, Belgium, Denmark, Finland, France, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
To propose questions on certification in the post graduate examinations for physicians	**9 :**	Austria, Belgium, Finland, Greece, Netherlands, Norway, Spain-Catalonia, UK-England, UK-Northern Ireland
To propose contents for the training course	**16 :**	Austria, Belgium, Denmark, Finland, France, Greece, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland

Belgium : Certificates to be filled in under the strict supervision of the head of service.
Luxembourg : To collaborate with professional associations.
Greece : Specific workshops.
UK-England : Public health and epidemiology training in undergraduate curricula; specialist modules for groups certifying neonatal deaths and stillbirths.

3.24 What items would you include in the training?

The concept of the causes of death sequence and the selection of the initial cause	**20 :**	All countries
The presentation of examples	**19 :**	Austria, Belgium, Finland, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland
A list of imprecise causes to avoid	**17 :**	Austria, Belgium, Finland, Denmark, France, Greece, Ireland, Italy, Luxembourg, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
An example of wrong certification	**12 :**	Austria, Belgium, Denmark, France, Greece, Ireland, Norway, Portugal, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland
An explanation of causes of death data as a public health indicator	**19 :**	Austria, Belgium, Finland, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
An example of useful data	**17 :**	Austria, Belgium, Finland, Denmark, France, Greece, Iceland, Ireland, Italy, Luxembourg, Norway, Portugal, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
Other items	**4 :**	Greece, Italy, UK-England, UK-Northern Ireland

Denmark : Legal consequences.
Germany : A list on imprecise causes to avoid is too much information.
Greece : The problem of contributory causes.
UK-England : Common causes of death correctly and incorrectly certified and causes of death frequently incorrectly certified.

3.25 Do you think that European recommendations on training practices could be easily applied in your country?

Yes	**9 :**	Finland, France, Greece, Iceland, Luxembourg, Portugal, Spain-Catalonia, Sweden, UK-Northern Ireland
No	**6 :**	Belgium, Germany, Netherlands, Norway, UK-England, UK-Scotland

3.26 Why?

Belgium : Helpful to put more importance on public health in training.
Denmark : No, we always think that we are the best. Yes : we do what we are told to!!!
Germany : High administrative costs, acceptance by the physicians.
Portugal : As we don't have much, it would be easier to adopt recommendations.
Spain-Catalonia : Yes because the responsible for training is connected to (public) health.
Sweden : The medical faculties do not want to increase the curriculum, but on the other hand Sweden usually follows EU recommendations.
UK-England : Difficult to impose standards across many different institutions and professional groups.

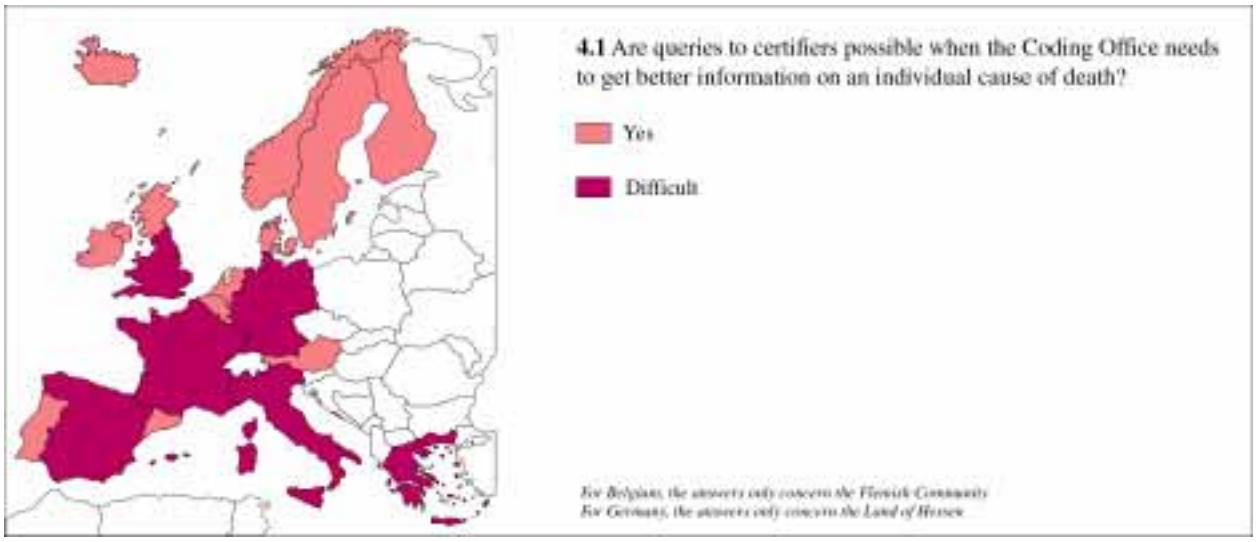
II.2.2.4 QUERY PRACTICES

A. GENERAL OVERVIEW

Queries are defined in this section as requirements by the causes of death statistics Office for additional information in order to improve the quality of the causes of death data entered in the death certificate (in case of incoherent sequences, imprecise cause of death...). The following expert's answers only concern this type of query. Answers to questions on other types of queries are reported at the end of this section.

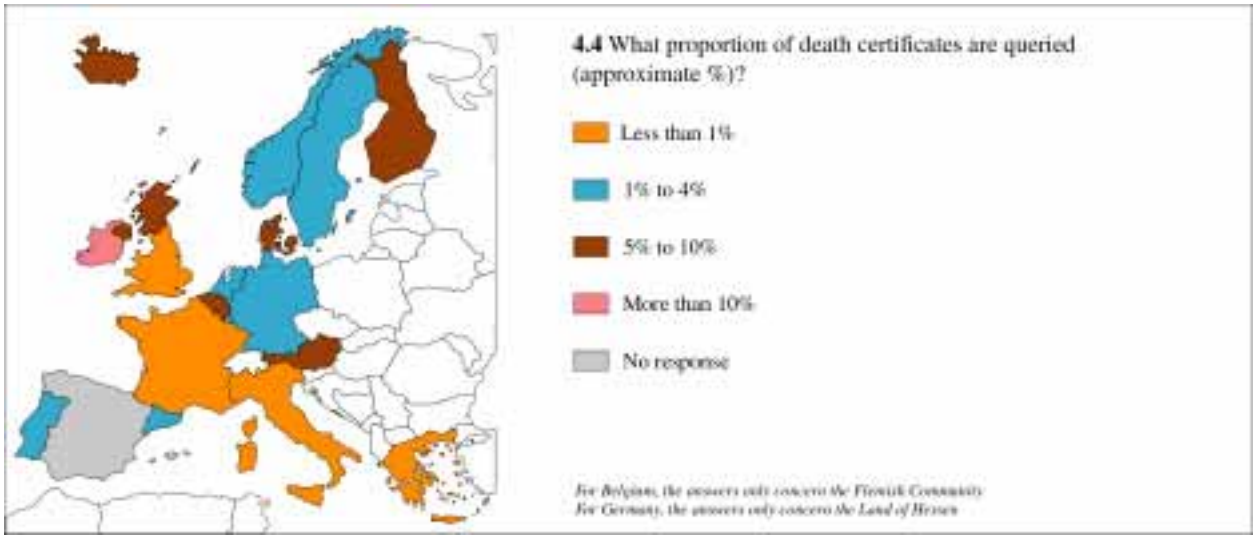
Feasibility for queries

In most European countries queries are possible, but 6 experts out of 20 answered that the procedure is difficult in their country **(**France, Germany, Greece, Italy, Spain, UK-England). The reasons why queries are difficult to undertake are varied. Germany and Greece stress confidentiality constraints. Problems of information circulation are pointed out by Germany and Portugal (the queries must pass via another administrative service). Problems of organisation in the office such as delays, lack of time or resources, concern England, France, Germany and Portugal. Problems with the certifiers (insufficient co-operation, infrequent replies or difficulties to identify the case) are stressed by England, Germany, Italy and Spain.



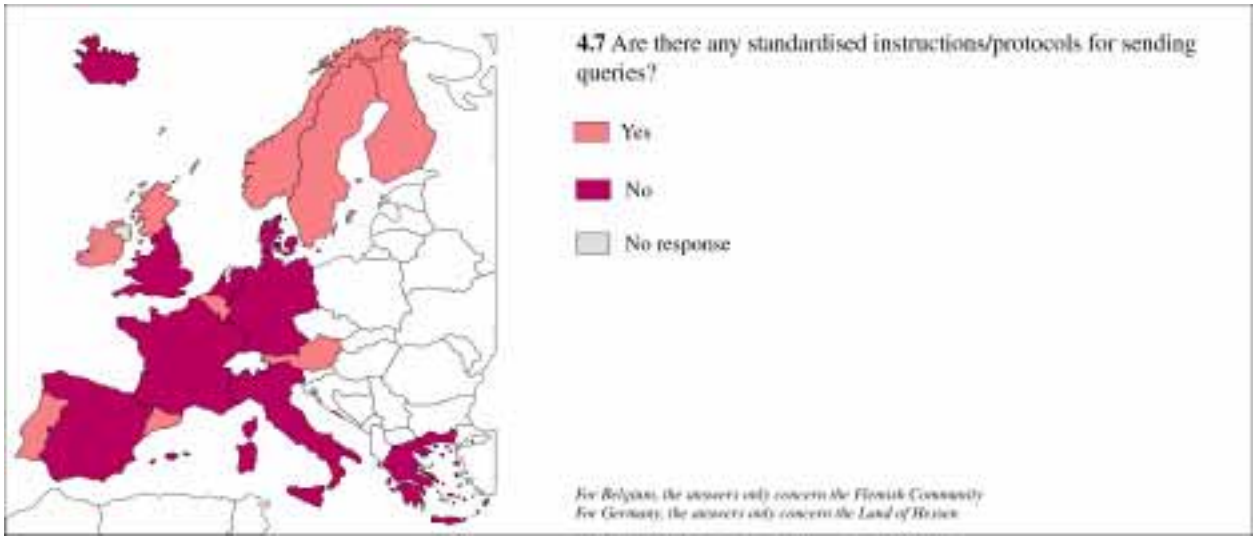
The countries where queries are difficult to undertake declare less than 1% of death certificates queried, with 2% for Germany (Land of Hessen). The countries where queries are the most frequent are Ireland (30% of certificates), Denmark, Finland and Iceland (9%). The proportion of death certificates queried remains stable in 9 countries out of 20. There is a significant evolution in the other 11 countries, with 6 increasing (Belgium, Denmark, Germany, Spain, Sweden, Northern Ireland) and 5 decreasing (England, Greece, Luxembourg, Portugal and Scotland). Explanations for such evolutions are specific to each country. For example, the introduction of automated coding might have opposite consequences: In Sweden, it results in an increase ('better

data validation software, suspicious cases more easily identified') and in England in a decrease ('queries were suspended in 1993 with the introduction of automated coding, except for following up autopsies').



Standardised instructions

There are standardised instructions for sending queries in 9 countries. These instructions may consist of standard letters, either connected or un-connected to specific pathologies. Some procedures are more elaborated as in Sweden where instructions are included in a document detailing every situation where a query is requested; this document points to cases related to surgery, suicide, murder and manslaughter, HIV-aids, neoplasm, pneumonia, and heart failures. In Ireland where 30 % of death certificates are queried, the list of 'main causes, which need to be queried,' is long with more than 20 pathologies or situations.

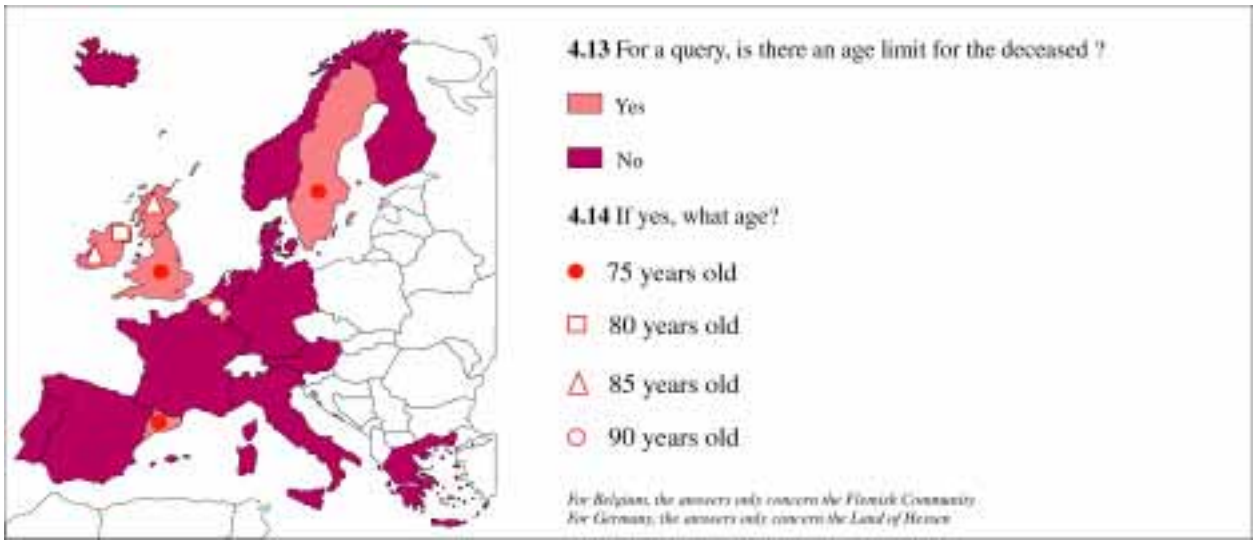


In some countries, instructions are more general, without mention of specific pathologies. In Catalonia, instructions consist of a phone-call interview in the case of ill-defined or imprecise underlying causes for decedents under 75 years old, or blank certificates for all ages of decedents.

Even if there are some permanent features such as ill-defined site neoplasms, operations and heart failures, the type of certification problems (or pathologies) most often queried varies from one country to another. For example, in Finland they concern (in decreasing order) symptoms, neoplasms, pulmonary embolisms, other circulatory diseases, and external causes. In Belgium they concern tumours, operations, suicides, accidents and problematic causal chain. In Ireland, septicaemias, neoplasm, fractures, operations and pulmonary embolisms.

Query modalities

In 7 out of 20 countries there is an official age limit in order for the case to be queried. In 3 countries (Spain-Catalonia, Sweden and UK-England), the age limit is 75 years old. In the 4 other countries, it goes from 80 to 90 years old.



Phone calls are used for queries in 6 countries (Belgium, Greece, Netherlands, Spain, Spain Catalonia and UK-Northern Ireland). In two other countries (Sweden and UK-Scotland), phone calls are rarely used; 'In some emergency cases with no time for a written query'. Phone calls are used because they are considered as more efficient (larger % of responses), easy and quick. The reasons why countries do not use phone calls concern mainly confidentiality, lack of resources, necessity for a written statement, or the risk of influencing the certifier.

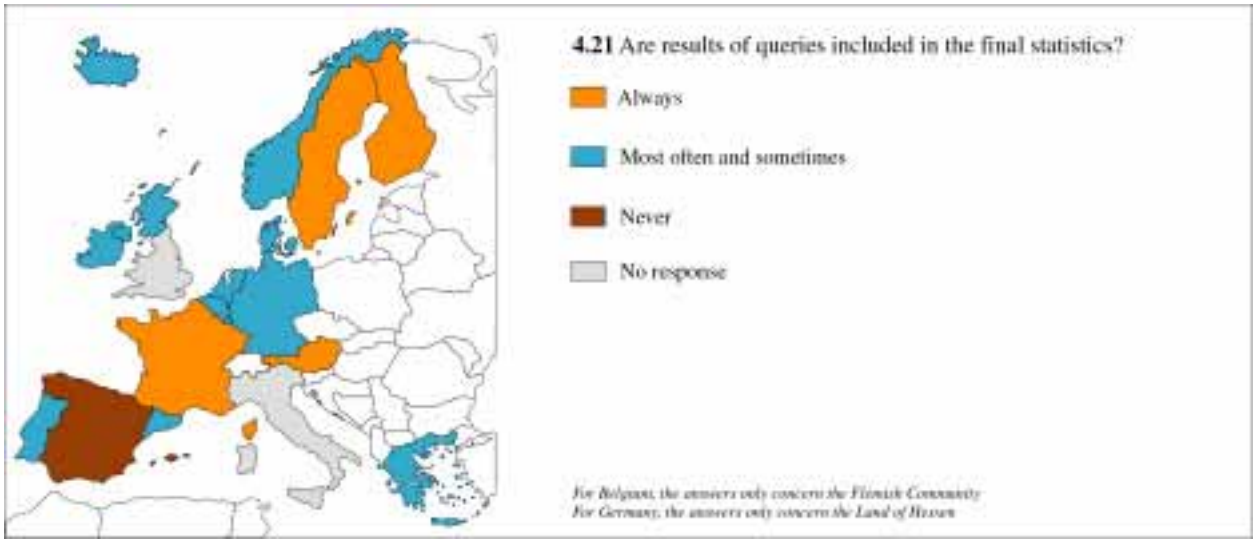
In the majority of European countries, the decision to send a query is taken either by the coder, alone, within a meeting, or with the head of the Office. In Catalonia, Sweden and Scotland, the decision is taken by an automatic program, and eventually validated. In 4 countries (Iceland, Netherlands, Norway and UK-Scotland), decisions on queries are under the responsibility of a medical advisor.

The mean delay between the death and a query varies from one country to another. It is less than 3 months for 7 countries, from 4 months to one year for 5 countries and more than one year for 4 others. The countries where delays are the longest (between one and two years), are all Nordic countries which is due to the implementation of ICD-10 which increases the delay for coding.

For half of the countries the delay is a problem for achieving quality of answers. Even in some countries such as Ireland where the delay is short compared to others. Usually, three/four months is considered as the optimal interval: 'the medical records had generally been returned to the archives at that point, but the physician in charge of the case still remembered the patient'.

Query results

The proportion of queries with a useful answer varies from 50% to 100%. 6 countries top the list with more than 90% of useful answers (Denmark, Iceland, Netherlands, Portugal, Spain-Catalonia and Sweden) and 4 countries have less than 70%. The relation between the delay and the quality of answers to queries is not simple. In general, countries with a short delay are more satisfied with the quality of answers but this is not always the case, showing that other factors may be important.



Most countries include results of queries 'most often' in the final statistics (13 out of 20) and 4 countries 'always' (Austria, Finland, France, Sweden). On the occasion of a query, nearly all European countries only ask for more precise information on causes of death. Five countries (Belgium, Denmark, Iceland, Norway and Sweden) ask for other type of information such as 'earlier diseases' or for documents such as hospital records or legal reports. When Causes of death statistics Offices send a query, they rarely accompany their request to the certifier with feed back (5 countries out of 20). Denmark and The Netherlands give information on causes of death statistics. Belgium and Finland send guidelines on certification, France gives the Web site address where precise causes of death statistics are available.

Opinions on query practices improvement and on European recommendations

Independent of the practice in their country, all countries think that the best procedure would be to query systematically imprecise causes of death whatever the type of pathologies. Only 4 countries recommend querying only young age groups or specific pathologies. The majority of European countries think that it would be important to send to the certifiers feed back on causes of death and guidelines on certification but some others think that queries should be more directly oriented and as precise and short as possible.

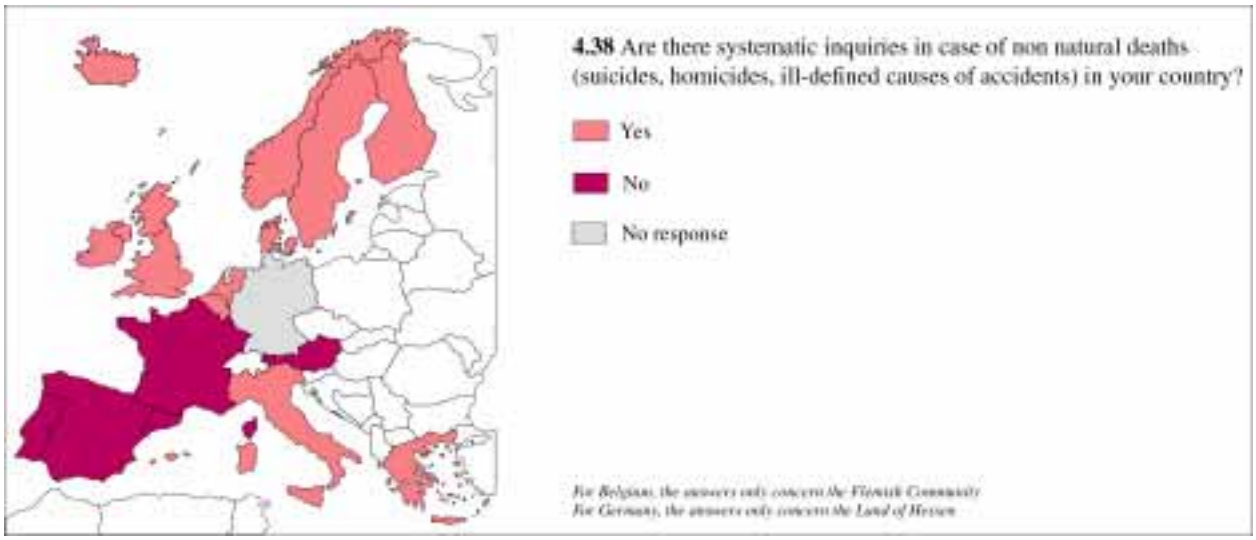
European recommendations for querying procedures are considered 'necessary' by 8 countries (Austria, Denmark, France, Ireland, Luxembourg, Portugal, Spain-Catalonia and Sweden) and 'feasible' by 9 countries (the same plus Italy and UK-Northern-Ireland, minus Ireland whose expert estimates European recommendations as 'necessary' but not 'feasible'). The main argument for harmonization is that querying influences the statistics, and 'it would be important for international comparisons to agree on what and when countries should query'. The priorities for

recommendations would be to propose guidelines on queries protocol and to propose some pathologies/cases where queries would be necessary.

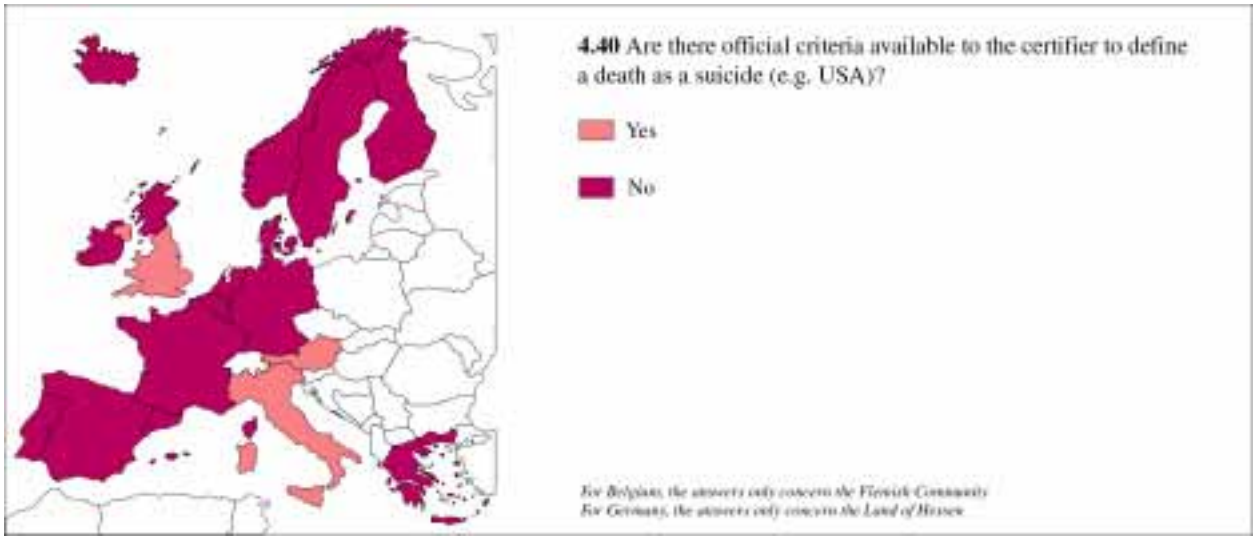
8 experts out of 20 think that such recommendations could be easily applied in their country, 6 think that they could not and the others don't give a precise answer because 'it would depend on the final contents of the recommendations'.

Other types of queries: inquiries

In the case of non-natural deaths, there is a systematic inquiry in the majority of European countries (15 out of 20). In five countries (Austria, France, Portugal, Spain, Spain-Catalonia), it is not a legal obligation. When there is an inquiry, the ways to certify the death vary. Certification can be the responsibility of non-medical professionals (in general with the help of physicians): policemen (Denmark, Greece and Ireland), coroners (England and Northern Ireland) or judges (Spain). In most countries it is the responsibility of physicians or forensic pathologists (in the case of autopsies).



In only 4 countries out of 20 (Austria, Italy, England and UK-Northern Ireland), are there official criteria to help the certifier to define a death as a suicide.



After the inquiry, the results (amended causes of death) are 'always' included in the mortality statistics by 13 countries (Austria, Belgium, Denmark, Finland, Germany, Iceland, Ireland, Luxembourg, Netherlands, Norway, Spain, UK-England, UK-Scotland), 'most of the time' and 'sometimes' by 6 countries, 'never' by two countries. The reasons why results are not always included is that they do not systematically come back to the Statistical Office, or that they come back too late.

B. DETAILED RESPONSES

NB : All questions concern for Belgium: The Flemish Community and for Germany: The Land of Hessen only

4.1 Are queries to certifiers possible when the coding Office needs to get better information on an individual cause of death ?

Yes	**14 :**	Austria, Belgium, Denmark, Finland, Iceland, Ireland, Luxembourg, Netherlands, Norway, Portugal, Spain Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
Difficult	**6 :**	France, Germany, Greece, Italy, Spain, UK-England

4.2 If no or difficult, why ?

Confidentiality constraint	**2 :**	Germany, Greece
Difficulty to identify the certifier	**2 :**	France, Portugal
Difficulty for the certifier to identify the case	**2 :**	Italy, Spain
Lack of resource	**2 :**	France, UK-England
Other reasons	**3 :**	Germany, Portugal, UK-England

4.3 Can you explain the reasons for these difficulties ?

France : Lack of time.
Germany : The certifiers do not cooperate, physicians do not remember (delay) or do not want to ; administrative procedures in hospitals, the circulation is complicated (the queries are sent to the local health Offices which contacts the physician).
Portugal : Difficult because the Office does not get the name of the certifier and has to send the query to the Civil Registration Office who will contact the physician.
UK-England : Delays, infrequent replies, not set up to do automated coding.

4.4 What proportion of death certificates are queried (approximate %) ?

Less than 1%	**4 :**	France, Greece, Italy, UK-England
1% to 3%	**7 :**	Germany, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden
4% to 6%	**7 :**	Austria, Belgium, Denmark, Finland, Iceland, UK-Northern Ireland, UK-Scotland
More than 10%	**1 :**	Ireland
No response	**1 :**	Spain

4.5 Is there a significant evolution in the proportion of death certificates queried ?

Yes increasing	**5 :**	Belgium, Denmark, Germany, Spain, UK-Northern Ireland
Yes decreasing	**4 :**	Greece, Luxembourg, Portugal, UK-Scotland
No (stable)	**11 :**	Austria, Finland, France, Iceland, Ireland, Italy, Netherlands, Norway, Spain-Catalonia, Sweden, UK-England

4.6 If yes, can you briefly describe the trend and explain it ?

Belgium : Increasing (motivation for the coders).
Denmark : Increasing only because death certificates are less and less correctly filled out (more unknown causes of death).
Portugal : Decreasing (unknown and unspecified causes of death are increasing).
Spain : The evolution is positive because there are more collaborations with the Institutos regionales de estatistica which are closer to certifyers.
Sweden : Increasing since the introduction of ICD-10. This is probably due to better data validation software - suspicious cases are more easily detected.

UK-Northern Ireland : Increasing as we get a better response from doctors.
UK-Scotland : Decreasing (for very specific information).
Greece : Decrease
UK England : Suspended in 1993 (automated coding) except to follow up autopsies.

4.7 Are there any standardized instructions/protocols for sending queries ?

Yes	**9 :**	Austria, Belgium, Finland, Ireland, Norway, Portugal, Spain-Catalonia, Sweden, UK-Scotland
No	**10 :**	Denmark, France, Germany, Greece, Iceland, Italy, Luxembourg, Netherlands, Spain, UK-England
No response	**1 :**	UK-Northern Ireland

4.8 If yes, can you briefly explain these instruction :

Austria : Letter + certificate.
Norway : Special forms are used for different diagnosis/ causes.
Portugal : Sheet of paper with 12 questions with boxes.
Spain-Catalonia : Yes, phone calls for ill-defined and unprecise causes for people < 75 years + blank certificates for all.
Sweden : Very precise instructions.
UK-Scotland : 1)Further info likely to be available, autopsy carried out, imprecise terms used, poor sequence .
UK-Northern Ireland : Further info to get, industrial disease.

4.9 Are there any standardized instructions on some pathologies to query as a priority ?

Yes	**10 :**	Austria, Belgium, Finland, Ireland, Norway, Portugal Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
No	**10 :**	Denmark, France, Germany, Greece, Iceland, Italy, Luxembourg, Netherlands, Spain, UK-England

4.10 If yes, what type of pathologies ?

Norway : Drowning, fractures, intox, cancer, suicide/autopsy, TBC, diabetes mellitus, pneumonia, mors subita, cirrhosis, depatis, cor pulmi, urrhemia, gangrene.
Sweden : Surgery, suicide, murder or manslaughter, HIV Aids, in some cases neoplasm's, pneumonia and heart failures.

4.11 More generally, what type of certification problems are queried ?
4.12 Which are the pathologies most queried by the coding service ?
(These questions have been analyzed together).

Accidents : Belgium, Germany, Luxembourg.
Autopsies : France, Netherlands.
Blank certificate : Netherlands.
Causal chain : Belgium, Finland.
Chirrosis hepatis : Norway.
Diabetes : Norway.
Drug abuse : Greece.
External causes : Finland, Portugal, Spain.
Fractures : UK-Northern Ireland.
Heart failure : Austria, Spain, Spain-Catalonia, UK-Northern Ireland, Sweden.*
HIV : France, Greece, Portugal.
Ill-defined conditions : Luxembourg, Portugal, Spain.
Infant death : Denmark.
Injuries : Portugal, Sweden.
Intoxication : Denmark.
*Liver Zirhosis : Austria**
Mesotheliom : UK-Northern Ireland.
Mors subita : Norway.

Multiorganic failure : Spain-Catalonia.
Other circulatory diseases : Finland.
Possible pregnancy : Portugal.
Pulmonary embolism : Austria, Finland.*
Respiratory failure : UK-Northern Ireland.
Septicemia : UK-Northern Ireland.
Still born : Denmark.
Suicides : Belgium, Germany.
Surgery : Austria, Belgium, Germany, France, Netherlands.*
Symptoms : Finland.
*Syndromes : Austria**
Tumors/neoplasm : Belgium, Denmark, Finland, Netherlands, Portugal, Sweden.
Unknown, insufficient, contradicting : Germany, France, Netherlands, Portugal.
Violent deaths : France.
Young persons with unknown causes of death : Denmark.

** Always in combination with age*

4.13 Is there an age limit for the deceased for a query ?

Yes	**7 :**	Belgium, Ireland, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No	**13 :**	Austria, Denmark, Finland, France, Germany, Greece, Iceland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain

4.14 If yes, what age ?

75 years old	**3 :**	Spain-Catalonia, Sweden, UK-England
80 years old	**1 :**	UK-Northern Ireland
85 years old	**2 :**	Ireland, UK-Scotland
90 years old	**1 :**	Belgium

4.15 Are phone calls used to query ?

Yes	**6 :**	Belgium, Greece, Netherlands, Spain, Spain-Catalonia UK-Northern Ireland,
Rarely	**2 :**	Sweden, UK-Scotland
No	**11 :**	Austria, Denmark, Finland, France, Germany, Iceland, Ireland, Luxembourg, Norway, Portugal, UK-England
No response	**1 :**	Italy

4.16 Why ?

Belgium : Phone calls are more efficient to get answers, the same for faxes.
Finland : Phone calls are more manpower resources consuming; the answer cannot be given by phone because the response is in general in the archives of the hospitals.
France : Too expensive, too time consuming (many calls before getting the right person); confidentiality.
Greece : Easier to find the certifier.
Luxembourg : Confidentiality, not easy to reach the right person, physicians may do not like to be disturbed.
Netherlands : Yes, quick results possible.
Spain-Catalonia : More direct intervention, less 'no responses' than letters.
Sweden : It is important to have the new information in a written statement from the physician. In telephone calls there is some risk that the person from our office who interviews the physician thinks too much in terms of ICD coding rules, and puts leading questions with some specific underlying cause in mind. (Telephone calls in "emergency" cases are still used- if a potentially important case just as we are about to close the file and there is no time for a written query.)
UK-England : Phone numbers not available.

4.17 Who takes the decision to send a query ?

The coder who has a problem	**12 :**	Belgium, Denmark, Finland, France, Germany, Greece,

		Ireland, Norway, Portugal, Sweden, UK-Northern Ireland, UK-Scotland
The group of coders among regular meetings	**6 :**	Belgium, Denmark, Finland, Spain-Catalonia, Sweden, UK- Northern Ireland
The head/manager of the coding service	**10 :**	Austria, Belgium, Denmark, France, Greece, Luxembourg, Portugal, Spain, Sweden, UK-Northern Ireland
An automatic program	**3 :**	Spain-Catalonia, Sweden, UK-Scotland
Other people/procedure	**4 :**	Iceland, Netherlands, Norway, UK-Scotland

Iceland, Netherlands, Norway : Medical adviser.
Spain-Catalonia : Specific cases in meetings.

4.18 What is the mean delay between the death and a query to the certifier ?

Less than 3 months	**7 :**	Austria, Belgium, Ireland, Netherlands, Portugal, UK-Northern Ireland, UK-Scotland
4 months to 1 year	**5 :**	France, Greece, Iceland, Luxembourg, Spain-Catalonia
More than 1 year	**4 :**	Denmark, Finland, Norway, Sweden
No response	**4 :**	Germany, Italy, Spain, UK-England

Sweden : At the moment, about 1 year. This is due to the delay caused by introducing ICD-10. During the ICD-9 period the office found that three-four months was the optimal interval - the medical records had generally been returned to the archives at that point, but the physician in charge of the case still remembered the patient.

4.19 Is the delay a problem for the quality of answers ?

Yes	**10 :**	Denmark, Finland, Greece, Ireland, Luxembourg, Norway Portugal, Spain-Catalonia, Sweden, UK-Northern Ireland
No	**8 :**	Austria, Belgium, France, Germany, Iceland, Netherlands, Spain, UK-Scotland
No response	**2 :**	Italy, UK-England

4.20 Approximate proportion of queries with useful answer :

More than 90%	**6 :**	Denmark, Iceland, Netherlands, Portugal, Spain-Catalonia, Sweden
80 to 90%	**3 :**	Belgium, Germany, UK-Northern Ireland
70 to 80%	**2 :**	Finland, Ireland
Less than 70%	**4 :**	France, Norway, UK-Scotland, Luxembourg
No response	**5 :**	Austria, Greece, Italy, Spain, UK-England

4.21 Are results of queries included in the final statistics ?

Always	**4 :**	Austria, Finland, France, Sweden
Most often/ Sometimes	**13 :**	Belgium, Denmark, Germany, Greece, Iceland, Ireland, Netherlands, Luxembourg, Norway, Portugal, Spain-Catalonia, UK-Northern Ireland, UK-Scotland
Never	**1 :**	Spain
No response	**2 :**	Italy, UK-England

4.22 If never, why ?

Spain : Never because there are 17 regional offices.

4.23 On the occasion of a query, does the causes of death statistics Office ask for :

Only more precise information on causes of death	**17 :**	Austria, Denmark, Finland, France, Germany, Greece, Ireland, Iceland, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
Hospital records of the deceased	**4 :**	Belgium, Denmark, Iceland, Sweden
Other type of information	**3 :**	Denmark, Iceland, Norway

Denmark : Legal reports.
Norway : Treatment, sequence, earlier diseases.

4.24 On the occasion of a query, does the causes of death statistics office send to physicians :

Information on causes of death statistics	**2 :**	Denmark, Netherlands
Guidelines on certification	**2 :**	Belgium, Finland
Other type of information	**1 :**	France

Austria, Luxembourg : Copy of the death certificate to complete.
Denmark : The guidelines are recommended to be read.
France : Address of the Web site.
Sweden : Some of the query letters contain basic information on why we need that particular piece of information, and sometimes refer to specific studies or objectives. In general, however, our main aim is to make the letters as short and easily understood as possible.

4.25 Independent of the practice in your country, what would you propose as a good procedure for queries :

To query only young age groups	**1 :**	Greece
To query only specific pathologies	**4 :**	Greece, Luxembourg, Spain, Sweden
To use phone calls	**5 :**	Belgium, Netherlands, Spain, UK-Northern Ireland, UK-Scotland
To ask for hospital records	**4 :**	Belgium, Denmark, Portugal, Sweden
To query imprecise causes of death whatever the type of pathologies	**18 :**	Austria, Belgium, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-Northern UK-Scotland

Belgium : A legal procedure to obtain the results of legal autopsies if the case is still in instruction.
Finland : The more information lies unwritten to the death certificate, the more queries should be sent.
Spain-Catalonia : Elderly have a lot of unprecise causes of death but to query this age group (>75) could increase a lot the number.

4.26 Independent of the practice in your country, what do you think would be interesting to send to the certifiers on the occasion of a query :

Information on causes of death statistics	**11 :**	Belgium, Denmark, Finland, France, Greece, Ireland, Italy, Netherlands, Portugal, Spain-Catalonia, UK-England
Guidelines on certification	**10 :**	Belgium, Denmark, Finland, France, Ireland, Italy, Luxembourg, Portugal, Spain-Catalonia, UK-England
Other type of information	**3 :**	Austria, Iceland, Spain-Catalonia

Austria : Copy of the death certificate to complete.
Belgium : Not too much information.
Finland : To present the cause of death as a source of medical research.
Spain-Catalonia : Plus how to obtain information and data.
Sweden : No. I don't think you should send physicians materials they haven't asked for. In general, we have found that we get more answers the shorter our questions are. Perhaps short questions show the physicians that we try to respect their heavy workload and do not want to add to it unless absolutely necessary. Likewise, sending them certification guidelines if they haven't asked for more information might imply that we don't value their work...

4.27 Do you think that it might be necessary/feasible to have European recommendations for query practices ?

NECESSARY

Yes	**8 :**	Austria, Denmark, France, Ireland, Luxembourg, Portugal, Spain-Catalonia, Sweden

No	**10 :**	Belgium, Germany, Greece, Iceland, Netherlands, Norway Spain, UK-England, UK-Northern Ireland, UK-Scotland
No response	**2 :**	Finland, Italy

FEASIBLE

Yes	**10 :**	Austria, Denmark, France, Iceland, Italy, Luxembourg, Portugal, Spain-Catalonia, Sweden, UK-Northern Ireland
No	**9 :**	Belgium, Germany, Greece, Ireland, Netherlands, Norway, Spain, UK-England, UK-Scotland
No response	**1 :**	Finland

4.28 Why ?

Austria : Quality of statistics depends on quality of queries; some countries might have problems with queries.
Belgium : More on a general level (government, universities) that on a concrete level as the redaction of letters.
Denmark : If (we have) international comparisons, it is necessary to agree on what and when to query.
France : International protocols would be interesting.
Finland : The finished death certificate is more complete than other EU countries.
Norway : Different information basis.
Portugal : For better comparability.
Spain : No because each country has specific problems.
Spain-Catalonia : Yes for better comparisons (example : our queries are focused on ill defined and unprecise, if it is not the same in another country, will our figures be comparable ?).
Sweden : Querying influences the statistics very much, especially querying of ill-defined causes.
UK-Scotland : Too different practices.

4.29 What would be the priority for a recommendation :

To propose guidelines to query	**11 :**	Austria, Denmark, France, Ireland, Italy, Luxembourg, Norway, Portugal, Sweden, UK-Northern Ireland, UK-Scotland
To propose some pathologies/cases where queries would be necessary	**11 :**	Austria, Denmark, Finland, France, Ireland, Luxembourg, Norway, Spain, Spain-Catalonia, Sweden, UK-Scotland

4.30 Do you think that European common recommendations for querying practices could be easily applied in your country ?

Yes	**8 :**	France, Ireland, Luxembourg, Norway, Portugal, Spain, Spain-Catalonia, Sweden
No	**6 :**	Austria, Germany, Greece, Netherlands, UK-England, UK-Northern Ireland
No response	**6 :**	Belgium, Denmark, Finland, Iceland, Italy, UK-Scotland

Portugal : Yes because it could be a good way of improvement + we don't have much tradition on queries.
Spain : Yes if it is limited to a selection of some pathologies to query.
Spain-Catalonia : Not easily but could.

4.31 Why ?

UK England : depends on patterns of certification and disease and other sources of information in each country
UK-Scotland : depend on proposals
Northern Ireland : attention not to give too much new instructions to physicians

OTHER TYPES OF QUERIES

Questions 4.32, 4.35, 4.36 on queries and random studies and originally in this section, have been included in Section V on Confidentiality.

4.32 Has the coding office already organised queries at random (or is it planned) ?

Yes	**3 :**	France, Greece, Sweden,
No	**17 :**	Austria, Belgium, Denmark, Finland, Germany, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, UK-England, UK-Northern Ireland, UK Scotland

4.33 Are there other types of queries in your country, different from queries define at the beginning of the section ?

Yes	**10 :**	Austria, Finland, Germany, Iceland, Norway, Spain, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland
No	**10 :**	Belgium, Denmark, France, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Sweden

4.34 Can you describe briefly the procedure and precise who is in charge with these other types of queries ?

Queries at random, studies	**2 :**	France, Sweden
Specific organisation for certification whatever the type of pathologies	**18 :**	Austria, Belgium, Denmark, Finland, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland

Austria : General information of the decedent (age, residence...) is checked and queried by an officer of vital statistics (same department).
Finland, Germany : In each region, there is a forensic doctor who receives all the France : Studies on specific pathologies (diabetes, uterus neoplasms, hepatitis B).
death certificates and control them before to send them to Statistics Finland (they depend the Ministry of Health).
Norway : The official physician in municipalities has a responsibility.
Spain-Catalonia : Civil register.
Sweden : In 1984 a random medical records (1200) were requested for a random sample of deaths below the age of 75. The then medical advisor, Lars-Olof Bygren (professor of social medicine at Umeå University), was in charge of the project. The records were used to evaluate the death certificates. In 1999 we requested medical records for a random sample (600) of cases that were rejected by ACME, and for the same number of controls (certificates with the same underlying cause that had been accepted by ACME). I am in charge of that study.
UK-Scotland : Procurator fiscal (coroner).

4.35 Are studies on comparison of individual causes of death with other medical records (in view of analysis of the reliability of causes of death statistics) possible in your country ?

Question addressed in 'Confidentiality'.

4.36 If no or difficult, why :

Confidentiality constraint	**5 :**	Belgium, Greece, Luxembourg, Netherlands, Spain
Difficulty in contacting the certifier	**0 :**	
Difficult for the certifier to identify the case	**0 :**	
Other reason	**2 :**	Luxembourg, UK-England

Belgium : Written consent.
France : Difficulty to obtain the authorisation, cost demanding, delay between deaths and studies, relations with hospitals.
Luxembourg : Relations with hospitals, difficult to identify the treating physician.

4.38 Are there systematic inquiries in cases of non natural deaths (suicides, homicides, ill-defined causes of accidents,) in your country ?

Yes	**14 :**	Belgium, Denmark, Finland, Greece, Iceland, Ireland, Italy, Luxembourg, Norway, Netherlands, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No	**5 :**	Austria, France, Portugal, Spain, Spain-Catalonia
No response	**1 :**	Germany

Austria : No but certifiers are specific people; if we don't have enough information on the certificate, we contact the police who gives us the necessary information.

4.39 In this case of inquiry, who is filling the death certificate ?

The police	**3 :**	Denmark, Greece, Ireland
Legal Professionals	**3 :**	UK-England, UK-Northern Ireland, Spain
Physicians or Forensic physicians	**14 :**	Austria, Belgium, Finland, France, Germany, Iceland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-Scotland

Denmark : Forensic Officer and police.
Greece : The police with a medical examiner.
Netherlands : Coroner.
Norway/ Finland : Forensic physician.
Spain : The judges.
Sweden : If the police decides that a forensic investigation is necessary, the death certificate is issued by the forensic pathologist. In most cases the pathologist has access to, and makes use of, materials from the police investigation. If there is no forensic autopsy, the death certificate is filled out by the deceased's treating physician, or - if there is no treating physician - by the head of the primary care unit responsible for the area in which the death occurred.
UK-Northern Ireland : Coroners.

4.40 Are there official criteria available to the certifier to define a death as a suicide (e.g. USA) ?

Yes	**4 :**	Austria, Italy, UK-England, UK-Northern Ireland
No	**16 :**	Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Iceland, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-Scotland

4.41 After the inquiry, are the results (new causes of death) included in the mortality statistics ?

Always	**13 :**	Austria, Belgium, Denmark, Finland, Germany, Iceland, Ireland, Luxembourg, Netherlands, Norway, Spain, UK-England, UK-Scotland
Most of the time/ Sometimes	**5 :**	France, Greece, Italy, Sweden, UK-Northern Ireland
Never	**2 :**	Portugal, Spain-Catalonia

France, Greece : Results are not coming back (autopsies, toxicological tests).
Norway : If sent.
Portugal : Not sent to the Statistical Office.
Sweden : Exceptions : If the enquiry takes a very long time (chemical analyses etc) and the results are not sent to Statistics Sweden before we close the annual file, the results will not be included. There are plans to update earlier files with information sent to us after the closing of the files, however.
UK-Northern Ireland : Too late.

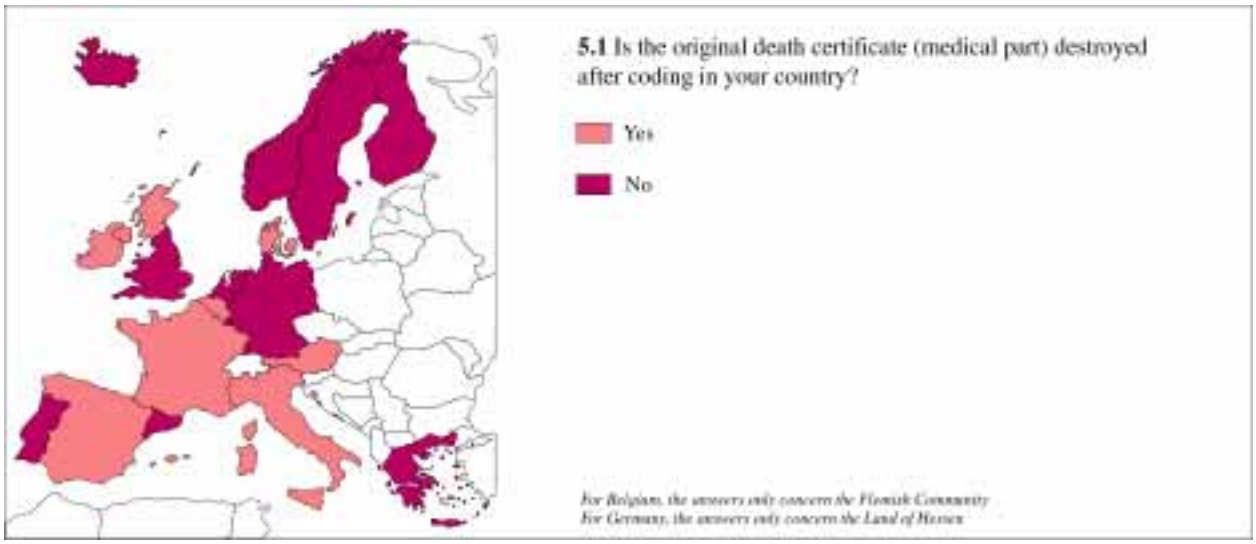
II.2.2.5 CONFIDENTIALITY PRACTICES

A. GENERAL OVERVIEW

Death certificates and causes of death storage

The ways to keep the death certificates (medical part) in Europe vary from north to south. The death certificates are kept in 11 countries and destroyed in 9. In Northern Europe, the death certificates are kept after coding except in Denmark. In Southern Europe, they are destroyed except in Greece, Portugal and Spain-Catalonia. In the British Isles, the only country-region where the death certificates are kept is England/Wales. In Ireland, Scotland and Northern Ireland they are destroyed.

When death certificates are destroyed, the destruction is in general not immediate after coding and occurs with a delay of one or two years.



However, in countries where the death certificates are destroyed, the information might be stored on microfilms (Denmark, Ireland and Northern Ireland) or digitised (Denmark, France Italy). In countries where the death certificates are kept as an original document, they might also be kept in another way; in Sweden, the death certificates are stored in microfilm and digitised; in Finland, Norway and England, they are digitalized. In Scotland, all relevant text and codes are kept on a database and a selection of information is kept in an official register.

Most of European countries record ICD codes for more than one cause of death (13 out of 20). 5 countries record ICD codes only for the underlying cause of death (Austria, Germany, Ireland, Portugal and Spain). Norway records a selection of ICD codes.

Access to individual causes of death

European confidentiality practices concerning the access to individual causes of death are far from harmonization. Depending on the different kinds of persons or professionals who can have access to individual causes of death (relatives, researchers, insurance Cies or law professionals), five main types of practices can be drawn from the strictest rules to the most flexible.

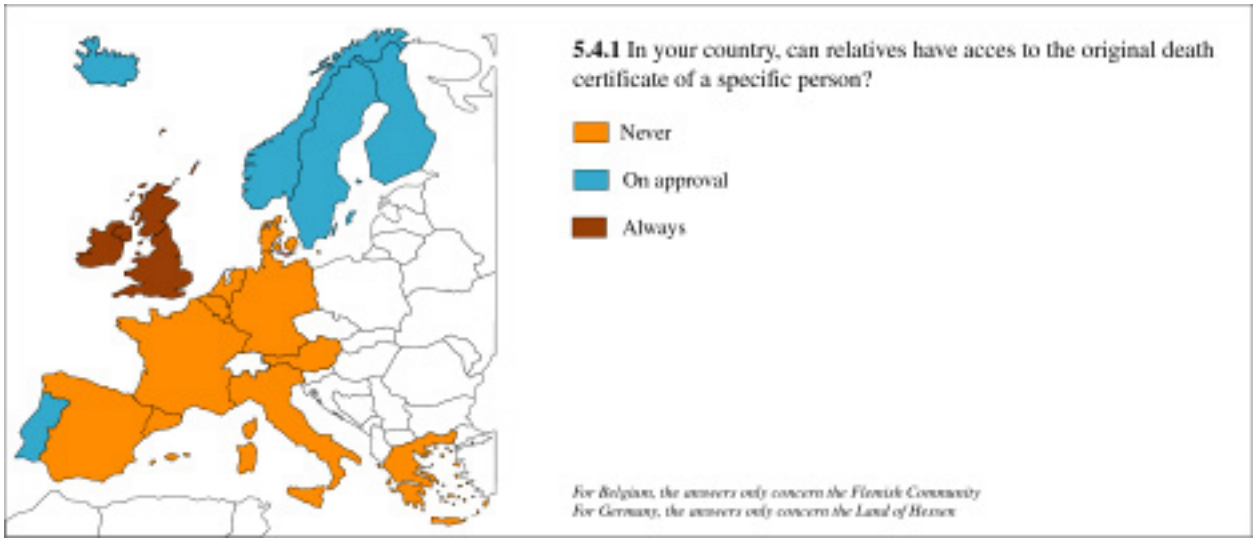
The first group includes Germany and The Netherlands where the information on individual causes of death can never be communicated, even to researchers.

The second group includes 5 countries/regions (Austria, Belgium, France, Spain and Spain-Catalonia) where the information on individual causes of death can be communicated only to researchers (in France, it can be given to legal professionals in some very specific and rare situations).

The third group is constituted with countries where the information on individual causes of death can be easily communicated to both researchers and judges (Italy and Luxembourg) or only to judges (Greece).

The fourth group comprises all Nordic countries and Portugal where information on individual causes of death can be communicated 'on approval' to persons or professionals who have a legitimate reason to ask for. In Finland or Portugal, this practice concerns all the categories of demands (relatives, researchers, insurance companies or law professionals). In other Nordic countries, there are exceptions: Denmark excludes relative, Iceland and Norway exclude insurance Cies and Sweden[1] insurance Cies and law professionals.

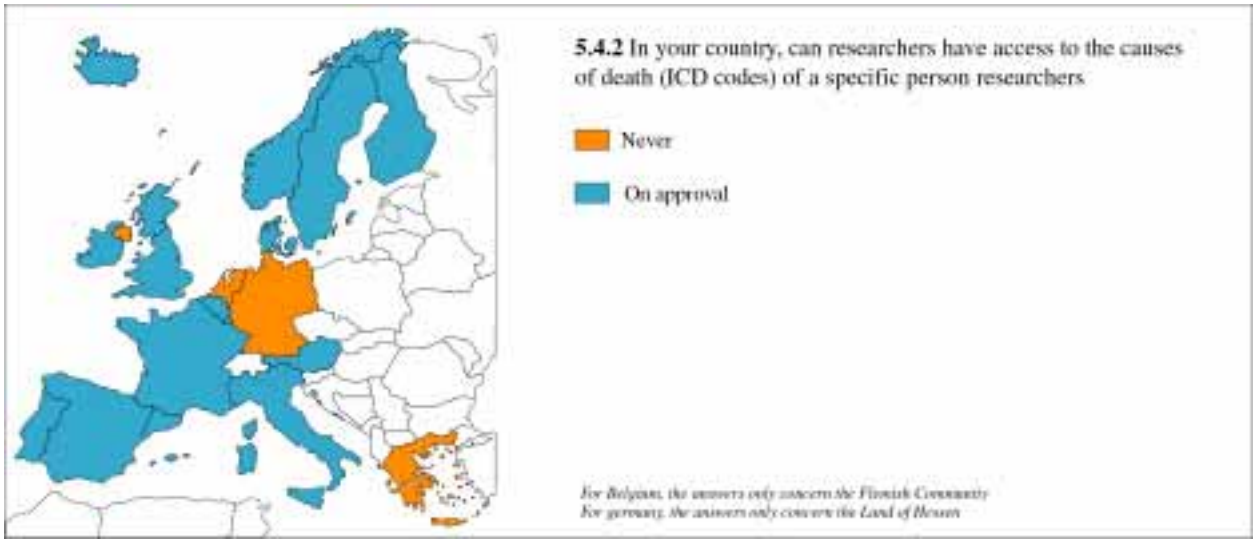
The fifth group is composed of the British Isles (UK-England/Northern Ireland/Scotland and Ireland) where confidentiality practices are quite specific. With some light discrepancies between the 4 countries-regions, the main principle is that the causes of death are a public register that can be consulted by anyone who asks for.



Original text or ICD codes?

The way to communicate the information on individual causes of death (original text or ICD codes) depends on the type of storage adopted by countries and on the characteristics of the requests. In most of Nordic countries where the death certificates are kept, confidentiality rules make no difference between the certificate itself and the ICD codes. If a person or institution obtains the permission to get individual causes of death, he will have the information in both ways. In the British Isles, the original text written by the physician is easily available but ICD codes which contains the query or inquiry results are never or very rarely communicated, even to researchers. In other countries, the researchers often only get the ICD codes.

When the access needs an approval, which is the case in most countries and situations, it requests always an ethical consent and a specific procedure whose conditions are generally defined by law.



Confidentiality practices and quality of the statistics

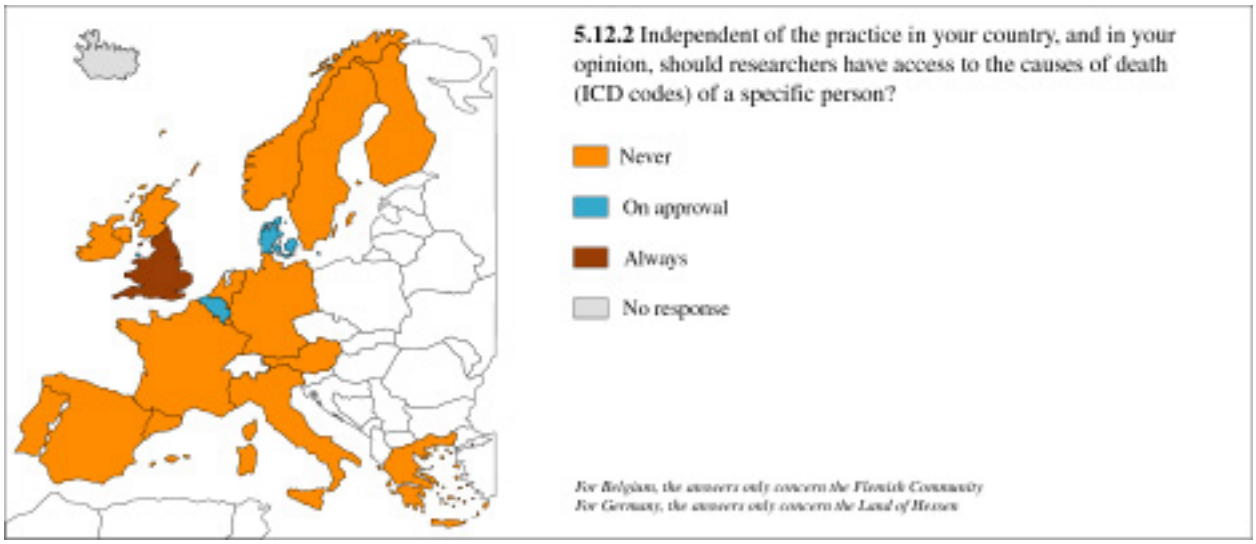
Half of the European experts think that the confidentiality practices in use in their country lead to an improvement in the quality of causes of death statistics. In contrast, 3 experts consider that the quality of causes of death statistics is deteriorated by the confidentiality practices in their country (7 experts can't answer).

When asking the experts what would they change in the access of relatives, researchers, insurance CIEs and law professionals to the information on individual causes of death, 10 of them agree with the practices in use in their country (Austria, Finland, France, Germany, Greece, Portugal, Iceland, Norway, Spain, UK Northern Ireland) and 10 would like to see changes or improvements (Belgium, Denmark, Ireland, Italy, Luxembourg, Netherlands, Spain-Catalonia, Sweden, UK-England, UK-Scotland). The main reasons for this are the heavy constraints for researchers (Italy, Spain), the possible 'pressures' on the certifiers (Sweden, UK-Scotland) or, conversely, the

usefulness to make the rule more flexible for families who might desire or need the information (Belgium, Denmark, Luxembourg, The Netherlands). Experts from two countries, Denmark and Spain-Catalonia, think that all requests should be possible on approval. This practice exists in Finland whose expert considers that a "multipurpose use of death certificates improves the quality of mortality statistics".

In the British Isles, all countries/regions experts except one would prefer to limit the access to the individual causes of death.

The majority of European experts (12 out of 20) think that some pathologies or external causes are more affected than others by confidentiality constraints in use in their country. The pathologies most often mentioned are: suicide (Belgium, France, Iceland, Italy, UK-Northern Ireland), drug abuse (Belgium, France, Iceland, Portugal, Sweden, UK-England), HIV (France, Italy, Portugal, UK-England) and alcoholism (France, Iceland, Sweden).

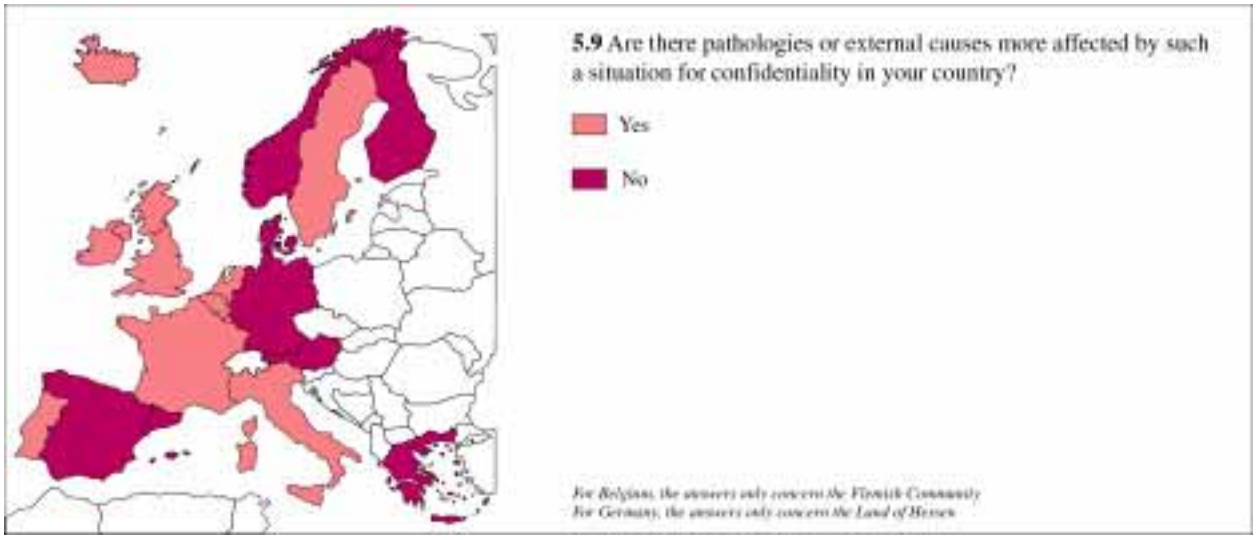


Necessity and feasibility of European recommendations

European recommendations for confidentiality practices are considered 'necessary' by 7 countries (Belgium, France, Ireland, Italy, Portugal, Spain-Catalonia and Sweden) and 'feasible' by 11 countries (the same plus Finland, Iceland, UK-England and UK-Northern Ireland, minus Ireland). The main arguments for harmonization is that level of confidentiality influences the certifier's objectivity and might introduce biases on sensitive causes of death. Europe must find a good balance between the protection of privacy and the use of mortality data for research or other purpose.

The main argument against harmonization is that national practices are too different and changes would be too problematic to implement.

Only 2 experts out of 20 consider that European recommendations on confidentiality practices could be easily applied in their country, 14 think that they could not and the other 4 don't answer because 'it would depend on the final precise contents of the recommendation'.



[1] Since April 2001, Swedish regulation has changed and relatives can no more have access to individual causes of death (they can ask for it from the certifier who keeps a copy of the dearth certificate).

B. DETAILED RESPONSES

NB : All questions concern for Belgium : The Flemish Community and for Germany : The Land of Hessen only

5.1 Is the original death certificate (medical part) destroyed after coding in your country?

Yes	**9 :**	Austria, Belgium, Denmark, France, Ireland, Italy, Spain, UK-Northern Ireland, UK-Scotland
No	**11 :**	Finland, Germany, Greece, Iceland, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-England

Portugal : The original death certificate is kept in the Civil Registration Office, the copy (without names of the deceased or physician) sent to the Statistical Office is kept 2 years and ICD codes are kept always.
Scotland : Yes but later.

5.2 How are the death certificates (medical part) kept after coding in your country?

Original document	**12 :**	Austria, Finland, Germany, Greece, Iceland, Luxembourg, Netherlands, Norway, Portugal, Spain-Catalonia, Sweden, UK-England
Microfilm	**4 :**	Denmark, Ireland, Sweden, UK-Northern Ireland
Digitalized	**8 :**	Denmark, Finland, France, Italy, Luxembourg, Norway, Sweden, UK-England
Other way	**4 :**	Finland, Ireland, UK-England, UK-Scotland

Portugal : The original document but in the Civil Registration Office.
Scotland : All relevant text and codes are kept on a database, a selection of information is kept in an official register.
Finland : Digitalized partly since 1998.

5.3 How are causes of death kept after coding in your country?

Exact words of the physician	**12 :**	Austria, Denmark, Finland, Iceland, Italy, Luxembourg, Netherlands, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
Summarized words of the physician	**1 :**	France
All ICD codes	**13 :**	Belgium, Denmark, Finland, France, Greece, Iceland, Italy, Luxembourg, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
Selection of ICD codes	**1 :**	Norway
Only ICD codes of the underlying cause	**5 :**	Austria, Germany, Ireland, Portugal, Spain

5.4.1 In your country, who can have access to the causes of death of a specific person? (original document) :

ANYONE

Never	**16 :**	Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden
On Approval	**1 :**	UK-England
Always	**3 :**	Ireland, UK-Northern Ireland, UK-Scotland

RELATIVE

Never	**11 :**	Austria, Belgium, Denmark, France, Germany, Greece, Italy, Luxembourg, Netherlands, Spain, Spain-Catalonia
On Approval	**5 :**	Finland, Iceland, Norway, Sweden, Portugal
Always	**4 :**	Ireland, UK-England, UK-Northern Ireland, UK-Scotland

RESEARCHERS

Never	**7 :**	Belgium, Germany, Greece, Italy, Netherlands, Spain, Spain-Catalonia

On Approval	**10 :**	Austria, Denmark, Finland, France, Iceland, Luxembourg, Norway, Portugal, Sweden, UK-England
Always	**3 :**	Ireland, UK-Northern Ireland, UK-Scotland

INSURANCE CIES

Never	**13 :**	Austria, Belgium, France, Germany, Greece, Iceland, Italy, Luxembourg, Netherlands, Norway, Spain, Spain-Catalonia, Sweden
On Approval	**2 :**	Portugal, UK-England
Always	**5 :**	Denmark, Finland, Ireland, UK-Northern Ireland, UK-Scotland

LAW

Never	**8 :**	Austria, Belgium, Germany, Luxembourg, Netherlands, Spain, Spain-Catalonia, Sweden
On Approval	**7 :**	Finland, France, Greece, Iceland, Portugal, Norway, UK-England
Always	**5 :**	Denmark, Ireland, Italy, UK-Northern Ireland, UK-Scotland

Sweden : Relatives on approval ("first-step" relatives only - parent, child, spouse, sibling).

5.4.2 In your country, who can have access to the causes of death of a specific person? (ICD codes) :

ANYONE

Never	**20 :**	Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Iceland, Italy, Luxembourg, Netherlands, Portugal, Norway, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland

RELATIVES

Never	**18 :**	Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
On Approval	**2 :**	Iceland, Norway

RESEARCHERS

Never	**4 :**	Germany, Greece, Netherlands, UK-Northern Ireland
On Approval	**16 :**	Austria, Belgium, Denmark, Finland, France, Iceland, Ireland, Italy, Luxembourg, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Scotland

INSURANCE CIES

Never	**18 :**	Austria, Belgium, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
On Approval	**1 :**	Finland
Always	**1 :**	Denmark

LAW

Never	**14 :**	Austria, Belgium, Germany, Greece, Iceland, Ireland, Luxembourg, Netherlands, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland
On Approval	**5 :**	Finland, France, Italy, Norway, UK-Scotland
Always	**1 :**	Denmark

5.5 Does the approval need a legal/ethical consent?

Yes	**18 :**	Austria, Belgium, Denmark, Finland, France, Greece, Iceland, Ireland, Italy, Luxembourg, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No response	**2 :**	Germany, Netherlands

5.6 Comments :

Finland : Conditions for access are defined by law. Statistics Finland examines the researchers applications.
Belgium : Ethical consent + consent of the commission in charge of the application of the privacy law.
Iceland : Relatives, physicians, the law obtain access for legitimate reasons.
Norway : For research Board of Health + Data protection register; other only Board of Health.
Portugal : By request to the Director of the Civil Registration Office with legitimate and fundamental interest.
Sweden : A written application for a copy of the death certificate is sent to the Board of Health. The applicant must explain why s/he needs the certificate. If it is the certificate of a relative, the applicant must prove (by a specific certificate from the population register) that s/he is a "first step" relative. If the certificates are needed for research, the aim of the project must be explained (only research intended for publication in medical journals is accepted). Physicians and researchers must sign a contract saying that the copies will be destroyed once the project has been completed, that they must not be used for any other purpose, that the relatives of the deceased may not be contacted, and that information on individual cases must never be left to a third party. The applications are examined by the Board of Health who decides from case to case if the applicant can obtain a copy or not. Some particularly sensitive cases (suicides, HIV deaths where the deceased has requested that relatives shall not be informed, etc) are never handed over to relatives.

5.7 Do you think that confidentiality practices in your country improve/deteriorate the quality of causes of death statistics?

Improve	**10 :**	Belgium, Finland, France, Germany, Greece, Iceland, Ireland, Luxembourg, Norway, Portugal
Deteriorate	**3 :**	UK-Northern Ireland, Spain, Sweden
No response	**7 :**	Austria, Denmark, Italy, Netherlands, Spain-Catalonia, UK-England, UK-Scotland

5.8 Why?

Belgium : If physicians know that the certificates are never communicated to police, law, judges, they mention such things as medical errors or decisions (e.g. euthanasia, active stopping...).
Finland : Cause of death must be accessible to researchers/physicians as a way also to motivate them on good certification.
Germany : Improve because the physician is not influenced in his decision but at the same time, there are no possible controls.
Spain : Deteriorate because there are too many constraints for researchers.
Sweden : The relatives' easy access to the certificates might deteriorate quality since physicians know that the relatives will probably see the death certificate, they sometimes avoid reporting stigmatising conditions (alcoholism, drug abuse, HIV...). It has happened that relatives have complained about the certificate and forced the physician to change it.
UK-Northern Ireland : Death certificates can be consulted by anyone, doctors don't always put free cause of death ("unsociable diseases").
UK-Scotland : Open access to register entries (including causes of death) may lead to omissions (e.g. drug related deaths, HIV).

5.9 Are there pathologies or external causes more affected by such a situation for confidentiality in your country?

Yes	**12 :**	Belgium, France, Iceland, Ireland, Italy, Luxembourg, Netherlands, Portugal, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
No	**8 :**	Austria, Denmark, Finland, Germany, Greece, Norway, Spain, Spain-Catalonia

5.10 Can you name them and explain briefly?

France, Belgium, Iceland, Italy, Portugal, Northern Ireland : Suicides.
France, Belgium, Iceland, Portugal, Sweden, UK England : Drug abuse.

France, Iceland, Sweden : Alcohol .
France, Italy, Portugal, Sweden, UK England : HIV.
Belgium : Cause of death with legal investigations .
Italy : Homicide, infectious diseases, mental disorder.
Luxembourg : External causes.

5.11 If confidentiality practices have negative consequences on the quality of causes of death statistics in your country, what would you suggest to improve the situation?

Have made suggestions	**7 :**	Belgium, France, Portugal, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
Have not	**13 :**	Austria, Denmark, Finland, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Spain, Spain-Catalonia

Belgium : To help with the confidentiality constraints in investigations.
Portugal : To improve the situation for research.
UK England : To allow the release of amended causes of death to public health directors, medical researchers, subject to ethical approval.
Scotland : Exclude cause of death from the public registers.
Northern Ireland : Coroners should be external confidential reporting.
Sweden : Give a EU recommendation that the confidentiality of the death certificate must be respected, and that information on the cause of death should be given to the relatives by other means than by a copy of the death certificate.

5.12.1 Independent of the practice in your country, and in your opinion, who should have access to the causes of death of a specific person? (original document) :

ANYONE		
Never	**18 :**	Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, UK-England, UK-Northern Ireland, UK-Scotland
On Approval	**2 :**	Spain-Catalonia, Sweden
RELATIVES		
Never	**13 :**	Austria, Germany, France, Greece, Ireland, Italy, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
On Approval	**7 :**	Belgium, Denmark, Finland, Iceland, Luxembourg, Netherlands, Norway
RESEARCHERS		
Never	**6 :**	Germany, Greece, Ireland, Netherlands, Spain, Spain-Catalonia
On Approval	**13 :**	Austria, Belgium, Denmark, Finland, France, Iceland, Italy, Luxembourg, Norway, Portugal, Sweden, UK-England, UK-Scotland
Always	**1 :**	UK-Northern Ireland
INSURANCE CIES		
Never	**14 :**	Austria, Belgium, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Spain, Spain-Catalonia, Sweden
On Approval	**5 :**	Denmark, Finland, Portugal, UK-England, UK-Scotland
Always	**1 :**	UK-Northern Ireland
LAW		
Never	**9 :**	Austria, Belgium, France, Germany, Ireland, Luxembourg, Netherlands, Spain, Sweden
On Approval	**9 :**	Denmark, Finland, Greece, Iceland, Italy, Norway, Portugal, Spain-Catalonia, UK-England
Always	**2 :**	UK-Northern Ireland, UK-Scotland

In Luxembourg, the judges can always have access, but no other legal people.

5.12.2 Independent of the practice in your country, and in your opinion, who should have access to the causes of death of a specific person? (ICD codes) :

ANYONE

Never	**19 :**	Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Iceland, Italy, Luxembourg, Netherlands, Portugal, Norway, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
On Approval	**1 :**	UK-England

RELATIVES

Never	**16 :**	Austria, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
On Approval	**2 :**	Belgium, Denmark
Always	**1 :**	UK-England
No response	**1 :**	Iceland

RESEARCHERS

Never	**3 :**	Germany, Greece, Netherlands
On Approval	**17 :**	Austria, Belgium, Denmark, Finland, France, Ireland, Iceland, Italy, Luxembourg, Portugal, Norway, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland

INSURANCE CIES

Never	**15 :**	Austria, Belgium, France, Germany, Greece, Ireland, Iceland, Italy, Luxembourg, Netherlands, Portugal, Norway, Spain, Sweden, UK-Northern Ireland
On Approval	**5 :**	Denmark, Finland, Spain-Catalonia, UK-England, UK-Scotland

LAW

Never	**13 :**	Austria, Belgium, Finland, France, Germany, Ireland, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden
On Approval	**5 :**	Denmark, Greece, Italy, UK-England, UK-Northern Ireland
Always	**1 :**	UK-Scotland
No response	**1 :**	Iceland

5.13 Why?

Austria : Individual data should be restricted to researchers.
Belgium : The only exception out of scientific purposes could be relatives who need to prove something about a specific disease (e.g. genetic).
Denmark : There is much to learn from certificates and they should be used more.
Finland : The approval is a good procedure even for non researchers (useful in some cases).
Germany : It is not the role of the Statistical Office to give the cause of death of a specific person.
Sweden : If anyone has access to the certificates, that will probably make the physicians censor what they put down. The same applies to relatives. Physicians should be able to obtain any medical information they need for following up a case via the ordinary routes (requests directed at the appropriate medical unit). In fact, most requests we've had from physicians (not for research) have been people who have been trying to find mistakes committed by other physicians! Researchers need access to the certificates in order to localise the medical records of interesting cases. For their use, the information in the cause-of-death register is often insufficient. Insurance companies : see my comments on "anyone" and "relatives". Law : If the police etc have free access to the certificates, that would make it even more difficult than today for the forensic pathologists to state their true opinion on the certificates.
UK-Northern Ireland : Free as it is now even if there are problems (not too many).

5.14 Independent of the practice in your country, do you think that heavy confidentiality constraints improve/deteriorate the quality of causes of death statistics?

Improve	**12 :**	Belgium, France, Germany, Greece, Iceland, Ireland, Netherlands, Norway, Portugal, Sweden, UK-Northern Ireland,

		UK-Scotland
Deteriorate	**7 :**	Austria, Finland, Italy, Luxembourg, Spain, Spain-Catalonia, UK-England
No response	**1 :**	Denmark

5.15 Why?

Some countries have understood 'heavy' even for researchers so they have answered 'deteriorate' (Italy because the law is very restrictive).
Finland : Multipurpose uses of death certificates improve the quality.
Luxembourg : Deteriorates, it hampers exchanges to complete information.
Portugal : Not too confidential, otherwise people consider that there is a secret and they try to find it.
Spain-Catalonia : Must not handicap the research and queries.
UK-Scotland : Doctors may give a fuller description.

5.16 Confidentiality practices among countries vary widely, do you think that it might be necessary/feasible to have European common recommendations?

NECESSARY

Yes	**7 :**	Belgium, France, Ireland, Italy, Portugal, Spain-Catalonia, Sweden
No	**10 :**	Denmark, Germany, Greece, Iceland, Netherlands, Norway, Spain, UK-England, UK-Northern Ireland, UK-Scotland
No response	**3 :**	Austria, Finland, Luxembourg

FEASIBLE

Yes	**11 :**	Belgium, Finland, France, Iceland, Italy, Luxembourg, Portugal, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland
No	**7 :**	Denmark, Germany, Greece, Ireland, Netherlands, Spain, UK-Scotland
No response	**2 :**	Austria, Norway

5.17 Why?

Finland : Not too detailed recommendations.
Luxembourg: Minimum common standards and stronger national rules.
Portugal : For better comparability but may be difficult (legal and cultural conditions).
Spain : No too many differences.
Spain-Catalonia : All countries must adopt European law about protection of the data.
Scotland : Not practicable.
Sweden : The level of confidentiality probably influences the certifyer's sincerity, so differences in confidentiality might bring about artificial differences in "sensitive" conditions.

5.18 What would you recommend as main common rules for confidentiality?

administrative routines differ between the countries, but it should be stressed that causes of death are confidential information and must not be disclosed to people who are not authorised to have it.
Belgium : 1) Access only for research with approval, never to law or insurances. 2) Professional secrecy cannot be invoked in order not to fill in correctly a death certificate.
Denmark : The only necessary rule is not to be able to pick out the cause of death of a specific person.
Finland : General confidentiality with exceptions described in a law.
Germany : The cause of death of a specific person must remain confidential.
Iceland : Restriction of access by relatives, right of the deceased to privacy.
Norway : 1) Protection of privacy. 2) Legal rules for access to causes of death. 3) Researchers must delete individual information after use.
Portugal : A short circuit from the certification to the coding and deposit.
Spain-Catalonia : To protect intimacy must not be in conflict with the use of mortality data for research or other purpose (good control committee, manual of "good practices" procedures, safe software).
Sweden : See 5.11. It is hard to give detailed recommendations since

UK-Northern Ireland : Double procedure public death certificate + confidential reporting in some cases.

5.19 Do you think that European recommendations on confidentiality practices could be easily applied in your country?

Yes	**2 :**	Iceland, Portugal
No	**14 :**	Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Netherlands, Norway, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland
No response	**4 :**	Austria, Luxembourg, UK-England, UK-Scotland

5.20 Why?

Germany : No, the high value of confidentiality has historical reasons.
Iceland : Has to be as restrictive as current practice.
Luxembourg : Yes, if in accordance with national law and code of ethics, no otherwise.
Spain-Catalonia : Very strict law on statistics, very difficult to change.
Sweden : Sweden has a very long tradition of "administrative open-ness", which means that all documents that have not been formally classified are accessible to the public. However, medical confidentiality also has a strong position, and perhaps the confidentiality of the death certificate would be accepted in view of that.
UK-Northern Ireland : Difficult to change for doctors and coroners.
UK-Scotland : Depends on proposals.

Additional comments on the section :

Belgium : Two meanings with the word confidentiality : 1) the attitude of the cause of death office which does not communicate cause of death to law or insurance people. 2) Confidentiality reasons for the physician to not communicate some sensible pathologies (privacy).

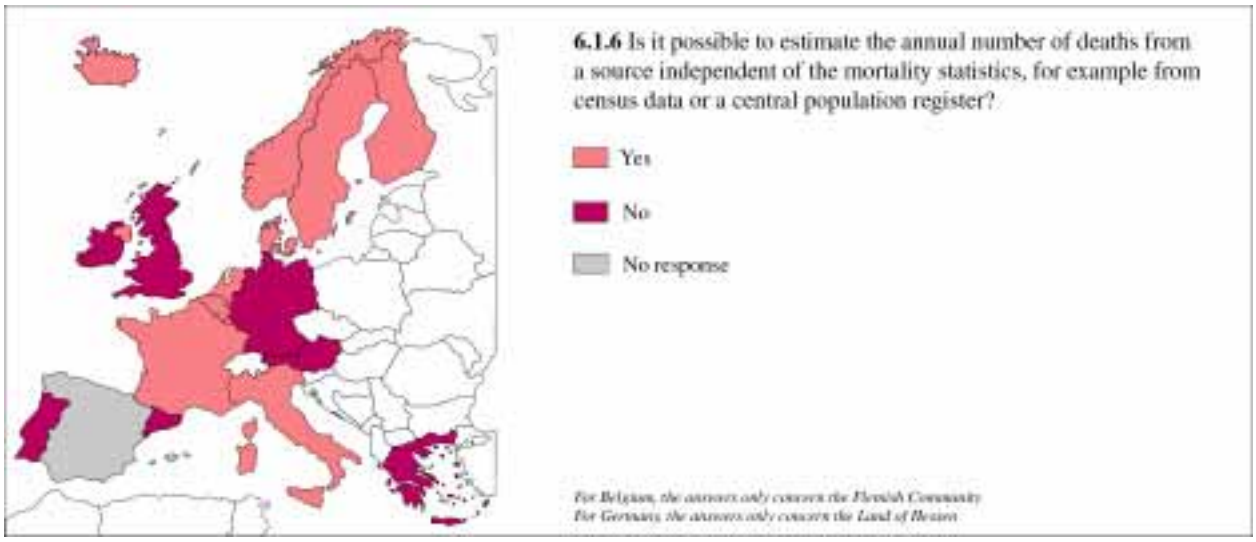
II.2.2.6 COVERAGE AND ILL-DEFINED CONDITIONS

A. GENERAL OVERVIEW

A.1 COVERAGE

Verification of the causes of death statistics with other sources

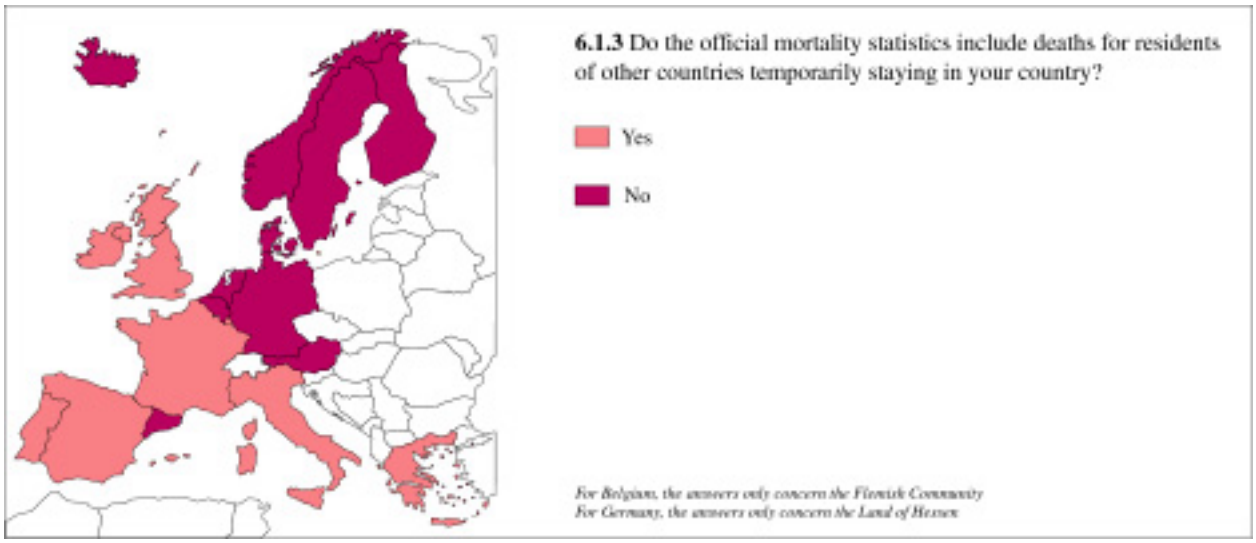
Death certification is mandatory in all European countries but, in some cases, the medical part of the death certificates does not reach the Mortality statistics Office. One way to measure this lack is to compare the deaths counted and analysed by the Statistical Office with another source. In 11 countries out of 20, the five Nordic countries plus Belgium, France, Italy, Luxembourg, Netherlands and UK-Northern Ireland, this procedure exists. The number of deaths registered by the Mortality statistics Offices is compared to a Central/National/General Population Register (usually the organisation where is centralised the administrative part of the death certificates). 9 Countries out of the 11 have given the average annual number of additional deaths they discovered via this verification. The difference is close to zero in Finland. It represents 0,4% to 0,6 % of all deaths (Number of deaths-Eurostat-1994) in 6 countries and more than 1% in two other countries. 7 Countries out of these 11 who can make such comparison include these additional deaths in the final official mortality statistics (Finland, France, Iceland Italy, Luxembourg, Norway and Sweden).



Non-residents deaths and deaths abroad

Practices concerning the registration of non-resident deaths and citizens deaths abroad are far from harmonization within European countries. Regarding citizens dying abroad, only 6 countries (Germany, Netherlands, and the Nordic countries except Denmark) have a procedure to collect the information and include all residents in their statistics. The 14 remaining countries do not include deaths occurring abroad. Concerning deaths of residents of other countries temporarily staying in

the country, there are two types of practices. 10 Countries include these deaths in the mortality statistics and 10 do not, with quite a clear distinction between Northern and Southern practices. The combination of these practices can lead to real problems of double counting or non-counting. For example, a Swedish person who dies in England is included in both the English and Swedish cause-of-death registers, but an Englishman who dies in Sweden is not included in statistics either.



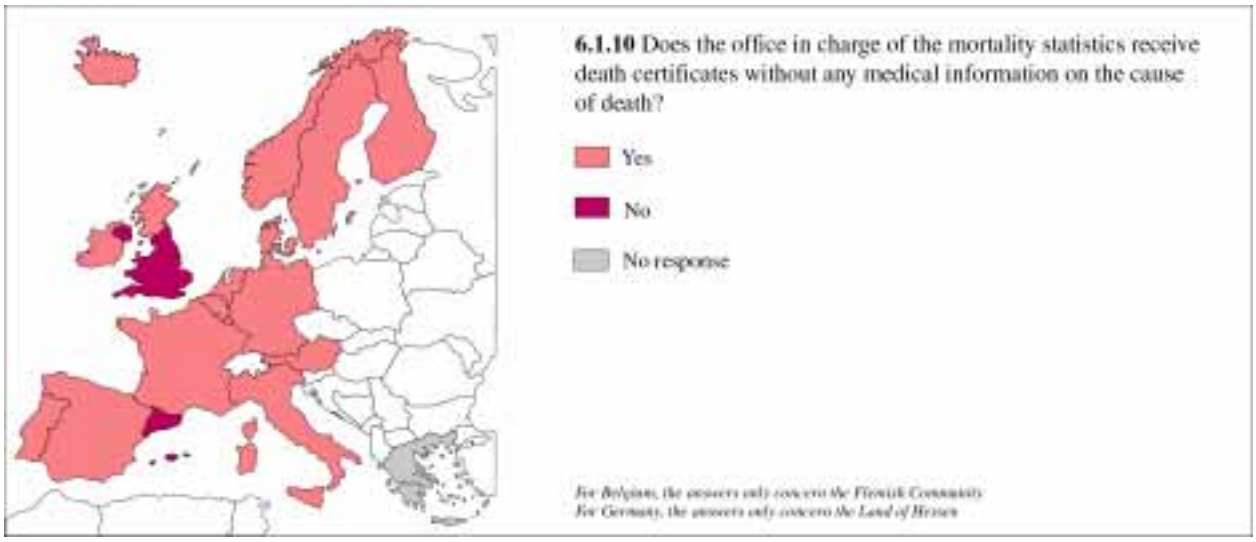
The quantitative impact of such varied practices can be partly measured. For deaths of citizens occurring abroad, only Norway and Sweden have related the information where such deaths represent 0,5% to 0,6% of all deaths (Eurostat-1994). Regarding deaths of residents temporarily staying in another country, the information is available in 6 countries. It represents between 0,3% and 0,4% of all deaths (Eurostat-1994) in 4 countries (UK, France, Italy and Portugal) and more than 0,5% in Greece and Spain.

Certificates without any information on causes of death

In the majority of European countries the statistical offices receive some death certificates without information on the cause of death. The proportion varies from near to zero in Finland to 1% in Germany or France. Thirteen countries consider that this lack of information may introduce biases related to age area of residence, and types of causes-of-death. These biases could specifically affect forensic cases, HIV, and deaths among the elderly, deaths at home or at private nursing homes, violent and sudden deaths, delivery/pregnancy deaths and deaths abroad.

Opinions on coverage and European recommendations

All experts are quite satisfied with the current completeness of their cause-of-death registers, but some



of them (Belgium, France, Luxembourg, Netherlands) highlight problems of quality (high proportion of ill-defined and unknown causes, biases in some ages and diseases groups). The coverage figures vary between 90% and 100% (Finland), but in most cases approach 100%. 8 countries suggested specific European recommendations regarding coverage and completeness. The recommendations most often proposed are i) to implement exchanges of information between countries concerning deaths abroad and to tabulate deaths for non-residents (country of origin, causes), ii) to include co-operation with other medical or administrative registers and closer contact with certifiers, for example via e-mail, iii) to prepare a common set of edits to check the validity of the data, iiii) to develop training of certifiers.

A.2 ILL-DEFINED CONDITIONS

Use of Rule A

For certificates with an ill-defined condition (ICD 9: chapter XVI and ICD 10: chapter XVIII) reported as the underlying cause, the ICD 9 modification rule 5 and the ICD 10 modification rule

A request the coder to re-select the underlying cause as if the ill-defined condition had not been mentioned. 18 countries out of 20 have answered that the office in charge of the mortality statistics always follows this instruction. However, the application of this rule is not uniform. Ireland applies it only for old people and 7 countries apply Rule A to more conditions than those specified by the ICD text (Denmark, France, Ireland, Portugal, Spain, Spain-Catalonia, Sweden). Among additional conditions treated as 'ill-defined' at the coding stage are cardiac arrest, heart failure, hypertension, circulatory failure, respiratory failure, renal failure, and complications of surgery. These conditions are now nearly all included in the revised version of Rule A decided in October 1999 by the WHO Collaborating ICD Centre Heads Meeting when they added cardiac arrest, unspecified hypertension, circulatory failure, acute or unspecified respiratory failure, and respiratory failure in new-born as ill-defined. The majority of the recommendations proposed by European experts regarding ill-defined conditions concerned improvements in training or query practices. Concerning coding, the recommendation suggested by experts is to apply this new version of ICD 10 Rule A.

B. DETAILED RESPONSES

NB : All questions concern for Belgium : The Flemish Community and for Germany : The Land of Hessen only.

6.1 Do the official mortality statistics in your country include residents of your country dying abroad?

Yes	**6 :**	Finland, Germany, Iceland, Netherlands, Norway, Sweden
No	**14 :**	Austria, Belgium, Denmark, France, Greece, Ireland, Italy, Luxembourg, Portugal, Spain, Spain-Catalonia, UK-England, UK-Northern Ireland, UK-Scotland

6.1.2 If yes, what is the average annual number?

Iceland	21 persons
Sweden	551 persons
Norway	250 persons

6.1.3 Do the official mortality statistics include deaths for residents of other countries temporarily staying in your country?

Yes	**10 :**	France, Greece, Ireland, Italy, Luxembourg, Portugal, Spain, UK-England, UK-Northern Ireland, UK-Scotland
No	**10 :**	Austria, Belgium, Denmark, Finland, Germany, Iceland, Netherlands, Norway, Spain-Catalonia, Sweden

6.1.4 If yes, what is the average annual number?

France	1800
Greece	500
Italy	2000
Luxembourg	80
Portugal	380
Spain	2300
UK-England	1500
UK-Northern Ireland	100
UK-Scotland	300

6.1.5 Is death certification mandatory for all deaths in your country?

Yes	**20 :**	All countries

6.1.6 Is it possible to estimate the annual number of deaths from a source independent of the mortality statistics, for example from census data or a central population register?

Yes	**11 :**	Belgium, Denmark, Finland, France, Iceland, Italy, Luxembourg, Netherlands, Norway, Sweden, UK-Northern Ireland
No	**8 :**	Austria, Germany, Greece, Ireland, Portugal, Spain-Catalonia, UK-England, UK-Scotland
No response	**1** :	Spain

6.1.8 Comparing the number of death certificates with the number of deaths according to the independent source of information, what is the approximate annual number of deaths for which the office in charge of the mortality statistics does not receive a medical certificate? (Deaths not recorded by official statistics).

Denmark	250
Finland	23
Iceland	10
Luxembourg	120
Netherlands	2000
Norway	220
Sweden	412
UK-Northern Ireland	150

6.1.9 Are such deaths a) notified to some other authority, but not to the office in charge of the causes of death statistics b) included in the official mortality register?

Yes	**8 :**	Finland, France, Germany, Iceland, Italy, Luxembourg, Norway, Sweden
No	**6 :**	Belgium, Denmark, Greece, Ireland, Netherlands, UK-Northern Ireland
No response	**6 :**	Austria, Portugal, Spain, Spain-Catalonia, UK-England, UK-Scotland

6.1.10 Does the office in charge of the mortality statistics receive death certificates without any medical information on the cause of death?

Yes	**16 :**	Austria, Belgium, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Sweden, UK-Scotland
No	**3 :**	Spain-Catalonia, UK-England, UK-Northern Ireland
No response	**1 :**	Greece

6.1.11 If yes, how many death certificates with no medical information are received each year by the office?

Belgium	52
Denmark	75
Finland	44
France	5300
Germany	10000
Iceland	10
Ireland	100
Luxembourg	120
Netherlands	500
Norway	150
Spain	333
Sweden	267

6.1.12 If the death certificate has no information on the cause of death, is that death still included in the statistics?

Yes	**14 :**	Belgium, Denmark, Finland, France, Germany, Iceland, Ireland, Luxembourg, Netherlands, Norway, Spain, Sweden, UK-Northern Ireland, UK-Scotland
No	**2 :**	Greece, Spain-Catalonia
No response	**4 :**	Austria, Italy, Portugal, UK-England

6.1.13.1 In your opinion, are some deaths typically more affected by lack of information on causes of death than others (e.g.: deaths investigated at a forensic institute, deaths at nursing homes, HIV related deaths...)?

Yes	**13 :**	Belgium, Denmark, Finland, France, Italy, Luxembourg, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland, UK-Scotland
No	**5 :**	Austria, Germany, Greece, Iceland, Netherlands
No response	**2 :**	Ireland, UK-England

6.1.13 2 Please specify:

Austria : Deaths abroad.
Belgium : Forensic cases, HIV, drugs, alcohol, deaths at casualty wards.
Denmark : Elderly people, HIV, forensic cases.
Finland : Deaths abroad, elderly people who die at nursing homes.
France : Deaths explored at a forensic institute.
France : Violent deaths of undetermined intent, specific circulatory diseases due to the number of ill-defined deaths.
Italy : Infectious diseases, skin diseases, respiratory system diseases.
Luxembourg : Sudden deaths at home and notified by physicians of the medical emergency service.
Netherlands : Deaths at nursing homes and old people in general.
Norway : Deaths abroad, fractures of unspecified cause, old age.
Spain : Violent deaths investigated by court of law.
Spain-Catalonia : Elderly people, sudden deaths, delivery/pregnancy deaths.
Sweden : Deaths at nursing homes and at home (private).
UK-Scotland : Very old, HIV, persons found dead.

6.1.14 What is the general assessment of the coverage and completeness of the mortality statistics in your country?

Belgium : Coverage almost 100%, quality of data not always good.
Denmark : 99.6%.
Finland : 99.9%.
France : Almost 100%, but a high proportion of ill-defined and unknown causes.
Germany : Complete.
Iceland : Includes all deaths.
Ireland : Good.
Italy : Satisfactory.
Luxembourg : Very good, if not total of deaths within the country, but serious bias in some age and disease groups (for example children being treated abroad)
Netherlands : More than 90%.
Norway : Near 100%.
Spain-Catalonia : Almost 100% (control by the Civil Register).
UK-England : Thought to be complete - a body cannot be disposed of without the death being registered.
UK-Northern Ireland : Coverage excellent but the quality not always good.
UK-Scotland : 100%.

6.1.15 Which European recommendations regarding coverage and completeness would you propose?

Austria : Co-operation between offices on deaths among non-residents: exchange of death certificates, or at least of information.
Belgium : Register studies, for example MONICA, other special medical registers, population offices, instructions to embassies and legations on the handling of deaths abroad.
Finland : Base certificate on information from autopsy, if performed, certificate should be issued by the physician in attendance, if possible. Close contact with certifiers, for example via email. Forward information on deaths abroad to the country of residence.
France : Exchanges between countries of information concerning deaths abroad, preparation a common set of edits to check the validity of the data.

Spain-Catalonia : Certificates for non-residents should be sent to the country of residence, common death certificate form. Tabulate deaths for non-residents (country of origin, causes).
Sweden : A recommendation as to the statistics ought to reflect deaths within a given year, or reported within a given year; also recommendations on how to handle non-residents transfer of information between countries, both vital events and causes of death.
UK-Northern Ireland : Certifying doctors will have to be educated in how to complete death certificates properly.

6.2 ILL-DEFINED OR OTHERWISE UNSATISFACTORY UNDERLYING CAUSE OF DEATH

6.2.1 For certificates with an ill-defined condition (ICD 9: chapter XVI and ICD 10: chapter XVIII) reported as the underlying cause, the ICD 9 modification rule 5 and the ICD 10 modification rule A request the coder to re-select the underlying cause as if the ill-defined condition had not been mentioned. Does the office in charge of the mortality statistics always follow this instruction?

Yes	**18 :**	Austria, Belgium, Denmark, Finland, France, Germany, Iceland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Spain-Catalonia, Sweden, UK-England, UK-Northern Ireland, UK-Scotland
Yes for old people	**1 :**	Ireland
No	**1 :**	Greece

6.2.2 Are there conditions <u>not</u> in ICD 9: chapter XVI or ICD 10: chapter XVIII that your office would consider likewise as ill-defined? (Other Conditions Cause of Death Ill-defined)

Yes	**10 :**	Belgium, Denmark, Finland, France, Iceland, Ireland, Portugal, Spain, Spain-Catalonia, Sweden
No	**8 :**	Austria, Greece, Italy, Luxembourg, Norway, UK-England, UK-Northern Ireland, UK-Scotland
No response	**2 :**	Germany, Netherlands

6.2.3 If yes, please specify:

Belgium : Cardiac arrest, cardio-respiratory arrest, heart failure, renal failure.
Denmark : Cardiac arrest.
Finland : Complications of medical procedures, "secondary" conditions, pulmonary embolism, acute renal failure etc.
France : Cardiac arrest.
Iceland : Dementia NOS.
Ireland : [conditions queried:] Hemiplegia, rheumatic heart disease NOS, pulmonary oedema and embolism, septicaemia, neoplasm of unspecified site and behaviour, immobility, gangrene, meningitis NOS.
Spain & Spain-Catalonia: Cardiac arrest.
Sweden : According to the new WHO recommendation: cardiac arrest, hypertension, circulatory insufficiency, acute or unspecified respiratory failure.

6.2.4 Do the coders in your country apply modification rules 5/A to these conditions as well? (Five A rule application)

Yes	**7 :**	Denmark, France, Ireland, Portugal, Spain, Spain-Catalonia, Sweden
No	**7 :**	Belgium, Finland, Germany, Greece, Iceland, UK-Northern Ireland, UK-Scotland
No response	**6 :**	Austria, Italy, Luxembourg, Netherlands, Norway, UK-England

6.2.5 If the reported underlying cause of death is ill-defined or otherwise unsatisfactory, will the coders try to obtain further information?

Yes	**13 :**	Belgium, Denmark, Finland, France, Germany, Iceland, Italy, Luxembourg, Norway, Spain,

		Spain-Catalonia, Sweden, UK-Northern Ireland
No	**6 :**	Austria, Greece, Ireland, Portugal, UK-England, UK-Scotland
No response	**1 :**	Netherlands

6.2.6 In your opinion, what is the general impact of certificates with ill-defined or otherwise unsatisfactory causes of death on the mortality statistics in your country?

Yes (replied)	**13 :**	Belgium, Denmark, Finland, France, Germany, Iceland, Italy, Luxembourg, Norway, Spain, Spain-Catalonia, Sweden, UK-Northern Ireland
No response	**7 :**	Austria, Greece, Ireland, Netherlands, Portugal, UK-England, UK-Scotland,

6.2.7 Which European recommendations regarding ill-defined causes of death or otherwise unsatisfactory causes of death would you propose?

Belgium : Identification of the physician to facilitate queries.
Denmark : Always query them.
Finland, Luxembourg : A common list of ill-defined conditions.
France : Definition of some categories to query, distinguish between ill-defined due to bad certification and ill-defined after proper investigation. Do not accept certificates without stated cause of death. Full confidentiality of the death certificate. More training for physicians. To add a tick box to the certificate about these investigations.
Norway : Queries.
Spain : Make the impact of poorly completed certificates clear to the doctors.
Spain-Catalonia : Design querying programmes and training. Register studies of multiple causes.
Sweden : To apply the new ICD recommendations, approved by the Heads of Centres meeting in Cardiff, 1999.
UK-Northern Ireland : Refer back to doctors.

II.3 RECOMMENDATIONS

The recommendations, which total 39, concern the different stages of death certification. They are classified under 8 items which aim to follow the certification process:

1- Coverage
2- Confidentiality
3- Organisation of the Causes of Death Statistics Offices
4- Infant causes of death certification
5- General causes of death certification
6- Query practices
7- Training practices
8- European collection of mortality statistics

The recommendations are based on the results of the questionnaire (Part 1) and on the discussions in two specific meetings: a Steering group meeting in Lisbon (April 2000) and a Plenary Group meeting in Barcelona (November 2000).
These recommendations consist of scientific guidelines. They have been proposed by experts who have a legitimate scientific point of view on causes of death statistics but who do not act as the official representative of their country. They are naturally thought of within the context of European countries varied situations but they do not take in account all administrative and political constraints. An exact study of the different levels of feasibility of these recommendations would be a future stage of work.

II.3.1 METHODOLOGY

The recommendations were first discussed at the Steering Group meeting in Lisbon (27-28 April 2000). Each one of the six sections of the questionnaire Part 1 (General death certificate, infant death certificate, training practices, query practices, confidentiality practices and coverage & ill-defined conditions) was the subject of a working sequence comprising: a presentation of the main results of the questionnaire, the recommendations proposed by the co-ordination team based on analysis of the results, and a discussion which had as it's major objective preparing the final recommendations to be proposed to the Plenary Group in Barcelona. After the meeting, the minutes gave a resumé of the discussions (participants could amend if they found necessary).

Three working groups in Barcelona

The second step of the work on recommendations was undertaken within the second Plenary Group meeting (Barcelona, 16 and 17 November 2000). During this last meeting on the project, the organisation was based on working in small groups because it appeared the best way to achieve the main objective of the two days: to reach a consensus on the definitive wording for the recommendations to be presented in the final report.
The six items from questionnaire Part 1 were divided into three groups: 1. General and infant death certificates, 2. Query practices and Coverage & ill-defined conditions, 3. Training practices and confidentiality practices. Each group included 7 or 8 participants selected upon geographical criteria with a selection of Steering Group experts. Two reporters in each group, one from the co-ordination team and one from the Steering Group, were in charge of the session and of the reporting to the Plenary Group. The participants had received the working documents related to their group one month before the meeting. These documents included the proposed text of the recommendations, the comments of the Steering Group and the results of the questionnaire related to the recommendation.

The 39 recommendations proposed to the European Commission

The Plenary Group agreed generally with the propositions of the 3 groups. Some of the recommendations were discussed again and re-worded, mainly for confidentiality and coverage

where national habits are fairly different. Finally, 39 definitively worded recommendation were adopted.
After the meeting, the recommendations were reorganised in a more logical order according to 8 items (a suggestion of the Plenary group). They were sent back to all participants of the network for possible amendments. 7 experts sent corrections that were included, or were the subject of further discussion.

PARTICIPANTS TO THE GROUPS

***Group 1* General and infant death certificates**

Susan Cole	UK Scotland
Finn Gjertsen	Norway
Peter Hooft	Belgium
Gloria Perez	Spain-Catalonia
Christiane Rosenow	Germany
Florence Rossollin	France
Mady Roulleaux	Luxembourg
Chara Zikou	Greece

Reporters: Susan Cole, Florence Rossollin

***Group 2* Query practices / Coverage and ill-defined conditions**

Renzo Asciak	Malta
Judite Catarino	Portugal
Mary Heanue	Ireland
Lars Johansson	Sweden
Antoine Niyonsenga	France
Gérard Pavillon	France
Giselle Renaud	France

Reporters: Lars Johansson, Gérard Pavillon

***Group 3* Training practices / Confidentiality practices**

Eric Jougla	France
Cleone Rooney	UK England
Gloria Perez (second part)	Spain Catalonia
Jacques Bonte	EU Eurostat
Richard Gisser	Austria
Sylvia Bruzzone	Italy
Hilkka Ahonen	Finland
Tanya Vandepoorter	France

Reporters: Cleo Rooney, Eric Jougla

II.3.2 CONTENTS OF THE RECOMMENDATIONS

Recommendation 0 (from the co-ordination team)

The information collected for this report and the recommendations settled on by the experts network needs to be updated and followed-up.

COVERAGE

Recommendation 1

Death count should be as complete as possible. Comparing the mortality files to other registers, such as population registers and registers on specific conditions may be very useful in this process.

Recommendation 2

Each European country should publish data on all deaths occurring in their country, but keep residents and non-residents apart when publishing and analysing this (to avoid double counting in Europe).

Recommendation 3

Each European country should forward copies of death certificates (or information) for non-residents to the Causes of Death Statistics Office in the country of residence of the deceased.

CONFIDENTIALITY

Principle

Understanding that the basic principle for confidentiality of Causes of Death data is to obtain the highest quality of information whilst protecting / respecting the deceased, his or her family and the certifying authority. This principle should be applied following the existing guidelines on statistical data in general and on Causes of Death data in particular.

Recommendation 4

Identifiable Causes of Death data should not be used for general administrative purposes (i.e. insurance, personal interest matters…) unless this is required by legislation and subsequently specifically requested.

Recommendation 5

Any change in privacy or data protection should avoid the possible adverse consequences on Causes of Death statistics and medical research.

Recommendation 6

It is essential that the implications of confidentiality regulations be properly understood. Thus the above principle should be respected whenever appropriate during the training of physicians or when communicating with lawyers, researchers and public.

Recommendation 7

Any use of identifiable data other than that for statistical purposes, including public health and medical research, is not the responsibility of the statistical bodies and therefore should not be subject to discussion in the framework of statistical issues. However, under certain conditions for research purposes, individual causes of death data could be used, following existing national rules and regulations.

Recommendation 8

Further investigation into the use of national rules and regulations of individual causes of death data for research purposes in European countries is recommended. This could lead to a list of best practices, aiming at the 'step-wise' improvement of common practices in European countries.

ORGANISATION OF CAUSES OF DEATH STATISTICS OFFICES

Recommendation 9

Each European country's Causes of Death Statistics Office should have close links with the Ministry or Department of Health.

Recommendation 10

Each European country's Causes of Death Statistics Office should have access to statistical, epidemiological and clinical advice either by having this expertise among its staff, or by their having easy access to it.

INFANT CAUSES OF DEATH CERTIFICATION

Preamble

The perinatal death certificate recommended by the WHO has been adopted by only a few European countries. Among the reasons for this non-application, the difficulty to select a sole underlying cause of death and thus include these deaths in routine cause of death statistics, is the most important.

Recommendation 11

The European Commission should facilitate consultations with the WHO concerning the perinatal death certificate.

Recommendation 12

Consideration should be given on ways to encourage the correlation / linkage of detailed birth information to infant deaths. Should that prove impractical, the standard death certificate should be extended to include a single cause of maternal morbidity (if any), relevant to the infant death.

Recommendation 13

Analysis of infant mortality is enhanced by additional data from events around the time of birth (ie.; birth weight, apgar score, single/multiple birth, delivery complications). To put these into context, both numerator (deaths) and denominator (births) should be used, and include the same additional variables.

Recommendation 14

Three main additional elements, relevant to the analysis of infant deaths, to be collected should be: birth weight, gestation and plurality.

GENERAL CAUSES OF DEATH CERTIFICATION

Recommendation 15

Each European country must use the 'International Form of Medical Certification of Cause of Death' with 4 lines (WHO Revision Conference 1989). Each European country should also apply the WHO rules, guidelines and regulations for selection of the underlying cause of death.

Recommendation 16

The basic additional information to be collected on the death certificate is:
– place of death; (home, hospital, nursing home etc.)
– place of accident;
– pregnancy state;
– country of usual residence;
– citizenship.

Recommendation 17

For the purpose of violent causes of death statistics, the definition of epidemiological criteria should be harmonised so that it is made clear whether the death is due to suicide, homicide, accident or could not be determined after investigation.

Recommendation 18

Information on autopsies should be recorded on death certificates, including:
– was an autopsy carried out?
– was it a legal or medical autopsy?
– has the result been used in certification?
– is an autopsy still on-going?

Recommendation 19

Information on other investigations should be recorded on death certificates, including:
– were specific investigations carried out to help in the certification of cause of death?
– are specific investigations still on-going?
If the answers to the above are 'yes', the certifyer should specify.

Recommendation 20

In case of legal inquest,
– the Causes of Death Statistics Office must be informed if there is an inquest (provisional death certificate);
– the Causes of Death Statistics Office could use a provisional cause of death before the final cause of death;
– the persons (or institutions) who state the final cause of death must transmit the information to the Causes of Death Statistics Office;
– the Causes of Death Statistics Office must ask for the final cause of death;
– the Causes of Death Statistics Office must include the final cause of death in statistics.

Recommendation 21

Causes of Death Statistics Offices should notify the Eurostat office of any change in their national death certificate when submitting annual data.

Recommendation 22

The development of electronic certification should be supported.

QUERY PRACTICES

Recommendation 23

Queries should be technically feasible. Therefore, the certifier should be identifiable by the Statistics Offices and the deceased should at least be identifiable by the certifier directly or indirectly. It may be useful to identify another physician to whom queries may be addressed (general practitioner, senior hospital consultant etc).

Recommendation 24

The certifier should be queried when the underlying cause of death selected by applying ICD 10 selection rules is an ill-defined condition according to the new ICD10 modification rule A.

Recommendation 25

A common list of certification problems for European countries to query in priority should be developed: pathologies and situations (unknown and ill-defined causes, inconsistent and incomplete sequences).

Recommendation 26

In case of an age limit to query, this age limit should be 80 years old.

Recommendation 27

To improve the quality of Causes of Death statistics, the delay between the death and the query should be as short as possible.

Recommendation 28

Changes as a result of late or further information (either spontaneous or in response to queries) should be included in final statistics.

Recommendation 29

Publication of information on query practices (number, % of useful answers, average delay etc.) in official European Causes of Death statistics, should be developed.

TRAINING PRACTICES

Recommendation 30

Basic training in death certification for medical students as well as continuous professional development for practising physicians should be developed.

Recommendation 31

Basic certification training should be:
– taught at the end of clinical training;
– integrated into appropriate courses in public health or epidemiology - if taught in legal medicine, emphasis on WHO guidelines and definitions is essential;
– the contents of the course and exams should be prepared by Causes of Death Statistics Offices in collaboration with university teachers.

Recommendation 32

Causes of Death Statistics Offices should, through collaborative effort, investigate the opportunities for continuous professional training for physicians, and integrate death certification as a training module (in many countries vocational training/continuous professional training is an obligation for physicians).

Recommendation 33

The creation of a basic training course package should be developed as reference on certification (sequence, underlying causes etc.) for specific national training purposes on Causes of Death certification, and be adapted by each European country.

Recommendation 34

To encourage awareness of the medical profession and improve certification, a common model or leaflet for inclusion in national training packages and campaigns should be developed. The main contents should be common and each country will adapt the final redaction and form to it's own context. The document has to be short, freely available and easily copied (e.g. small plastic card, filofax). Certification must be explained with text and examples of case histories of 4/5 lines. These case histories have to be prepared with hospital practitioners. The Causes of Death Statistics Offices should find specific opportunities to disseminate the document.

Recommendation 35

The creation of a common website on Causes of Death certification should be developed within existing networks of Eurostat and WHO (to be adapted by each European country).

Recommendation 36

Causes of Death Statistics Offices should take advantage of opportunities for informing doctors on death certification via: queries, medical and public health journals, conferences and congresses for physicians.

The follow-up of these recommendations on certification training needs to be organised (capacity and authority) with a possible responsibility of Ministries of Health and delegation to the Causes of death Statistics Offices.

EUROPEAN COLLECTION OF MORTALITY STATISTICS

Recommendation 37

European countries should implement WHO ICD10 updates. They should be applied by the beginning of a new data year and be subjected to tests on their impact on statistics.

Recommendation 38

European countries must supply individual data to Eurostat. The record should contain information on citizenship, usual country of residence and country of death.

Recommendation 39

Eurostat should publish quality indicators for Causes of Death data, which could include at a national level : autopsy rate, query rate, unknown cause of death rate (investigated by a query/not investigated) and missing forms.

III. KNOWLEDGE BASE ON THE 65 CAUSES OF DEATH (EUROSTAT SHORT LIST)

This section of the report on the 'Knowledge base on the 65 causes of death' comprises two parts: a published studies database and an analysis on specific causes of death. The published studies database is the result of an international literature review of studies published on the quality and comparability of causes of death statistics since the eighties. The analysis on specific causes of death consists of an overview of four groups of pathologies; suicide and events of undetermined intent, cardiovascular diseases, pulmonary diseases (including larynx/trachea/bronchus/lung cancers), and malignant neoplasm of breast.

III.1 PUBLISHED STUDIES DATABASE

To improve the quality and comparability of European causes of death statistics, the first priority was to make an inventory of the international knowledge available on this item. This had not previously been achieved apart from a literature review undertaken by the National Center for Health Statistics–NCHS (USA) in which papers had been selected and annotated (Annotated Bibliography of cause-of-death validation studies: 1958-1980). This particular literature review gave us an important amount information but the articles analysed were not recent.

With a total of 943 articles ranged according to the Eurostat short list of 65 causes of death (+ general studies not focused on a specific pathology), the database is an important production of the project. It provides a large source of information for the European Commission and researchers. It must also be considered as a basic material for future projects and analysis.

III.1.1 METHODOLOGY

The methodology has been divided in three main steps:
- the interrogation of the bibliographic databases
- the selection of the articles
- the organisation of the database.

Interrogation of the bibliographic databases

Two bibliographic databases have been considered: Medline and Embase. Medline has been interrogated on line from year 1985 to year 1990. Embase has been interrogated using a CD-ROM from years 1988 to 1998 (an additional French bibliographic database 'Pascal' was also interrogated at the end of the process).

The procedure of interrogation followed successive steps using the existence of specific key words in the project title, the summaries, and the bibliographic databases own descriptors.
The initial step was to accept papers for which the titles incorporated the words 'mortality' or 'death(s)' . These were linked with one (or more) of the following words: 'classification', 'coding' ('codification', 'codifying', 'codified'), 'certificate's ('certification', 'certifying'), 'notification', 'registration', 'reporting', 'underreporting', 'underlying', 'recording', 'bias(es)', 'accuracy', 'reliability', 'comparability'.
The second step was to accept the papers for which the word 'mortality' or 'death(s)' was present in the title and linked with one of the aforementioned words in the summary.
After these two steps the interrogation used the Medline and Embase descriptors. The articles accepted were classified by the following descriptors: 'death', 'cause of death', 'death certificates', 'mortality'. The article was chosen when one of the above words featured in either the title or summary.
These interrogations at this step permitted us to select nearly 2000 papers that then needed to be overviewed and submitted to a process of re-selection.

Overview and final selection of the studies

For each article, the summary was printed and reviewed by the project leader. The following process of elimination rejected more than one paper out of two because they were not strictly adapted to the aim of the project.

Some other reasons led to the exclusion of certain papers, even if they were focused on the quality or comparability of mortality statistics ; the nature of the editor, the country of the study or the language. The only articles accepted (with a few exceptions) were:

– papers published in scientific revues which had been subjected to a 'Reading committee' who controlled the scientific value of the study;

– studies undertaken in developed countries (the problems in developing countries are not at the same level, e.g. the absence of Civil Registry etc.);

– papers published in English and French.

Other articles have added to the ones selected by this process. These were articles from a previous study undertaken by the project leader and others ordered by the researchers while analysing the specific causes of death.

Organisation of the data base

After this final overview, the task was to put the papers in order. As an important research Centre, CépiDc INSERM receives the most important international revues concerning public health. This made it possible to make direct copies of half of the papers selected. The other half was ordered by the specialised French Institute (INIST – Institute de l'information scientifique et technique; http://www.inist.fr).

The articles were then arranged according to the Eurostat short list of 65 causes of death. This grouping consisted of the identification of the diseases investigated, and the possible link between one or more papers. Each study was grouped with the scientist's reactions if any existed (comments, letters...).

The database was presented in three ways; files, tables and a bibliography.

The files are the material classification of the articles. For each pathology there is a file where the studies are stored with two copies of the article and the bibliography data base notes and summary when available.

The tables (presented in the following section) consist of an index arranged by cause of death under which the main information concerning that study can be found ; a bibliographic data base number, and a pathology number, title, author, revue, year of publication, country (where the study has been done), language, relation (comment, letter...). An identification number given by the co-ordination team enables us to easily locate any article when needed.

The bibliography follows the classic way of presentation for scientific international revues. As for the files and the tables, the scientific bibliography is listed by pathology.

Example of the bibliography (edited in total in Annexes)

INFECTIOUS AND PARASITIC DISEASES Eurostat shortlist n° 01

Gideon NM, Mannino DM. Sarcoidosis mortality in the United States, 1979-1991:an analysis of multiple-cause mortality data. The American Journal of Medicine 1996;100(4):423-27.

MacDorman MF, Hoyert DL, Rosenberg HM. Cause-of-death categories. (comment on:Read JS;1997). American Journal of Public Health 1997;87(12):2054-55.

Perkins BA, Flood JM, Danila R, et al. Unexplained deaths due to possibly infectious causes in the United States:defining the problem and designing surveillance and laboratory approaches. Emerging Infectious diseases 1996;2(1):47-53.

Read JS, Troendle JF, Klebanoff MA. Infectious disease mortality among infants in the United States, 1983 through 1987. (see comment:MacDorman;1997). American Journal of Public Health 1997;87(2):192-98.

White MC. Mortality associated with nosocomial infections:analysis of multiple cause-of-death data. J Clin Epidemiol 1993; 46(1):95-100.

The tables and the bibliography are available for the studies on specific pathologies. The general studies not attributed to a specific cause of death are stored on file but not listed in detail.

III.1.2 CONTENTS OF THE DATA BASE

In this section are analysed and listed the 532 papers attributed to specific causes of death. First a brief analysis describes the distribution of the articles by country and pathology. Then the papers are presented in tables arranged by cause of death according to the Eurostat short list.

III.1.2.1 GENERAL FEATURES

The over representation of English speaking countries

Out of the 532 papers attributed to specific causes of death, 221 concern European countries, 274 concern other developped countries and 37 are international studies.

The representation of European countries is altered because of language differences (only articles in English and French have been kept). The UK published 122 papers but naturally it is over-represented because a major part of scientific revues only accept studies written in English. As the co-ordination team also accepted articles in French, France is over-represented with 25 papers. In contrast, countries speaking languages other than English or French are under-represented (i.e. Germany had 40 articles published in German, and Spain 26 articles published in Spanish).

Apart from the UK, two countries have published more than ten articles in English: Sweden and Italy (14 papers).

Within the 274 articles concerning countries outside Europe, most are from the USA (225) and ranking second is Australia with 23 papers. International studies are rare. We found 37, and 13 of these concerned European countries.

Table 1 **Studies by country**

European Union and EFTA Member States	**221**
UK	122
France *	25
Sweden	14
Italy	14
Ireland	9
Belgium	8
Finland	7
Denmark	7
Netherlands	4
Germany*	4
Other MS	7
Other countries	**274**
USA	225
Australia	23
New-Zealand	10
Canada	8
Japan	6
Other	2
International Studies	**37**
Nordic countries	3
European countries	13
Other international	22
General total	**532**

* Only articles in English and French have been kept. This explains why there is a higher representation of English and French speaking countries. Opposingly, countries speaking languages other than English or French are under represented

'Conditions originating in the perinatal period', neoplasms and suicide: the three causes of death the most studied

According to the Eurostat short list of 65 causes of death, the pathologies in which most studies concentrate on the quality and comparability of statistics are: 'certain conditions

originating in the perinatal period', neoplasms and suicide. These three causes of death total 187 papers out of the 532 affected to specific pathologies.
A second group of 6 causes of death totals between 20 and 30 articles each; asthma, AIDS, ischaemic heart diseases, alcohol abuse, diseases of the circulatory system and accidents.
A third group is constituted of 8 other causes of death (between 10 and 20 articles) : complications of pregnancy-childbirth, external causes of injury and poisoning, diabetes, cerebrovascular diseases, mental disorders, sudden infant death, diseases of the nervous system and drug dependence.
26 causes of death have less than 10 papers, and for 22 we did not find any specific study published.

Table 2. **Studies by Cause of Death** (Eurostat Short List)

Nr	Disease or External Cause	Number of Articles	
01	**Infectious and parasitic diseases**	5	
02	Tuberculosis	5	
03	Meningococcal infection	/	
04	AIDS (HIV-disease)	27	
05	Viral Heptitis	/	
06	**Neoplasms**	58	
07	Malignant neoplasms	/	
08	of which Malignant neoplasm of lip, oral cavity, pharynx	/	
09	of which Malignant neoplasm of oesophagus	/	
10	of which Malignant neoplasm of stomach	/	
11	of which Malignant neoplasm of colon	3 (1)	
12	of which Malignant neoplasm of rectum and anus	1	
13	of which Malignant neoplasm liver and the intrahepatic bile ducts	1	
14	of which Malignant neoplasm of pancreas	/	
15	of which Malignant neoplasm of larynx and trachea/bronchus/lung	7	
16	of which Malignant melanoma of skin	1	
17	of which Malignant neoplasm of breast	6	
18	of which Malignant neoplasm of cervix uterus	1	)
19	of which Malignant neoplasm of other parts of uterus	1	)same article
20	of which Malignant neoplasm of ovary	1	)
21	of which Malignant neoplasm of prostate	/	
22	of which Malignant neoplasm of kidney	/	
23	of which Malignant neoplasm of bladder	4	
24	of which Malignant neoplasm of lymph./haematopoietic tissue	2	
25	**Diseases of the blood (-forming organs), immunol.disorders**	/	
26	**Endocrine, nutritional and metabolic diseases**	1	
27	Diabetes mellitus	17	
28	**Mental and behavioural disorders**	13	
29	Alcohol abuse (including alcoholic psychosis)	25	
30	Drug dependence, toxicomania	11	
31	**Diseases of the nervous system and the sense organs**	12	
32	Meningitis (other than 03)	/	
33	**Diseases of the circulatory system**	21	
34	Ischaemic heart diseases	27	
35	Other heart diseases	/	
36	Cerebrovascular diseases	16	
37	**Diseases of the respiratory system**	9	
38	Influenza	/	
39	Pneumonia	1	
40	Chronic lower respiratory diseases	/	
41	of which asthma	28	
42	**Diseases of the digestive system**	2	
43	Ulcer of stomach, duodenum and jejunum	/	
44	Chronic liver disease	2	
45	**Diseases of the skin and subcutaneous tissue**	/	
46	**Diseases of the musculoskeletal system/connective tissue**	/	
47	Rheumatoid arthritis and osteoarthrosis	6	
48	**Diseases of the genitourinary system**	2	
49	Diseases of kidney and ureter	/	
50	**Complications of pregnancy, childbirth and puerperium**	19	
51	Certain conditions originating in the perinatal period	76	
52	Congenital malformations and chromosomal abnormalities	1	
53	Congenital malformations of the nervous sytem	/	
54	Congenital malformations of the circulatory system	/	
55	Symptoms, signs, abnormal findings, ill-defined causes	5	
56	Sudden infant death syndrome	13	

57	Unknown and unspecified causes	1
58	External causes of injury and poisoning	19
59	Accidents	20
60	of which Transport accidents	4
61	of which Accidental falls	1
62	of which Accidental poisoning	/
63	Suicide and intentional self-harm	53
64	Homicide, assault	4
65	Events of undetermined intent	/
66	All causes	411
TOTAL		943

III.1.2.2 TABLES OF THE ARTICLES ACCORDING TO THE 65 CAUSES OF DEATH (EUROSTAT SHORT LIST)

This section presents the tables listing the 532 articles on the quality and comparability of mortality statistics attributed to specific causes of death (excluding the general articles on the item). They are arranged from cause of death 1 to cause of death 65 (Eurostat short list). When there is no article according to the pathology, the name and number of the cause of death is indicated with the mention: 'no article'.

Key grid permitting to understand the following tables

This keygrid permits to understand the information collected for each paper.

N°	INSERM reference *; when there are two numbers with : a/…
Base Nr	Number of Embase or Medline / if no number : other sources
Base	Base 1 : Medline – 2 : Embase – if no number : other sources
Path.	Number of the cause of death in the Eurostat shortlist
Title	Title of the article
Journal	Journal in which the article appeared **
Year	Year in which the article appeared
Author	First author of the article
Country	Country to which the study refers
Lg	Language 1 : English – 2: French
Pages	Page numbers concerned
Relation	CM : xxxx comment pertaining to this article with its INSERM reference number CM on xxxx = this is a comment on the article with its INSERM reference number

* Numbers
1 to 999 : articles selected from the two data bases
1000 to 1999 : articles found from another study
2000 to 2999 : comments or letters ordered later / articles from other sources
3000 : additional articles asked for by authors

** (abbreviations)

INFECTIOUS AND PARASITIC DISEASES – Eurostat shortlist n° 01

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
437	96194604	1	1	Sarcoidosis mortality in the United States, 1979-1991: an analysis of multiple-cause mortality d	American J of Medicine	1996	Gideon NM	USA	1	423-27	
22	98093333	1	1	Cause-of-death categories	American J of Public Health	1997	MacDorman MF	USA	1	2054-55	CM on 371
401	97064069	1	1	Unexplained deaths due to possibly infectious causes in the United States: defining the problen	Emerging Infectious Diseases	1996	Perkins BA	USA	1	47-53	
371	97226116	1	1	Infectious disease mortality among infants in the United States, 1983 through 1987	American J of Public Health	1997	Read JS	USA	1	192-98	CM : 22
154	93163821	1	1	Mortality associated with nosocomial infections: analysis of multiple cause-of-death data	J Clin Epidemiol	1993	White MC	USA	1	95-100	

TUBERCULOSIS-Eurostat shortlist n° 02

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
3035			2	Trends in mortality from tuberculosis in England and Wales: effect of age on deaths from non-r	Thorax	1995	Doherty MJ	UK	1	976-79	
26	97374103	1	2	Tuberculosis mortality-deaths with, rather than from tuberculosis ?	Irish Medical Journal	1997	McKeown PJ	Ireland	1	17	
3030			2	The impact of comorbidity on mortality follwing in-hospital diagnosis of tuberculosis	Chest	1998	Rao VK	USA	1	1244-52	
433	96219058	1	2	Tuberculosis surveillance using death certificate data, New York City, 1992	Public Health Reports	1996	Washko RM	USA	1	251-55	
426	96268017	1	2	Tuberculosis mortality associated with AIDS and drug or alcohol abuse: analysis of multiple cau	Public Health	1996	White MC	USA	1	185-89	

MENINGOCOCCAL INFECTION - Eurostat shortlist n° 03 (no article)

AIDS (HIV - DISEASE) - Eurostat shortlist n° 04

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1001	93006436		4	Impact of HIV infection on mortality in young men in a London health authority	BMJ	1992	Aldous J	UK	1	219-21	CM : 1024-1054-1057
457	96139644	1	4	Completeness of AIDS reporting and quality of AIDS death certification in Tuscany (Italy) : a lin	European J of Epidemiology	1995	Barchielli A	Italy	1	513-17	
2133	94338617	1	4	Specificity of the World Health Organization clinic AIDS case definition	AIDS	1994	Borgdorff M	Inter-OMS	1	714	CM on 137
2154			4	Unnatural death, AIDS, and coroners	The Lancet	1996	Brahams D	UK		777	
137	94338617	1	4	Clinical and epidemiological implications of the centers for disease control/World Health Organi	AIDS	1993	Brettle RP	UK	1	531-39	CM : 2133
61	93072560	1	4	The reporting of HIV/AIDS deaths in women	American J of Public Health	1992	Buehler JW	USA	1	1500-05	CM : 2092
2101	91283685	1	4	Unrecognised HIV related deaths	BMJ	1991	Bull AD	UK	1	54	CM on 166
759	93294984	2	4	Causes of death among persons reported with AIDS	American J of Public Health	1993	Chu SY	USA	1	1429-32	
399	97094235	1	4	Suicide and HIV infection. Mortality follow-up of 4147 HIV-seropositive military service applican	JAMA	1996	Dannenberg AL	USA	1	1743-46	
155	91094706	1	4	Inconsistencies in statistics of deaths from AIDS	Med J of Australia	1991	Donovan JW	Australia	1	90-92	
1024/561	93006436	1	4	HIV infection and certification of death	BMJ	1992	Edeh J	UK	1	647-48	CM on 1001
2100	91283685	1	4	Completeness of reporting of AIDS cases. Doctors should beware of "reporting fatigue"	BMJ	1991	Evans BG	UK	1	1351-52	CM on 166
567	92385245	1	4	Linkage of death certification of AIDS and cancer registration in Vaud, Switzerland	European J of Cancer	1992	Franceschi S	Switzerland	1	1487-90	
1122/666	87290428	1	4	Review of death certificates to assess completeness of AIDS case reporting	Public Health Reports	1987	Hardy AM	USA	1	386-91	
1123/631	90082302	1	4	A retrospective death certificate study of AIDS and AIDS-related conditions in OHIO : 1984-198	OHIO Medicine	1989	Herzog AA	USA	1	985-89	
1029/581	92189121	1	4	Impact of HIV infection on mortality and accuracy of AIDS reporting on death certificates	American J of Public Health	1992	Hessol NA	USA	1	561-64	
3	98174066	1	4	Relation between hospital HIV/AIDS caseload and mortality	Clin Invest Med	1998	Hogg RS	Canada	1	27-32	
635	89376248	1	4	Using death certificates to estimate the completeness of AIDS case reporting in Ontario in 198	Can Med Assoc J	1989	Johnson RJ	Canada	1	537-40	
1107/625	89229586	1	4	AIDS on the death certificate : the final stigma	BMJ	1989	King MB	UK	1	734-36	
662	88250195	1	4	The medical examiner and AIDS. Death certification, safety procedures, and future medicolega	Am J Forensic Med Pathol	1988	Klatt EC	USA	1	141-48	
166	91283685	1	4	Unrecognised HIV related deaths	BMJ	1991	McCormick A	UK	1	1365-67	CM : 2100-2101
2092	93072560	1	4	HIV and trends in cervical cancer death rates among young women	American J of Public Health	1993	McKenna MT	USA	1	1792-93	CM on 61
1054/546	93006437	1	4	HIV infection and certification of death	BMJ	1992	Pugh K	UK	1	648	CM on 1001
1057/562	93006434	1	4	HIV infection and certification of death	BMJ	1992	Riley A	UK	1	647	CM on 1001
792	94283756	2	4	Mortality before AIDS : a review of causes of death in young men in the city of Edinburgh (1979	Public Health	1994	Ryan DH	UK	1	357-65	
206	89049555	1	4	Autopsy patterns in patients dying of acquired immunodeficiency syndrome in New York City	Arch Pathol Lab Med	1988	Wilkes MS	USA	1	1221-23	
359	92032965	2	4	Underreporting of HIV-related deaths	Am Fam Phys	1991	Am Fam Phys	UK	1	2186	

VIRAL HEPATITIS - Eurostat shortlist n° 05 (no article)

NEOPLASMS - Eurostat shortlist n° 06

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
409	97067567	1	6	Missing cause of death information in the analysis of survival data	Statistics in Medicine	1996	Andersen J	USA	1	2191-201	
119	85299240	1	6	Comparison of occupations recorded at cancer registration and death	Public Health	1985	Balarajan R	UK	1	169-73	
693	87095303	1	6	The accuracy of local death certifcates in cancer of lung and stomach	Tumori	1986	Barchielli A	Italy	1	475-79	
2048			6	An autopsy study of cancer patients. Accuracy of the clinical diagnoses (1955 to 1965) Boston	JAMA	1972	Bauer FW	USA	1	1471-74	
2049			6	An autopsy study of cancer patients. Hospitalizations and accuracy of diagnoses (1955 to 1965	JAMA	1973	Bauer FW	USA	1	299-301	
271	90048113	1	6	Relative value of incidence and mortality data in cancer research	Recent Results in Cancer Res	1989	Boyle P	International	1	41-63	
806	96358377	2	6	Analyse des causes de décès chez 283 patients âgés avec un cancer avancé : contrôle des sy	Medecine et Hygiene	1996	Bréchet JP	Switzerland	2	2136,38-40	

1121/485	95367512	1	6	Limitations of the death certificate only index as a measure of incompleteness of cancer registr	British J of Cancer	1995	Brenner H	Germany	1	506-10	
386	97046628	1	6	Accuracy of death certification of pleural mesothelioma in Italy	European J of Epidemiology	1996	Bruno C	Italy	1	421-23	
1016/571	92350863	1	6	Use of death certificates for mesothelioma surveillance	Public Health Reports	1992	Davis LK	USA	1	481-83	
1017/598	91310241	1	6	Comparison of diagnoses of cancers of the respiratory system on death certificates and at autc	Autopsy Epidem and Med Res	1991	Delendi M	Italy	1	55-62	
1018/548	93118637	1	6	Cancer identification using a tumor registry versus death certificates in occupational cohort stu	American J of Epidemiology	1992	Demers PA	USA	1	1232-40	
2067			6	Some factors affecting the accuracy of cancer diagnosis	J Chronic Dis	1975	Ehrlich D	Isreal	1	359-64	
2068			6	Accuracy of death certification in an autopsied population with specific attention to malignant ne	American J of Epidemiology	1980	Engel LW	USA	1	99-112	
777	95161697	2	6	United States non-Hodgkin's lymphoma surveillance by occupation 1984-1989 : a twenty-four s	American J of Industrial Med	1995	Figgs LW	USA	1	817-35	
297	87042118	1	6	Decline of U.S. cancer mortality rates : expert estimates of past underreporting	Regul Toxicology Pharmacol	1986	Gori GB	USA	1	261-73	
294	88153217	1	6	Variation in international cancer mortality : factor and cluster analysis	International J of Epidemiol	1987	Groves FD	USA	1	501-08	
467	96043721	1	6	Is the apparent rise in cancer mortality in the elderly real ? Analysis of changes in certification a	Int J Cancer	1995	Grulich AE	UK	1	164-68	
2036			6	Note relative aux décès par mésothéliomes	INSERM	1992	Hatton F	France	1		
157	92368872	1	6	Completeness of cancer and death follow-up obtained through the National Health Register for	British J of Cancer	1992	Hawkins MM	UK	1	408-13	
1030/534	93294888	1	6	Influence of death certificate errors on cancer mortality trends	J of the National Cancer Inst	1993	Hoel DG	USA	1	1063-68	
2161			6	Cancer diagnosis is often missed	BMJ	1998	Hopkins Tanne JH	USA	1	1033	
612	91090309	1	6	Accuracy of cause-of-death certification in Hiroshima and Nagasaki, Japan	Annals NY Academy of Sciences	1990	Jablon S	Japan	1	100-08	
1075/674	88031873	1	6	The effect of inaccuracies in death certification and coding practices in the European Economic	International J of Epidemiology	1987	Kelson M	UK	1	411-14	
2162			6	Trends in mortality from cancer in the European Union, 1955-94	The Lancet	1999	Levi F	Europe	1	742-43	
3034			6	Cancer mortality in Europe, 1990-92	European J of Cancer Prev	1995	Levi F	Europe	1	389-417	
573	92318052	1	6	Excess cancer among white-collar workers in studies based on death certificates	J Occup Med	1992	Loomis DP	USA	1	592-93	
105	88009661	1	6	Certification and coding of two underlying causes of death in the Netherlands and other countri	J Epidemiol Community Health	1987	Mackenbach JP	Europe	1	156-60	
672	88077744	1	6	Occupation and five cancers : a case-control study using death certificates	British J of Industrial Med	1987	Magnani C	USA	1	769-76	
2039			6	Lung cancer deaths in the United States from 1979 to 1992 : an analysis using multiple-cause	International J of Epidemiol	1998	Mannino DM	USA	1	159-66	
115	85303378	1	6	Comparison between diagnoses in the Stockholm regional cancer register and certified underly	Acta Radiologica Oncology	1985	Mattsson B	Sweden	1	219-26	
1041/698	87016635	1	6	Reliability of death certifications for different types of cancer	Pathol Res Pract	1986	Mollo F	Italy	1	442-47	
687	87140392	1	6	Occupation and industry data obtained from death certificates : the effect and influence of case	J Occup Med	1987	Nelson DE	USA	1	52-56	
472	96048083	1	6	Declaring pediatric brain death : current practice in a Canadian pediatric critical care unit	Can Med Assoc J	1995	Parker BL	Canada	1	909-16	
182	90048108	1	6	International comparability of coding cancer data : present state and possible improvement by t	Recent Results in Cancer Res	1989	Percy C	International	1	240-52	
611	91090333	1	6	Effect of changes in cancer classification and the accuracy of cancer death certificates on trend	Annals NY Academy of Sciences	1990	Percy C	USA	1	87-97	
1050			6	Accuracy of cancer death certificates and its effect on cancer mortality statistics	American J of Public Health	1981	Percy C	USA	1	242-50	
1083			6	Comparison of the coding of death certificates related to cancer in seven countries	Public Health Reports	1978	Percy C	USA	1	335-50	
1084/643	89205505	1	6	The international comparability of cancer mortality of cancer data. Results of an international de	American J of Epidemiology	1989	Percy C	USA	1	934-46	
1114/689	87017528	1	6	Identifying mesotheliomas on death certificates	Public Health Reports	1986	Percy C	USA	1	457	
2037			6	Apparent changes in cancer mortality, 1968. A study of the effects of the introduction of the Eig	Public Health Reports	1974	Percy C	USA	1	418-28	
1124/504	95186395	1	6	Why are a quarter of all cancer deaths in south-east England registered by death certificate onl	British J of Cancer	1995	Pollock AM	UK	1	637-41	
37	98123947	1	6	International differences in survival from colon cancer : more effective care *versus* less comple	British J of Surgery	1998	Prior P	Europe	1	101-04	
2041			6	Changes in incidence of and mortality from breast cancer in England and Wales since introduc	BMJ	1995	Quinn M	UK	1	1391-95	
73	91266173	1	6	Reliability of cancer mortality statistics in Ontario : a comparison of incident and death diagnose	Canadian J of Public Health	1991	Reynolds DL	Canada	1	120-26	
1055/594	92016392	1	6	Death certificate categorization of malignant pleural and peritoneal mesothelioma in a cohort of	J Soc Occup Med	1991	Ribak J	USA	1	137-39	
1056/599	91310240	1	6	Comparison between diagnoses of cancers of stomach, colon, rectum, gall-bladder, liver and p	Autopsy Epidem and Med Res	1991	Riboli E	Italy	1	45-54	
549	93071941	1	6	Influence of age at death on accuracy of death certificate disease diagnosis : findings in 475 co	American J of Industrial Med	1992	Selikoff IJ	USA	1	505-10	
550	93071940	1	6	Death certificates in epidemiological studies, including occupational categories	American J of Industrial Med	1992	Selikoff IJ	Canada-USA	1	493-504	
1116/551	93071939	1	6	Use of death certificates in epidemiological studies, including occupational hazards : variations	American J of Industrial Med	1992	Selikoff IJ	USA	1	481-92	
3028			6	Cancer occurrence in the elderly : agreement between three major data sources	Ann Epidemiol	1999	Stang A	USA	1	60-67	
786	95071352	2	6	Childhood cancers and competing causes of death	Leukemia Research	1995	Stewart A	UK	1	103-11	
1065/620	90235525	1	6	Accuracy of death certificates and mortality statistics in victorian testis cancer death 1950-1977	Community Health Studies	1990	Stone JM	Australia	1	54-60	
2040			6	An assessment of occupation and industry data from death certificates and hospital medical re	American J of Public Health	1984	Swanson GM	USA	1	464-67	
196	89287257	1	6	Interpretation of England and Wales cancer mortality data : the effect of enquiries to certifiers fo	British J of Cancer	1989	Swerdlow AJ	UK	1	787-91	
701	86261687	1	6	Occupational risk factors for brain tumors. A case-referent death-certificate analysis	Scand J Work Environ Health	1986	Thomas TL	USA	1	121-27	
173	90289758	1	6	Use of coded mortality data to assess area cancer rates : impact of residence reporting and co	American J of Epidemiology	1990	Williams AN	USA	1	s178-82	
690	86310644	1	6	Use of death certificates for surveillance of work-related illnesses - New Hampshire	MMWR	1986	(MMWR)	USA	1	537-40	

MALIGNANT NEOPLASMS - Eurostat shortlist n° 07 (no article)

OF WICH MALIGNANT NEOPLASM OF LIP, ORAL CAVITY, PHARYNX - Eurostat shortlist n° 08 (no article)

OF WICH MALIGNANT NEOPLASM OF OESOPHAGUS - Eurostat shortlist n° 09 (no article)

OF WICH MALIGNANT NEOPLASM OF STOMACH - Eurostat shortlist n° 10 (no article)

OF WHICH MALIGNANT NEOPLASM OF COLON - Eurostat shortlist n° 11

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1013/576	92269429	1	11	Death cetificate reporting of colon and rectal cancers	JAMA	1992	Chow WH	USA	1	3028	
450	96206637	1	11	Why did treatment rates for colorectal cancer in South East England fall between 1982 and 198	J Public Health Med	1995	Pollock AM	UK	1	419-28	
780	94368402	2	11	The impact on colorectal cancer survival of cases registered by 'death certificate only': implicat	British J of Cancer	1994	Pollock AM	UK	1	1229-31	

OF WHICH MALIGNANT NEOPLASM OFRECTUM AND ANUS - Eurostat shortlist n° 12

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1013/576	92269429	1	12	Death cetificate reporting of colon and rectal cancers	JAMA	1992	Chow WH	USA	1	3028	

OF WHICH MALIGNANT NEOPLASM LIVER AND THE INTRAHEPATIC BILE DUCTS - Eurostat shortlist n° 13

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1051/609	90341475	1	13	The accuracy of liver cancer as the underlying cause of death on death certificates	Public Health Reports	1990	Percy C	USA	1	361-67	

OF WICH MALIGNANT NEOPLASM OF PANCRÉAS - Eurostat shortlist n° 14 (no article)

OF WHICH MALIGNANT NEOPLASM OF LARYNX AND TRACHEA / BRONCHUS / LUNG - Eurostat shortlist n° 15

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
2114	94092810	1	15	Spurious bias in the attribution of lung cancer as a cause of death	Epidemiology	1993	Archer VE	USA	1	562-63	CM on 52
3037			15	Mortality from respiratory system cancer in New South Wales and Sydney	Australian J of Public Health	1992	Burnley IH	Australia	1	251-61	
1025/580	92208079	1	15	Inaccuracies of death certificate information	Epidemiology	1992	Flanders WD	USA	1	03-05	
47	95110611	1	15	Comparison of autopsy, clinical and death certificate diagnosis with particular reference to lung	APMIS	1994	Lee PN	UK	1	01-42	
194	86287907	1	15	The "missing cases" of pleural malignant mesothelioma in Minnesota, 1979-81: preliminary rep	Public Health Reports	1986	Lilienfeld DE	USA	1	395-99	
52	94092810		15	Bias in the attribution of lung cancer as cause of death and its possible consequences for calcu	Epidemiology	1992	Sterling TD	USA	1	11-16	CM : 2114
434	96211034	1	15	Pulmonary fibrosis and lung cancer in the United States: analysis of the multiple cause of deatl	Southern Medical Journal	1996	Wells C	USA	1	505-10	

OF WHICH MALIGNANT MELANOMA OF SKIN - Eurostat shortlist n° 16

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1068/66	92152357	1	16	Inaccuracies in certification of nonmelanoma skin cancer deaths	American J of Public Health	1992	Weinstock MA	USA	1	278-80	

OF WHICH MALIGNANT NEOPLASM OF BREAST - Eurostat shortlist n° 17

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1009			17	Death certification in cancer of the breast	BMJ	1984	Brinkley D	UK	1	465-67	
767	92032407	2	17	Verification of the cause of death in the trial of early detection of breast cancer. UK trial detectic	British J of Cancer	1991	Chamberlain J	UK	1	1151-56	
394	97092792	1	17	Breast cancer as cause of death. A study over the validity of the officially registered cause of d	Acta Oncologica	1996	Garne JP	Sweden	1	671-75	
500	95234328	1	17	Determination of cause of death among breast cancer cases in the Swedish randomized mamr	Acta Oncologica	1995	Nyström L	Sweden	1	145-52	
21	98030460	1	17	Statistical modelling of breast cancer incidence and mortality rates in Scotland	British J of Cancer	1997	Robertson C	UK	1	1248-52	
114	86099888	1	17	Validity of certified causes of death in breast carcinoma patients	Acta Radiologica Oncology	1985	Rutqvist LE	Sweden	1	385-90	

OF WHICH MALIGNANT NEOPLASM OF CERVIX UTERI - Eurostat shortlist n° 18

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1019/597	91310242	1	18	Comparison between diagnoses on death certificates and autopsy reports in trieste: gynaecolo	IARC Sci Publ	1991	Di Bonito L	Italy	1	63-71	

OF WHICH MALIGNANT NEOPLASM OF OTHER PARTS OF UTERUS - Eurostat shortlist n° 19

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1019/597	91310242	1	19	Comparison between diagnoses on death certificates and autopsy reports in trieste: gynaecolo	IARC Sci Publ	1991	Di Bonito L	Italy	1	63-71	

OF WHICH MALIGNANT NEOPLASM OF OVARY - Eurostat shortlist n°20

N°	Base Nr	Base	Path.	Title	Journal	year	Author	Country	Lg	Pages	Relation
1019/597	91310242	1	20	Comparison between diagnoses on death certificates and autopsy reports in triest: gynaecolog	Autopsy in Epidem & Med Research	1991	Di Bonito L	Italy	1	63-71	

OF WHICH MALIGNANT NEOPLASM OF PROSTATE - Eurostat shortlist n° 21 (no article)

OF WHICH MALIGNANT NEOPLASM OF KIDNEY - Eurostat shortlist n° 22 (no article)

OF WHICH MALIGNANT NEOPLASM OF BLADDER - Eurostat shortlist n° 23

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Observation
510	94303671	1	23	A comparison of analyses of occupational bladder cancer: death certificate vs. population-base	American J of Industrial Med	1994	Burnett CA	USA	1	677-88	
2163			23	Underreporting and misclassification of urinary tract cancer cases on death certificates	Epidemiology	1996	Chow WH	USA	1	517-20	
564	92392722	1	23	Occupation and bladder cancer: a death certificate study	Br J Cancer	1992	Dolin PJ	UK	1	568-78	
706	86001382	1	23	Effect of coroners' rules on death certification for alcoholic liver disease	BMJ	1985	Maxwell JD	UK	1	708	

OF WHICH MALIGNANT NEOPLASM OF LYMPH. / HAEMATOPOIETIC TISSUE - Eurostat shortlist n° 24

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
12	97327522	1	24	Comparison of the diagnosis of leukaemia from death certificates, cancer registration and histo	British J of Cancer	1997	Rushton L	UK	1	1694-98	
663	88151025	1	24	A death-certificate case-control study of non-Hodgkin's lymphoma and occupation in men in Nc	American J of Industrial Med	1988	Schumacher MC	USA	1	317-30	

DISEASES OF THE BLOOD (-FORMING ORGANS), IMMUNOL, DISORDERS -Eurostat shortlist n° 25 (no article)

ENDOCRINE, NUTRITIONAL AND METABOLIC DISEASES - Eurostat shortlist n° 26

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
402	97060814	1	26	Cystic fibrosis deaths in the United States from 1979 through 1991	Arch Pediatr Adolesc Med	1996	Halliburton CS	USA	1	1181-85	

DIABETES MELLITUS - Eurostat shortlist n° 27

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
45	95063439	1	27	The value of death certification statistics in measuring mortality in persons with diabetes	Scand J Prim Health Care	1994	Andersson DKG	Sweden	1	114-20	
601	91284803	1	27	Underreporting of diabetes on death certificates	Diabetes Care	1991	Andresen EM	USA	1	352-53	
1003/533	93319011	1	27	Underreporting of diabetes on death certificates, King County, Washington	American J of Public Health	1993	Andresen EM	USA	1	1021-24	CM : 2149
753	93083962	2	27	European study of the certification and coding of causes of death of six clinical case histories o	International J of Epidemiol	1993	Balkau B	Europe	1	116-26	
2150			27	Certification of cause of death in French diabetic patients	J Epidemiol Community Health	1992	Balkau B	France	1	63-65	
1006/578	92235641	1	27	Frequency of recording of diabetes on U.S. death certificates: analysis of the 1986 national mo	J Clin Epidemiol	1992	Bild DE	USA	1	275-81	
790	94322792	2	27	Causes of death in Japanese diabetic patients examined by autopsy	Diabetes Research & Clinical Practice	1994	Goto Y	Japan	1	s291-94	
1082/555	93053156	1	27	Death certificate coding practices related to diabetes in European countries - The 'EURODIAB	International J of Epidemiol	1992	Jougla E	Europe	1	343-51	
2149	93319011	1	27	Needed : universal monitoring of all serious diseases of global importance	American J of Public Health	1993	LaPorte RE	USA	1	941-43	CM on 1003/533
453	96167058	1	27	Insulin treated diabetes mellitus: causes of death determined from record linkage of population	J Epidemiol Community Health	1995	Raymond NT	UK	1	570-74	
715	85261812	1	27	Causes of death in japanese diabetics. A 20-year study of death certificates	J Chron Dis	1985	Sasaki A	Japan	1	655-61	
1060/527	94008456	1	27	The proportion of death certificates of diabetic patients that mentioned diabetes in Osaka Distri	Diabetes Research & Clinical Practice	1993	Sasaki A	Japan	1	241-46	
19	98037533	1	27	Linking a hospital diabetes database and the National Health Service Central Register: a way t	Diabetic Medicine	1997	Weng C	UK	1	877-83	
174	90271793	1	27	Deaths from diabetes are under-reported in national mortality statistics	Med J of Australia	1990	Whittall DE	Australia	1	598-600	
1070/778	95022563	2	27	Reporting of diabetes on death certificates with coronary heart disease as underlying cause of	Diabetes Care	1995	Wild SH	USA	1	135-37	
588	92046598	1	27	Sensitivity of death certificate data for monitoring diabetes mortality-diabetic eye disease follow	JAMA	1991	(JAMA)	USA	1	2812	
593	92017530	1	27	Sensitivity of death certificate data for monitoring diabetes mortality-diabetic eye disease follow	MMWR	1991	(MMWR)	USA	1	739-41	

MENTAL AND BEHAVIOURAL DISORDERS - Eurostat shortlist n° 28

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
370	97171521	1	28	Mental disorder as a contributing cause of death in the U.S. in 1992	Psychiatric Services	1997	Dembling B	USA	1	45	
1021/570	92357164	1	28	Vascular dementia a clinical and death certificate study	Neuroepidemiology	1992	Dollear W	USA	1	53-58	
446	96109169	1	28	Alzheimer's disease death certificates	Neurology	1995	Frecker MF	USA	1	2298-99	
228	86191174	1	28	A pseudo-epidemic of deaths from mental disorder	Community Medicine	1986	Jessop EG	UK	1	89	
1034/645	89163816	1	28	Regional differences in mortalilty from dementia in Australia: an analysis of death certificate da	Acta Psychiatr Scand	1989	Jorm AF	Australia	1	179-85	
1038/572	92340777	1	28	Sensitivity and specificity of death certificate diagnoses for dementing illnesses, 1988-1990	J of the American Geriat Soc	1992	Macera CA	US	1	479-81	
184	89124789	1	28	Usefulness of mortality data in determining the geography and time trends of dementia	J Epidemiol Community Health	1988	Martyn CN	UK	1	134-37	
775	95356746	2	28	To what extent is dementia underreported on British death certificates	Inter J of Geria Psychia	1995	Morgan K	UK	1	987-90	
1045/524	94045395	1	28	Death certification after a diagnosis of presenile dementia	J Epidemiol Community Health	1993	Newens AJ	UK	1	293-97	
686	87185290	1	28	Organic solvents and presenile dementia: a case referent study using death certificates	British J of Industrial Med	1987	O'Flynn RR	UK	1	259-62	
1049/487	95362976	1	28	Death certificate reporting of dementia and mortality in an Alzheimer's disease research center	J of the American Geriat Soc	1995	Olichney JM	USA	1	890-93	
781	94349466	2	28	CERAD part VII: accuracy of reporting dementia on death certificates of patients with Alzheime	Neurology	1994	Raiford K	USA	1	2208-09	
762	93074220	2	28	Mortalité et causes de décès dans la schizophrénie. Revue de la littérature	L'Encéphale	1993	Tabbane K	International	2	23-28	

ALCOHOL ABUSE (INCLUDING ALCOHOLIC PSYCHOSIS) - Eurostat shortlist n° 29

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1000/684	87220222	1	29	Validation of diagnoses on death certificates for male alcoholics in Stockholm	Forensic Sci International	1987	Agren G	Sweden	1	231-41	
259	91279123	1	29	Alcohol, cardiovascular diseases and total mortality: epidemiological evidence	New Zealand Med J	1991	Beaglehole R	New-Zealand	1	249-51	
629	90123277	1	29	Alcohol and death certification: influencing current practice and attitudes	British J of Addiction	1989	Bell G	UK	1	1523-25	
665	87300620	1	29	Alcohol and death certification: a survey of current practice and attitudes	BMJ	1987	Bell G	UK	1	95	
728	88069110	2	29	Accuracy of death certificates in the diagnosis of alcoholic liver cirrhosis	Alcohol Clin Exp Research	1988	Blake JE	USA	1	168-72	
770	91132874	2	29	The manner and cause of death in a forensic series of chronic alcoholics	Forensic Sci International	1991	Hansen AU	Denmark	1	171-78	
661	88250196	1	29	Death certificates, natural death, and alcohol. The problem of underreporting	Am J Forensic Med Pathol	1988	Hanzlick R	USA	1	149-50	
156	90241350	1	29	Validity of post-mortem alcohol reports	Alcohol & Alcoholism	1990	Karhunen PJ	Finland	1	25-32	
679	87274771	1	29	The reliability of death certification as a measure of the level of alcohol problems	Community Medicine	1987	Kemp I	UK	1	146-51	
691	86215864	1	29	Accuracy of death certification for alcoholic liver disease	British J of Addiction	1986	Maxwell JD	UK	1	168-69	
3043			29	Effect of coroners' rules on death certification for alcoholic liver disease	BMJ	1985	Maxwell JD	UK	1	708	
139	94324720	1	29	Abuse of alcohol in sudden out-of-hospital deaths in Finland	Alcohol Clin Exp Research	1994	Perola M	Finland	1	255-60	
1053/682	87254648	1	29	Underreporting of alcohol-related mortality on death certificates of young US Army veterans	JAMA	1987	Pollock DA	USA	1	345-48	
273	89241929	1	29	Underreporting of alcohol-related mortality from cirrhosis is declining in Sweden and Denemark	Scand J Gastroenterol	1988	Prytz H	Swed-Denm	1	1035-43	
395	97075696	1	29	Chronic alcoholism in a forensic material. 2. Causes and manners of death in alcoholics	Med. Sci. Law	1996	Thomsen JL	Denmark	1	209-16	
300	85279869	1	29	The influence of alcohol abuse as a hidden contributor to mortality	Alcohol	1985	Van Natta P	USA	1	535-39	
257	91319047	1	29	County data on alcohol-related mortality - United States	MMWR	1991	(MMWR)	USA	1	555,61-62	
329	93375956	1	29	Quarterly table reporting alcohol involvement in fatal-motor vehicle crashes	MMWR	1993	(MMWR)	USA	1	729-32	
330	93275298	1	29	Quarterly table reporting alcohol involvement in fatal-motor vehicle crashes	MMWR	1993	(MMWR)	USA	1	463	
331	93188821	1	29	Quarterly table reporting alcohol involvement in fatal-motor vehicle crashes	MMWR	1993	(MMWR)	USA	1	215	
333	93062615	1	29	Quarterly table reporting alcohol involvement in fatal-motor vehicle crashes	MMWR	1992	(MMWR)	USA	1	910	
334	92092262	1	29	Quarterly table reporting alcohol involvement in fatal-motor vehicle crashes	JAMA	1992	(JAMA)	USA	1	347	
339	91163529	1	29	Quarterly table reporting alcohol involvement in fatal-motor vehicle crashes	MMWR	1991	(MMWR)	USA	1	187-88	
340	91171421	1	29	Quarterly table reporting alcohol involvement in fatal-motor vehicle crashes	JAMA	1991	(JAMA)	USA	1	1807	
667	87257638	1	29	Underreporting of alcohol-related mortality on death certificates of young U.S. Army veterans	MMWR	1987	(MMWR)	USA	1	437-40	

DRUG DEPENDANCE, TOXICOMANIA - Eurostat shortlist n° 30

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
289	85108373	1	30	A potential use of the National Death Index for postmarketing drug surveillance	JAMA	1985	Edlavitch SA	USA	1	1292-95	
356	93256229	2	30	Mortality among drug injectors and notified addicts	J Epidemiol Community Health	1993	Frischer M	UK	1	336	
518	94160974	1	30	Misclassification of deaths caused by cocaine: further discussion and possible solution for deat	Am J Forensic Med Pathol	1993	Hanzlick R	USA	1	351-52	CM on 1079/144
772	91095053	2	30	When is cocaine the cause of death ?	Am J Forensic Med Pathol	1991	Karch SB	USA	1	01-02	
138	94327264	1	30	Drug-related mortality in Switzerland from 1987 to 1989 in comparison to other countries	International J of Addictions	1994	Marx A	Switzerland	1	837-60	
142	94131378	1	30	Undetected drug addict fatalities	Forensic Sci International	1993	Schulz-Schaeffer W	Germany	1	157-59	
44	95197315	1	30	Problems of accuracy in official statistics on drug-related deaths	International J of Addictions	1994	Shai D	USA	1	1801-11	
33	96272771	1	30	Drug addict deaths in the Nordic countries: a study based on medicolegally examined cases in	Forensic Sci International	1996	Steentoft A	Nordic countries	1	109-18	
143	94022839	1	30	Mortality attributed to misure of psychoactive drugs, 1979-88	Public Health Reports	1993	Wysowski DK	USA	1	565-70	
1079/144	93263114	1	30	Misclassification of deaths caused by cocaine. An assessment by survey	Am J Forensic Med Pathol	1993	Young TW	USA	1	43-47	CM : 518
20	98024246	1	30	North Carolina board of pharmacy releases figures from mandatory reports of drug-related dea	Am J Health-Syst Pharm	1997	(Am J Health-Syst Pharm)	USA	1	2434	

DISEASES OF THE NERVOUS SYSTEM AND THE SENSE ORGANS- Eurostat shortlist n° 31

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1012/547	93123925	1	31	Acuracy of death certificate diagnosis of amyotrophic lateral sclerosis	J Epidemiol Community Health	1992	Chiò A	Italy	1	517-18	
1015/503	95206413	1	31	Death certificates: an efficient source for ascertainment of Creutzfeldt-Jakob disease cases	Neuroepidemiology	1995	Davanipour Z	USA	1	01-06	
771	91101404	2	31	Certified cause of death in children and young adults with cerebral palsy	Arch of Disease in Childhood	1990	Evans PM	UK	1	325-29	
688	87106758	1	31	Causes of death in Huntington disease as reported on death certificates	Genetic Epidemiology	1986	Haines JL	USA	1	417-23	
440	96182721	1	31	Causes of death need confirmation	BMJ	1996	Jellinger KA	UK	1	704-05	CM on 2105
793	94216523	2	31	Causes of death associated with Alzheimer disease: variation by level of cognitive impairment	J of the American Geriat Soc	1994	Kukull WA	USA	1	723-26	
298	86065830	1	31	In defense of death data: an example with multiple sclerosis	Neurology	1985	Kurtzke JF	USA	1	1787-90	
2105			31	Comparison of terapeutic effects and mortality data of levodopa and levodopa combined with s	BMJ	1995	Lees AJ	UK	1	1602-07	CM : 440
445	96064346	1	31	Are death certificates reliable to estmate the incidence of Parkinson's disease ?	Movement Disorders	1995	Paulson GW	USA	1	678	
2097			31	Validity of mortality data for Parkinson's disease	J Epidemiol Community Health	1999	Phillips NJ	UK	1	587-88	
441	96182740	1	31	Parkinson's disease is rarely a primary cause of death	BMJ	1996	Silva MT	UK	1	703	
1069/542	93086274	1	31	How accurate is death certification of multiple system atrophy ?	The Lancet	1992	Wenning GK	UK	1	1481-82	

MENINGITIS (OTHER THAN 03) - Eurostat shortlist n° 32 (no article)

DISEASES OF THE CIRCULATORY SYSTEM - Eurostat shortlist n° 33

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1004			33	United States mortality from ill-defined causes 1968-1988: potential effects on heart disease m	International J of Epidemiol	1995	Armstrong DL	USA	1	522-27	
2050			33	An assessment of certain medical aspects of death certificate data for epidemiologic study of a	J chronic Dis	1963	Beadenkopf WG	USA	1	249-62	
2064			33	Nosological coding of cause of death	American J of Epidemiology	1983	Curb JD	USA	1	122-28	
1081/678	87274970	1	33	Standardized physician preparation of death certificates	Controlled Clinical Trials	1987	Davis BR	USA	1	110-20	
209	88220298	1	33	Comparability of mortality follow-up before and after the National Death Index	American J of Epidemiology	1988	Edlavitch SA	USA	1	1164-78	
2069			33	Accuracy of death certification in an autopsied population with specific attention to malignant ne	American J of Epidemiology	1980	Engel LW	USA	1	99-112	
2131			33	Asymptomatic hypercholesterolaemia	BMJ	1991	Gray DP	UK	1	1022	
1028/639	89293168	1	33	Accuracy of diagnosis on death certificates for underlying causes of death in a long-term autop	J Clin Epidemiol	1989	Hasuo y	Japan	1	577-84	
2147			33	Autopsy and the cause of death	New Zealand Med J	1989	Hay DR	New-Zealand	1	23	CM on 656
2079			33	Investigation of deaths from pulmonary, coronary, and cerebral thrombosis and embolism in wo	BMJ	1968	Inman WHW	UK	1	193-99	
1	98334083	1	33	Validation of death certificate diagnosis of out-of-hospital sudden cardiac death	Am J Cardiol	1998	Iribarren C	USA	1	50-53	
71	91316387	1	33	Deaths certified as due to coronary artery disease	BMJ	1991	Jenkins M	UK	1	53-54	CM on 72
189	87232527	1	33	Multiple cause-of-death analysis of hypertension-related mortality in New York State	Public Health Reports	1987	Jow-Ching Tu E	USA	1	329-35	
2080			33	Quality of death cetificate diagnoses of arteriosclerotic heart disease	Public Health Reports	1967	Kuller L	USA	1	339-46	
439	96177836	1	33	Sudden death from cardiac causes in children and youg adults	New England J of Medicine	1996	Liberthson RR	USA	1	1039-44	
2052			33	Evaluation of diagnostic information supporting medical certification of deaths from cardiovascu	Nat Cancer Inst Monograph	1963	Moriyama IM	USA	1	405-19	
222	87097680	1	33	The effect of physician terminology preference on coronary heart disease mortality: an artifact u	American J of Public Health	1987	Sorlie PD	USA	1	148-52	
656	89083040	1	33	Coronary heart disease death certificate diagnoses	New Zealand Med J	1988	Stehbens WE	New-Zealand	1	829	CM : 2147
72	91283706	1	33	Deaths certified as due to coronary artery disease	BMJ	1991	Sumner KR	UK	1	1402	CM : 71 / CM on2131
168	91188117	1	33	Comparison of official mortality statistics with data obtained from myocardial infarction and stro	Rev Epidém et Santé Publ	1990	Szczesniewska D	Poland	1	435-39	
60	93110201	1	33	Sudden death in adults: principle causes and reliability of the Liege	Rev. Med Liege	1992	Vivario M	Belgium	2	628-36	

ISCHAEMIC HEART DISEASES - Eurostat shortlist n° 34

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Observation
1002/353	95038836	2	34	The inadequacy of death certificates claiming myocardial infarction without autopsy verification	Forensic Sci Int	1995	Ambach E	Austria	1	75-76	
458	96092768	1	34	The accuracy of hospital records and death certificates for acute myocardial infarction	Aust NZ J Med	1995	Boyle CA	Australia	1	316-23	
352	95255022	2	34	Explaining the French paradox	J R Soc Health	1995	Burr M L	France	1	217-219	
3004			34	Life style and national and international trends in coronary heart disease mortality	Postgrad Med J	1984	Clarke C	International	1	03-08	
783	94098082	2	34	Validation of primary and secondary outcomes and classification of mode of death among patie	J Cardio.Pharma.	1993	Cleland JGF	UK	1	s22-s27	
2158			34	Misclassification of coronary heart disease in mortality statistics. Evidence from the WHO-MON	J Epid Com Health	1998	De Henauw S	Belgium	1	513-19	
2065			34	Death certification and coding for ischemic heart disease in Australia (letter)	American J of Epidemiology	1983	Dobson AJ	Australia	1	397-405	
3045			34	Why mortality from heart disease is low in France	BMJ	2000	Ducimetière P	France	1	249-50	
685	87210061	1	34	Out-of-hospital coronary death in an urban population-validation of death certificate diagnosis	American J of Epidemiology	1987	Folsom AR	USA	1	1012-18	
77	90124057	1	34	Decline of acute myocardial infarction death rates not due to cause of death coding	Canadian J of Public Health	1989	Giubert RL	Canada	1	418-22	
1033/658	89040741	1	34	Validation of coronary heart disease death certificate diagnoses	N Z Med J	1988	Jackson R	New-Zealand	1	658-60	
2148			34	Coroners and coronaries	Lancet	1991	Knapman PA	UK	1	1599	CM on 160
707	85227194	1	34	Changes in incidence and prognosis of ischaemic heart disease in Finland: a record linkage stu	BMJ	1985	Koskenvuo M	Finland	1	1773-75	
348	348	2	34	Exploitation of autopsy in determining natural cause of death: trends in Finland with special ref	Forensic Sci Int	1998	Lahti RA	Finland	1	109-21	
1076/673	88049332	1	34	Variation in death certification of ischemic heart disease in Australia and New Zealand	Aust NZ J Med	1987	Leitch DGM	New-Zealand	1	309-15	
220	87251172	1	34	Estimation of myocardial infarction mortality from routinely collecteddata in Western Australia	J Chronic Dis	1987	Martin CA	Australia	1	661-69	
1040/709	86110731	1	34	Certification of death from ischaemic heart disease in Belfast	International J of Epidemiol	1985	McIlwaine WJ	Ireland	1	560-65	
160	92048005	1	34	Coroners, procurators fiscal, and deaths from coronary heart disease	Lancet	1991	Moulton C	UK	1	1336-37	CM:2148
1048/607	90301685	1	34	Validité des certificats de décès pour l'étude des cardiopathies ischémiques	Presse Med	1990	Nuttens MC	France	2	1143-46	
3001			34	Variation in mortality from ischaemic heart disease between England and Scotland	Quarterly J of Medicine	1987	Phillips R	UK	1	441-48	
1062/563	92411960	1	34	Death certification and coding for ischaemic heart disease in Tasmania	Aust NZ J Med	1992	Sexton PT	Australia	1	114-18	
680	87254732	1	34	Recent morbidity trends in myocardial infarction in Japan: investigation of death certificates and	Japanese Circulation Journal	1987	Shimamoto T	Japan	1	314-18	
217	87286207	1	34	Statistical consequences of variation in cause-of-death terminology for chronic ischemic heart d	Md Med J	1987	Sorlie PD	USA	1	339-42	
3017			34	The effect of physician terminology preference on coronary heart disease mortality: an artifact u	Am J Public Health	1987	Sorlie PD	USA	1	148-52	
172	90165024	1	34	Review of the validity of national coronary heart disease mortality rates	Angiology	1990	Stehbens WE	New-Zealand	1	85-94	
1066/650	89161594	1	34	A validation of cause of death certification for ischaemic heart disease in two Swedish municipa	Scand J Prim Health Care	1988	Sundman L	Sweden	1	205-11	
3044			34	Contribution of trends in survival and coronary-event rates to changes in coronary heart diseas	Lancet	1999	Tunstall-Pedoe H	International	1	1547-57	

OTHER HEART DISEASES - Eurostat shortlist n° 35 (no article)

CEREBROVASCULAR DISEASES - Eurostat shortlist n° 36

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Observation
2044			36	Mortality from stroke among U.S. veterans in Georgia and 5 western states: quality of death ce	J Chronic Dis	1973	Acheson R	USA	1	405-14	
1007/649	89161595	1	36	Mortality from stroke among women in a Swedish community, Strömstad	Scand J Prim Health Care	1988	Björkelund C	Sweden	1	213-18	
2071			36	A study of the valildity of the diagnosis of stroke in mortality data. Certificate analysis	Yale J Biol Med	1967	Florey CV	USA	1	148-63	
2164			36	A study of the valildity of the diagnosis of stroke in mortality data. Comparison by computer of a	American J of Epidemiol	1969	Florey CV	USA	1	15-24	
272	89097438	1	36	Declining trends in mortality from cerebrovascular disease at ages 10-65 years: a test of validity	Neuroepidemiology	1989	Garland FC	USA	1	01-23	
2023			36	Decline of acute myocardial infarction death rates not due to cause of death coding	Can J Public Health	1989	Guibert RL	Canada	1	418-22	
1032/614	91051504	1	36	Accuracy of death certificate diagnosis of intracranial hemorrhage and nonhemorrhagic stroke	American J of Epidemiol	1990	Iso H	USA	1	993-98	
2021			36	Patterns of incidence and trends in diagnostic classification of cerebrovascular disease disease	American J of Epidemiol	1982	Kramer S	USA	1	398-411	
2025			36	Nationwide cerebrovascular disease mortality study	American J of Epidemiol	1969	Kuller LH	USA	1	536-78	
246	93118100	1	36	Decline in autopsies for deaths attributed to cerebrovascular disease	Stroke	1993	Lanska DJ	USA	1	71-75	
2024			36	Death rates from coronary disease-progress and a puzzling paradox	New England J Med	1998	Levy D	USA	1	915-17	
13	97034605	1	36	Reliability of brain death diagnostics	Intensive Care Med	1996	Link J	Italy	1	836-37	CM on 15
15	96093027	1	36	Reliability in diagnosis of brain death	Intensive Care Med	1995	Paolin A	Italy	1	657-62	CM : 13
288	85210753	1	36	Information about strokes lost between post-mortem and reported cause of death	J R Soc Med	1985	Peach H	UK	1	445-51	
451	96188459	1	36	Reliability of death certificates in the study of stroke mortality	Ital J Neurol Sci	1995	Reggio A	Italy	1	567-70	
1063/360	91153593	2	36	Validity of cerebrovascular mortality rates	Angiology	1991	Stehbens WE	New-Zealand	1	261-67	

DISEASES OF THE RESPIRATORY SYSTEM - Eurostat shortlist n° 37

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1010/604	91213913	1	37	Death certificate reporting of confirmed airways obstructive disease	American J of Epidemiology	1991	Camilli AE	USA	1	795-800	
1073/714	96056100	1	37	Death certification of farmer's lung and chronic airway diseases in different countries of the EE	Br J Dis Chest	1985	Farebrother MJB	Europe	1	352-60	
3038			37	History of smoking from the Washington State death certificate	Am J Prev Med	1994	Frost F	USA	1	335-39	
1074			37	The effect of death certification and coding practices on observed differences in respiratory dis	Rev Epid Sante Pub	1983	Kelson MC	UK	1	423-32	
105	88009661	1	37	Certification and coding of two underlying causes of death in the Netherlands and other countri	J Epid Com Health	1987	Mackenbach JP	Europe	1	156-60	
435	96210199	1	37	Pulmonary fibrosis deaths in the United States, 1979-1991. An analysis of multiple-cause morta	Am J Respi Crit Care Med	1996	Mannino DM	USA	1	1548-52	
3036			37	Clinical characteristics of fatal pulmonary embolism in a referral hospital	Mayo Clin Proc	1995	Morgenthaler TI	UK	1	417-24	
1077			37	Validité des données de mortalité par maladies respiratoires en France et dans sept autres pay	R ev Mal Resp	1984	Neukirch F	Europe	2	361-67	
3033			37	Death from airways obstruction: accuracy of certification in Northern Ireland	Thorax	1996	Smyth ET	UK	1	293-97	

INFLUENZA - Eurostat shortlist n° 38 (no article)

PNEUMONIA - Eurostat shortlist n° 39

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
422	96326099	1	39	Death rates among patients hospitalized with community-acquired pneumonia: a reexamination	American J of Public Health	1996	Markowits JS	USA	1	1152-54	

CHRONIC LOWER RESPIRATORY DISEASES - Eurostat shortlist n° 40 (no article)

ASTHMA - Eurostat shortlist n° 41

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
6	98032011	1	41	Trends in asthma mortality. Death certification in asthma is inaccurate (Letter)	BMJ	1997	Berrill WT	UK	1	1013	
3019			41	Is the death rate from asthma exaggerated ? Evidence from West Cumbria	BMJ	1993	Berrill WT	UK	1	193-94	
1072/630	90116802	1	41	The effect of death certification practice on recorded national asthma mortality rates	Rev Epidém Santé Publ	1989	Burney PGJ	Europe	1	385-89	
1011/574	92293024	1	41	Accuracy of asthma statistics from death certificates in South Australia	Medical Journal of Australia	1992	Campbell DA	Australia	1	860-63	
560	93038270	1	41	Certification of asthma death by general practitioners	Australian Family Physician	1992	Coates JR	Australia	1	1325-28	
3025			41	National trends in the morbidity and mortality of asthma in the US. Prevalence, hospitalization a	Chest	1987	Evans R	USA	1	65-74S	
3024			41	Geographical variations in the epidemic of asthma deaths	Br J Prev Soc Med	1971	Fraser P	UK	1	34-36	
392	97105609	1	41	Accuracy of recording of deaths from asthma in the UK: the false negative rate	Thorax	1996	Guite HF	UK	1	924-28	
1031/536	93218057	1	41	Accuracy of the death certificate in a population-based study of asthmatic patients	JAMA	1993	Hunt LW	USA	1	1947-52	CM : 2146
362	90051062	2	41	Accuracy of asthma mortality in France	Chest	1990	Jackson R	France	1	508-09	
2102	90125980	1	41	International trends in asthma mortality: 1970 to 1985	Chest	1988	Jackson R	France	1	914-18	CM : 178
57	93208226	1	41	Accuracy of asthma death statistics in Australia	Australian J of Public Health	1992	Jenkins M	Australia	1	427-29	
253	92152453	1	41	Increasing asthma mortality in Denmark 1969-88 not a result of changed coding practice	Annals of Allergy	1992	Juel K	Denmark	1	180-82	
2146			41	Asthma deaths. A social or medical problem ?	JAMA	1993	Kaliner MA	USA	1	1994-95	CM on 1031
269	90153050	1	41	Fall and rise in asthma mortality in Italy, 1968-84 (Letter)	Int J Epidemiol	1989	La-Vecchia C	Italy	1	998-99	
3021			41	Gains in life expectancy after elimination of major causes of death: revised estimates taking int	J Epidemiol Community Health	1999	Mackenbach JP	Netherlands	1	32-37	
1042/502	95224293	1	41	Preventable factors and death certification in death due to asthma	Respiratory Medecine	1995	Model D	UK	1	21-25	
3029			41	Age-dependent inaccuracy of asthma death certification in Northern England, 1991-1992	Eur Respir J	1998	Reid DWEC	UK	1	1079-83	

178	90125980	1	41	Accuracy of asthma mortality in France	Chest	1990	Riou B	France	1	507-09	CM on 2102
3020			41	Decline in lung function and mortality: The Busselton Health Study	J Epidemiol Community Health	1999	Ryan G	Australia	1	230-34	
291	87030662	1	41	Why are deaths from asthma increasing ?	Eur J Respir Dis	1986	Sears MR	New-Zealand	1	175-81	
1061/695	87046016	1	41	Accuracy of certification of deaths due to asthma - a national study	American J of Epidemiology	1986	Sears MR	New-Zealand	1	1004-11	
3026			41	Increasing asthma mortality-fact or artifact ?	J Allergy Clin Immunol	1988	Sears MR	New-Zealand	1	957-60	
287	85252476	1	41	Are asthma mortality rates changing ?	Br J Dis Chest	1985	Stewart CJ	UK	1	229-34	
225	87029556	1	41	Worldwide differences in asthma prevalence and mortality. Why is asthma mortality so low in th	Chest	1986	Woolcock AJ	International	1	40s-45S	
1071/515	94174470	1	41	Asthma mortality and death certification in Northern Ireland	Thorax	1994	Wright SC	Ireland	1	141-43	
3027			41	Accuracy of death certificates in bronchial asthma. Accuracy of certification procedures during t	Thorax	1984	Brit Thor Assoc	UK	1	505-09	
3018			41	Death from asthma in two regions of England	BMJ	1982	Brit Thor Assoc	UK	1	1251-55	

DISEASES OF THE DIGESTIVE SYSTEM - Eurostat shortlist n° 42

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1047/497	95289336	1	42	The cause of death in inflammatory bowel disease: a comparison of death certificates and hosp	American J of Gastroenterol	1995	Nordenholtz KE	USA	1	927-32	
390	97079753	1	42	Inguinal hernia repair: incidence of elective and emergency surgery, readmission and mortality	Int J Epidemiol	1996	Primatesta P	UK	1	835-39	

ULCEROF STOMACH, DUODENUM AND JEJUNUM - Eurostat shortlist n° 43 (no article)

CHRONIC LIVER DISEASE - Eurostat shortlist n° 44

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1008/647	88161598	1	44	Accuracy of death certificates in the diagnosis of alcoholic liver cirrhosis	Alcohol Clin Exp Res	1988	Blake JE	Canada	1	168-72	
236	95102905	1	44	Worldwide patterns and trends in mortality from liver cirrhosis, 1955 to 1990	AEP	1994	La Vecchia C	International	1	480-86	

DISEASES OF THE SKIN AND SUBCUTANEOUS TISSUE - Eurostat shortlist n° 45 (no article)

DISEASES OF THE MUSCULOSKELETAL SYSTEM / CONNECTIVE TISSUE - Eurostat shortlist n° 46 (no article)

RHEUMATOID ARTHRITIS AND OSTEOARTHROSIS - Eurostat shortlist n° 47

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1036/699	86315726	1	47	Death certificate and mortality in rheumatoid arthritis	Scand J Rheumatol	1986	Laakso M	Finland	1	129-33	
120	85208145	1	47	Problems in the classification of cause of death diagnoses affecting the reliability of mortality st	J Chronic Dis	1985	Lindahl BIB	Sweden	1	409-18	
711	86059918	1	47	In what sense is rheumatoid arthritis the principal cause of death ?	J Chronic Dis	1985	Lindahl BIB	Sweden	1	963-72	
1111/718	85131558	1	47	The causal sequence on death certificates: errors affecting the reliability of mortality statistics fo	J Chronic Dis	1985	Lindahl BIB	Sweden	1	47-57	
795	94042616	2	47	Cause of death in 81 autopsied patients with rheumatoid arthritis	J Rheumatology	1994	Suzuki A	Japan	1	33-36	
660	88293037	1	47	Australian mortality statistics for rheumatoid arthritis 1950-81: analysis of death certificate data	Ann Rheum Dis	1988	Wicks IP	Australia	1	563-69	

DISEASES OF THE GENITOURINARY SYSTEM - Eurostat shortlist n° 48

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
391	97016349	1	48	Underreporting and misclassification of urinary tract cancer cases on death certificates	Epidemiology	1996	Chow WH	USA	1	517-20	
1052/523	94082632	1	48	Cause of death in patients with end-stage renal disease: death certificates vs registry reports	American J of Public Health	1993	Perneger TV	USA	1	1735-38	

DISEASES OF KIDNEY AND URETER - Eurostat shortlist n° 49 (no article)

COMPLICATIONS OF PREGNANCY, CHILDBIRTH AND PUERPERIUM - Eurostat shortlist n° 50

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
475	95405824	1	50	Maternal mortality in developed countries: not just a concern of the past	Obstet & Gynecol	1995	Atrash HK	International	1	700-05	
70	92064377	1	50	Reasons for the underreporting of maternal mortality in France, as indicated by a survey of all d	Int J Epidemiol	1991	Bouvier-Colle MH	France	1	717-21	
165	92166287	1	50	Mortalité maternelle en France. Fréquence et raisons de sa sous-estimation dans la statistique	J Gynecol Obstet Biol Reprod	1991	Bouvier-Colle MH	France	2	885-91	
2016			50	Les causes obstétricales de décès expliquent-elles les différences de mortalité maternelle entr	J Gynecol Obstet Biol Reprod	1999	Coeuret-Pellicer M	Europe	2	62-68	
765	92199107	2	50	Trauma: the leading cause of maternal death	J of Trauma	1992	Fildes J	USA	1	643-45	
261	91157448	1	50	Implications of the ICD-10 definitions related to death in pregnancy, childbirth or the puerperiun	World Health Stat Q	1990	Fortney JA	USA	1	246-48	
378	97188715	1	50	Anesthesia-related deaths during obstetric delivery in the United States, 1979-1990	Anesthesiology	1997	Hawkins JL	USA	1	277-84	
270	90081497	1	50	When is a maternal death a maternal death ? A review of maternal deaths at the Mercy Matern	Med J Aust	1989	Henry OA	Australia	1	628-31	
400	97087240	1	50	Mortalité maternelle à Nice. Résultats d'une enquête de type "RAMOS" à partir des registres d	J Gynecol Obstet Biol Reprod	1996	Huss M	France	2	636-44	
410	96421368	1	50	Maternal mortality in the Irish Republic, 1989-1991	Ir Med J	1996	Jenkins DM	Ireland	1	140-41	
488	95358895	1	50	Monitoring maternal mortality using vital records linkage	Am J Prev Med	1995	Jocums S	USA	1	75-78	
2109			50	A propos de l'article "Mortalité maternelle et structure des naissances : une explication possible	Rev Epidém et Santé Publ	1996	Leclerc A	France / UK	2	181-82	CM on 478
190	89248576	1	50	La mortalité maternelle en France et ses incertitudes	Bull Acad Natle Med	1988	Magnin P	France	2	1213-22	
478	95397045	1	50	Mortalité maternelle et structure des naissances : une explication possible de la surmortalité en	Rev Epidém et Santé Publ	1995	Salanave B	France / UK	1	301-07	CM : 2109
2015			50	Classification differences and maternal mortality: a European study	Int J Epidemiol	1999	Salanave B	Europe	1	64-69	
27	97351536	1	50	Underreporting of maternal mortality in The Netherlands	Obstet & Gynecol	1997	Schuitemaker N	Netherlands	1	78-82	
193	86310662	1	50	Misclassification of maternal deaths-Washington State	MMWR	1986	(MMWR)	USA	1	621-23	
508	95139933	1	50	Pregnancy-related mortality-Georgia, 1990-1992	MMWR	1995	(MMWR)	USA	1	93-96	

CERTAIN CONDITIONS ORIGINATING IN THE PERINATAL PERIOD - Eurostat shortlist n° 51

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
2157			51	A new hierarchical classification of causes of infant deaths in England and Wales	Archives Disease Childhood	1994	Alberman E	UK	1	403-09	
2084			51	Certifying death in infancy	BMJ	1985	Alderson MR	UK	1	153	
2103			51	Annotation: the accurate measurement of gestational age - a critical step toward improving feta	American J of Public Health	1997	Alexander GR	USA	1	1278-79	
152	93343344	1	51	Improving cause-of-death statistics: the case of fetal deaths	American J of Public Health	1993	Atkinson D	USA	1	1084-85	CM : 2099
1080/606	91129832	1	51	Underlying causes of death in down syndrome: accuracy of British Columbia death certificate d	Canadian J of Public Health	1990	Baird PA	Canada	1	456-61	
93	90071493	1	51	Acta commentary. Classification and audit of perinatal deaths: the Icelandic and other example	Acta Obstet Gynecol Scand	1989	Bergsjo P	Sweden	1	99-100	
350	97311369	2	51	Le certificat médical de décès néonatal	Arch Pediatr	1997	Blondel B	France	2	1012-15	
2128			51	Registration of births of very low birthweight infants	Lancet	1990	Blondel B	France	1	1317-18	CM on 2126
2156			51	Mort subite du nourrisson: aspects épidémiologiques, histoire et statistiques	mt pédiatrie	1998	Bouvier-Colle MH	France	2	253-60	
787	94377692	2	51	Contribution of developmental disabilities to childhood mortality in the United States: a multiple-	Paediatr Perinat Epidemiol	1994	Boyle CA	USA	1	411-22	
35	95364511	1	51	Effect of changing the stillbirth definition on evalutation of perinatal mortality rates	Lancet	1995	Cartlidge PHT	UK	1	486-88	CM on 34
509	95135236	1	51	Value and quality of perinatal and infant postmortem examinations: cohort analysis of 400 cons	BMJ	1995	Cartlidge PHT	UK	1	155-58	CM : 2113
153	93330655	1	51	Infant mortality statistics do not adequately reflect the impact of short gestation	Pediatrics	1993	Carver JD	USA	1	229-32	
345	87100869	1	51	Commentary on current World Health Organization definitions used in perinatal statistics	Br J Obstet Gunaecol	1986	Chiswick ML	UK	1	1236-38	
69	92084020	1	51	Classification of perinatal deaths	Eur J Obstet Gynecol Reprod Bio	1991	Cole S	International	1	17-19	
94	90071479	1	51	International collaborative effort (ICE) on birth weight, plurality, perinatal and infant mortality	Acta Obstet Gynecol Scand	1989	Cole S	USA	1	113-17	
1014/642	89250260	1	51	Accuracy of death certificates in neonatal deaths	Community Med	1989	Cole SK	UK	1	01-08	
295	87210426	1	51	The reliability of perinatal mortality statistics in the Netherlands	Am J Obstet Gynecol	1987	Doornbos JPR	Netherlands	1	1183-87	
245	93213572	1	51	Annotation. Determining the accuracy and relevance of mortality rates for extremely low birthwe	J Paediatr Child Health	1993	Doyle LW	Australia	1	01-03	
1023/692	87100868	1	51	A validation of underlying cause of death, as recorded by clinicians on stillbirth and neonatal de	Br J Obstet Gunaecol	1986	Duley LMM	UK	1	1233-35	
229	86182891	1	51	The search for perinatal definitions and standards	Acta Paediatr Scand Suppl	1985	Dunn PM	UK	1	07-16	
2126			51	European community collaborative study of outcome of pregnancy between 22 and 28 weeks' d	Lancet	1990	EC Group	International	1	782-84	CM : 68 ; 2128 ; 2127
102	88104365	1	51	The 1989 revisions of the US standard cetificates of live birth and death and the US standard r	American J of Public Health	1988	Freedman MA	USA	1	168-72	
25	97425218	1	51	Quality assessment of fetal death records in Georgia: a method for improvement	American J of Public Health	1997	Gaudino JA	USA	1	1323-27	CM : 2103
235	95175404	1	51	Impact of induced abortions and statistical definitions on perinatal mortality figures	Paediatr Perinat Epidemiol	1994	Gissler M	Finland	1	391-400	
1027/637	89349569	1	51	Fetal death ratios in a prospective study compared to state fetal death certificate reporting	American J of Public Health	1989	Goldhaber MK	USA	1	1268-70	
368	97171510	1	51	Sudden infant death syndrome and parental smoking - a literature review	Paediatr Perinat Epidemiol	1997	Golding J	UK	1	67-77	
251	92305746	1	51	What counts as cot death ?	BMJ	1992	Gordon RR	UK	1	1508	CM on 2151
41	96040921	1	51	Registration of vital data: are live births and stillbirths comparable all over Europe ?	Bull Word Health Organ	1995	Gourbin G	Europe	1	449-60	
116	87296449	1	51	Accuracy of fetal death reports: comparison with data from an independent stillbirth assessmen	American J of Public Health	1987	Greb AE	USA	1	1202-06	
696	87023520	1	51	A comparative study of hospital fetal death records and Washington State fetal death certificate	American J of Public Health	1986	Harter L	USA	1	1333-34	
449	96210398	1	51	Autopsies of sudden infant death syndrome - classification and epidemiology	Acta Paediatr	1995	Hatton F	France	2	1366-71	CM : 2153
241	94154443	1	51	Sudden natural death in childhood. A review of forensic autopsy protocols in cases of sudden d	Acta Paediatr	1993	Helweg-Larsen K	Denmark	1	975-78	
103	88055139	1	51	Quality of perinatal death registration. A study in Hainaut, Belgium	Eur J Pediatr	1987	Hertoghe L	Belgium	1	473-76	
296	87068883	1	51	Problèmes de définition et de classification des décès périnatals	Rev Epidém et Santé Publ	1986	Hertoghe L	Belgium	2	161-67	
403	97047508	1	51	Selective abortion. Dead fetuses might have to be registered as stillbirths	BMJ	1996	Heys RF	UK	1	1004	

2127		1		Registration of births at less than 22 weeks' gestation	Lancet	1990	Heys RF	UK	1	1192	CM on 2126
99	89300670	1	51	Deaths in infants and children. The importance of correct certification of the manner of death	Am J Forensic Med Pathol	1989	Hollander N	USA	1	93-94	
240	94234420	1	51	International infant mortality rates: bias from reporting differences	American J of Public Health	1994	Howell EM	International	1	850-52	
2086			51	Definitions and recommendations related to perinatal, neonatal, infant and maternal mortality st	OMS	1989	INSERM	France	1	7p	
163	91194464	1	51	When is a fetus a dead baby ?	Lancet	1991	Iskander R	UK	1	856	CM on 164
379	97193699	1	51	Risk status at discharge and cause of death for postneonatal infant deaths: a total population s	Pediatrics	1997	Kempe A	USA	1	338-44	
2099			51	The coding of underlying cause of death from fetal death certificates: issues and policy conside	American J of Public Health	1993	Kirby RS	USA	1	1088-91	CM on 152
118	86156399	1	51	Underreporting of infant deaths: then and now	American J of Public Health	1986	Kleinman JC	USA	1	365-66	
669	87176313	1	51	Analysis of unlinked infant death certificates from the NIMS project	Public Health Rep	1987	Lambert DA	USA	1	200-04	
397	97085366	1	51	Potentially avoidable perinatal deaths in Denmark and Sweden 1991	Acta Obstet Gynecol Scand	1996	Langhoff-Roos J	Denmark-Sweden	1	820-25	
293	88280720	1	51	Under reporting of perinatal mortality	Aust N Z Obstet Gynaecol	1987	Lawson GW	UK	1	312-14	
2151			51	What counts as cot death?	BMJ	1992	Limerick SR	UK	1	1176	CM : 251
358	92323382	2	51	International infant mortality ranking: a look behind the numbers	Health Care Financ Rev	1992	Liu K	International	1	105-18	
498	95267473	1	51	Validity of the Maternal and Child Health Services Block Grant as an indicator of state infant mo	Am J Prev Med	1995	Margolis LH	USA	1	40-45	
1112			51	Santé et mortalité infantile. Indicateurs et comparabilité	Chaire Quetelet	1995	Masuy-Stroobant G	Belgium	2	371-99	
68	91087653	1	51	Registration of stillbirths and neonatal deaths of very low birthweight babies	Lancet	1991	Matthias GSH	Australia	1	117	CM on 2126
2087			51	The underregistration of neonatal deaths: Georgia 1974-77	American J of Public Health	1980	McCarty	USA	1	977-82	
34	96011435	1	51	Changing the definition of perinatal mortality	Lancet	1995	Morrison JJ	UK	1	1038	CM : 35
180	90132358	1	51	Contrasts in the multiple causes of stillbirth, neonatal death and postneonatal death	J Epid Com Health	1989	Murphy M	UK	1	343-45	
501	95233794	1	51	Suffocation, choking, and strangulation in childhood in England and Wales: epidemiology and p	Arch Dis Child	1995	Nixon JW	UK	1	06-10	
2112			51	Editorial: Ethnicity, socioeconomic status, and the 50-year US infant mortality record	American J of Public Health	1995	Oeschli FW	USA	1	905-06	CM on 498
387	97055107	1	51	Validity of hospital discharge data regarding intentionality of fatal pediatric injuries	Epidemiology	1996	Olsen SJ	USA	1	644-47	
191	87176316	1	51	The NCHS pilot project to link birth and infant death records: stage 1	Public Health Rep	1987	Prager K	USA	1	216-23	
247	93191741	1	51	Mort subite du nourrisson. Doit-on changer la définition ?	Ann Pathol	1992	Rambaud C	France	2	325-27	
364	97313292	1	51	Pediatric window-cord strangulations in the United States, 1981-1995	JAMA	1997	Rauchschwalbe R	USA	1	1696-98	
653	89121172	1	51	New birth and death certificates	Del Med J	1988	Richards ML	USA	1	726	
2153			51	SIDS or not SIDS ? Classification problems of sudden infant death syndrome	Acta Paediatr	1996	Rognum TO	Norway	1	401-03	
67	91124995	1	51	Voluntary notification of fetal death before 28 weeks	Lancet	1991	Settatree R	UK	1	495	
493	95328659	1	51	Infant mortality in the United States: trends, differentials, and projections, 1950 throught 2010	American J of Public Health	1995	Singh GK	USA	1	957-64	CM : 2112
327	87124308	1	51	Stillbirth	Am Fam Physician	1987	Stack JM	USA	1	117-24	
668	87176314	1	51	Experiences with linked birth and infant death certificates from the NIMS project	Public Health Rep	1987	Strauss LT	USA	1	204-10	
466	96068376	1	51	Birthweight-specific infant mortality risks for Native Americans and Whites, United States,1960	Soc Biol	1995	VanLandingham M	USA	1	83-94	
226	87018529	1	51	Vous avez dit mortinatalité ?	Rev Fr Gynecol Obstet	1986	Viel JF	France	1	373-75	
2113			51	Perinatal and infant postmortem examination	BMJ	1995	Waldron G	UK	1	870	CM on 509
32	97108969	1	51	Infant mortality: some international comparisons	Pediatrics	1996	Wegman ME	International	1	1020-27	
307	94301892	1	51	The utility of autopsies in a pediatric emergency department	Pediatr Emerg Care	1994	Whitehouse SR	Canada	1	72-75	
192	87176315	1	51	Using linked birth and infant death files for program planning and evaluation: NIMS workshop le	Public Health Rep	1987	Zahniser C	USA	1	211-16	
164	91155522	1	51	When is a fetus a dead baby ?	Lancet	1991	(Lancet)	UK	1	526	CM : 163
438	96198586	1	51	Infant mortality - United States, 1993	MMWR	1996	(MMWR)	USA	1	211-15	
537	93196604	1	51	Classification of American Indian race on birth and infant death certificates - California and Mor	MMWR	1993	(MMWR)	USA	1	220-23	

CONGENITAL MALFORMATIONS AND CHROMOSAL ABNORMALITIES - Eurostat shortlist n° 52

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
725	88243494	2	52	Evaluation de l'enregistrement des anomalies congénitales dans les statistiques belges d'état c	Arch Belg Med Soc Hyg Med Trav Med Leg	1987	De Wals P	Belgium	2	441-51	

CONGENITAL MALFORMATIONS OF THE NERVOUS SYSTEM - Eurostat shortlist n° 53 (no article)

CONGENITAL MALFORMATIONS OF THE CIRCULATORY SYSTEM - Eurostat shortlist n° 54 (no article)

SYMPTOMS, SIGNS, ABNORMAL FINDINGS, ILL-DEFINED CAUSES - Eurostat shortlist n° 55

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
2056			55	A brief original contribution. Symptoms, signs, and ill-defined conditions: a leading cause of dea	American J of Epidemiology	1990	Becker TM	USA	1	664-68	
65	92161083	1	55	Risk factors associated with the classification of unspecified and/or unexplained causes of deat	American J of Public Health	1992	Cragle DL	USA	1	455-57	CM : 758
2030			55	Répartition des décès de causes non spécifiées parmi les causes médicales spécifiées	Santé Sécurité Sociale	1975	Derriennic F	France	2	01-29	
758	94027546	2	55	Classifying unspecified and/or unexplained causes of death	American J of Public Health	1993	Hanzlick R	USA	1	1492-93	CM on 65
2017			55	Décès pour causes non specifiées ou mal définies	Les causes de décès INSEE	1947	Ledermann S	France	2	509-14	

SUDDEN INFANT DEATH SYNDROME - Eurostat shortlist n° 56

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
252	92304181	1	56	Fréquence des autopsies en France. Conséquence sur l'estimation des taux de mort subite pa	Arch Fr Pediatr	1992	Bouvier-Colle MH	France	2	181-86	
452	96170408	1	56	Minor inflammatory lesions and sudden infant death: cause, coincidence or epiphenomena ?	Pediatr Pathol Lab Med	1995	Byard RW	Australia	1	649-54	
477	95389420	1	56	Has changing diagnostic preference been responsible for the recent fall in incidence of sudden	J Paediatr Child Health	1995	Byard RW	Australia	1	197-99	
2136			56	Sudden infant death syndrome: will establishing risk factors spuriously reduce incidence ?	JAMA	1993	Hanzlick R	USA	1	2684-85	
1101/511	94296212	1	56	Sudden infant death syndrome: risk factors, cause of death , and the death certificate	Arch Pathol Lab Med	1994	Hanzlick R	USA	1	679-80	
1102/489	95356341	1	56	Improving the accuracy of death certificates	JAMA	1995	Hanzlick R	USA	1	537-38	
716	85236090	1	56	Identification of cases of sudden infant death syndrome from death certificates	J Epid Com Health	1985	Keeling JW	UK	1	148-51	
43	95282449	1	56	Sudden infant death (SIDS) in Austria. How reliable is the diagnosis ?	Wien Klin Wochenschr	1995	Kerbl R	Austria	1	237-41	
738	88195682	2	56	Sudden infant deaths: Cause for concern	Health Visitor	1988	Limerick S	UK	1	233-34	
483	95380227	1	56	Prematurity, sudden infant death syndrome, and age of death	Pediatrics	1995	Malloy MH	USA	1	464-71	
484	95371378	1	56	Incidence of sudden infant death syndrome in Olmsted County, Minnesota: 1945 through 1992	Mayo Clin Proc	1995	McLaughlin SA	USA	1	837-43	
207	89010429	1	56	SIDS and autopsies: does the medico-legal system in Georgia work for SIDS deaths ?	J Med Assoc Ga	1988	Samuels BN	USA	1	649-53	
486	95366011	1	56	Bronchus-associated lymphoid tissue (BALT) in the lungs of children who had died from sudde	Thorax	1995	Tschernig T	Germany	1	658-60	

UNKNOWN AND UNSPECIFIED CAUSES - Eurostat shortlist n° 57

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
758	93295002	2	57	Classifying unspecified and/or unexplained causes of death	American J of Public Health	1993	Hanzlick R	USA	1	1492-93	

EXTERNAL CAUSES OF INJURY AND POISONING - Eurostat shortlist n° 58

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
1092/496	95294520	1	58	The medical examiner. When to report and help with death certificates	J Fla Med Assoc	1995	Adams VI	USA	1	255-60	
1125/512	94233271	1	58	Certificates of death, beating and wounding: issuing and consequences. Requirements	Rev Prat	1994	Baccino E	France	2	133-39	
242	94055329	1	58	Comparative analysis of mortality due to violence in developed countries and in a few developi	World Health Stat Q	1993	Bourbeau R	International	2	avr-32	
159	92157854	1	58	The certification and disposal of the dead in major disasters	Med Sci Law	1992	Busuttil A	UK	1	sept-13	
431	96258732	1	58	Certification of cause of death in patients dying soon after proximal femoral fracture	BMJ	1996	Calder SJ	UK	1	1515	CM : 405;406407
104	88051340	1	58	Death notification	Bull Am Acad psychiatry Law	1987	Eth S	USA	1	275-81	
74	91112576	1	58	Death notification	Am J Forensic Med Pathol	1990	Haglund WD	USA	1	342-47	
275	89021422	1	58	The problem of determining the manner of death as suicide or accident in borderline cases	Z Rchtsmed	1988	Huusko R	Finland	1	207-13	
62	92377783	1	58	The perils of investigating and certifying deaths in police custody	Am J Forensic Med Pathol	1992	Luke JL	USA	1	98-100	
1044/626	90053495	1	58	Validity of death certificates for injury-related causes of death	American J of Epidemiology	1989	Moyer LA	USA	1	1024-32	
1126/600	91289047	1	58	Death certificates, assault and battery certificates. Issuing of certificates and its consequences	Rev prat	1991	Muller PH	France	2	1202-06	
405	97024356	1	58	Mortality inferred from death certificates reflects coroners' practice, not the true mortality	BMJ	1996	Parker M	UK	1	879	CM on 431
406	97024357	1	58	Postmortem examination should always be carried out for death due to trauma	BMJ	1996	Roberts ISD	UK	1	879	CM on 431
3040			58 /63	Homicide, suicide, motor vehicle crash, and fall mortality: United States' experience in compare	American J of Public Health	1989	Rockett IRH	USA	1	1396-400	
3041			58	Injuries in relation to chronic disease: an international view of premature mortality	American J of Public Health	1987	Rockett IRH	International	1	1345-46	
407	97024355	1	58	All such deaths must be reported to the coroner	BMJ	1996	Rutty GN	UK	1	879	CM on 431
277	88229590	1	58	Determinaton of cause and mode of death before and after medicolegal autopsy: a comparative	J Forensic Sci	1988	Segerberg-Konttinen M	Finland	1	441-47	
63	92265074	1	58	Reliability of data sources for poisoning deaths in Massachusetts	Am J Emerg Med	1992	Soslow AR	USA	1	124-27	
24	97445688	1	58	Recommended framework for presenting injury mortality data	MMWR	1997	(MMWR)	USA	1	1-30	

ACCIDENTS - Eurostat shortlist n° 59

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
255	92075085	1	59	Population and registered vehicle data vs. road deaths	Accid Anal & Prev	1991	Andreassen D	International	1	343-51	
311	93200249	1	59	Quality control in fatally injured patients: the value of the necropsy	Eur J Surg	1993	Barendregt WB	Netherlands	1	9-13	
459	96107983	1	59	Accuracy of ICD-9 coding with regard to childhood accidents	Health Bulletin	1995	Beattie TF	UK	1	395-97	
148	94072234	1	59	Child accident data: accessible and available ?	J Public Health Med	1993	Deane M	UK	1	226-28	CM : 2137
1020/513	94226142	1	59	Medical examiner data in injury surveillance: a comparison with death certificates	American J of Epidemiology	1994	Dijkhuis H	USA	1	637-43	
1022/636	89367719	1	59	Death certification in fractured neck of femur	Public Health	1989	Donaldson LJ	UK	1	237-43	
213	88020991	1	59	Injuries and death among elderly persons	American J of Epidemiology	1987	Fife D	USA	1	936-41	
2000			59	International comparative analysis of injury mortality. Findings from the ICE on injury statistics	Advance Data	1998	Fingerhut LA	USA	1	01-20	
147	94072241	1	59	Use of Coroner's reports for surveillance of accidental death	J Public Health Med	1993	Gaffney BP	Ireland	1	272-76	
1089/499	95259691	1	59	The accuracy of death certificates in identifying work-related fatal injuries	American J of Epidemiology	1995	Kraus JF	USA	1	973-79	
2160			59	International comparisons of injury mortality in the elderly: issues and differences between Ne	Int J Epid	1995	Langlois JA	USA/New Zeala	1	136-43	
2159			59	La mortalité par accident des enfants et des adolescents dans huit pays développés	Population	1980	Lévy C	International	2	291-320	
341	90234120	1	59	Differences in reported car weight between fatality and registration data files	Accid Anal & Prev	1990	Partyka SC	USA	1	161-66	
2082			59	Determinig injury at work on the California death certificate	American J of Public Health	1997	Peek-Asa C	USA	1	998-1002	
205	89209688	1	59	Are hip fractures underestimted as a cause of death ? The influence of coroners and pathologis	Community Medicine	1988	Pemberton J	UK	1	117-23	

553	93071904	1	59	Unspecified injuries on death certificates: a source of biais in injury research	American J of Epidemiology	1992	Romano PS	USA	1	863-72	
1059/585	92081891	1	59	Representativeness of deaths identified through the injury-at-work item on the death certificate	American J of Public Health	1991	Russel J	USA	1	1613-18	
2137			59	Child accident data	J Public Health Med	1994	Sidhu K	UK	1	117-18	CM on 148
162	91229144	1	59	Effectiveness of source documents for identifying fatal occupational injuries: a synthesis of stud	American J of Public Health	1991	Stout N	USA	1	725-28	
208	88307735	1	59	Fatal occupational injuries in US industries, 1984: comparison of two national surveillance syst	American J of Public Health	1988	Stout-Wiegand N	USA	1	1215-17	

OF WHICH TRANSPORT ACCIDENTS - Eurostat shortlist n° 60

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
100	89193903	1	60	Matching fatal accident reporting system cases with National Center for health statistics motor	Accid Anal and Prev	1989	Fife D	USA	1	79-83	
346	86133067	1	60	Reliability of motor vehicle fatality statistics: an international perspective	Canadian J Public Health	1985	Hutchinson TP	International	1	413-14	
50	95000134	1	60	Accuracy of fatal motorcycle-injury reporting on death certificates	Accid Anal and Prev	1994	Lapidus G	USA	1	535-42	
355	94034891	2	60	Inaccuracies in the official statistics of fatal traffic accidents - Comparative studies in West Ger	J Traffic Med	1993	Metzner G	Germany	1	165-69	

OF WHICH ACCIDENTAL FALLS - Eurostat shortlist n° 61

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
739	88146761	2	61	Are hip fractures underestimated as a cause of death ? The influence of coroners and patholog	Community Medicine	1988	Pemberton J	UK	1	117-23	

OF WICH ACCIDENTAL POISONING - Eurostat shortlist n° 62 (no article)

SUICIDE AND INTENTIONAL SELF-HARM - Eurostat shortlist n° 63

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
768	91353093	2	63	Causes of death in a cohort of 50 465 young men - validity of recorded suicide as underlying ca	Scandinavian Journal of Social Medi	1991	Allebeck P	Sweden	1	242-47	
3039			63	Predictors of completed suicide in a cohort of 50 465 young men: role of personality and deviar	British Medical Journal	1988	Allebeck P	Sweden	1	176-78	
3010			63	The comparability of suicide rates	British J of Psychiatry	1975	Atkinson MW	International	1	247-56	
659	89023034	1	63	The use of mental status in death certification of suicide	American J Forensic Med Pathol	1988	Batten PJ	USA	1	203-06	
349	97359224	2	63	Death diagnoses among suicides: an overview based on official Danish records, 1972-93	Nord J Psychiatry	1997	Bille-Brahe U	Denmark	1	339-49	
479	95397001	1	63	The reporting of in-patient suicides: identifying the problem	Public Health	1995	Blain PA	UK	1	293-301	
263	91054140	1	63	Australian suicide data and the use of "undetermined" death category (1968-1985)	Australian and New Zealand J of Psychiatry	1990	Cantor CH	Australia	1	381-84	
592	92022727	1	63	Suicide in the elderly: a two-year study of data from death certificates	Southern Medical Journal	1992	Casey DA	USA	1	1185-87	CM : 2143
470	96044466	1	63	Trends and patterns in suicide in England and Wales	International J of Epidemiol	1995	Charlton J	UK	1	s45-52	
3011			63	Suicide rates in Ireland	Psycological Medicine	1983	Clarke-Finnegan M	Ireland	1	385-91	
490	95393711	1	63	Under-reporting of suicide in an Irish county	Crisis	1995	Connolly JF	Ireland	1	34-38	
3012			63	Suicide: who's counting ?	Public Health Reports	1977	Farberow NL	USA	1	223-32	
3013			63	The social scientist as coroner's deputy	J of Forensic Sciences	1971	Farberow NL	USA	1	15-39	
3003			63	Assessing the epidemiology of suicide and parasuicide	British J of Psychiatry	1988	Farmer RDT	UK	1	16-20	
3009			66	The truth about suicide in Portugal	Acta Psychiatr Scand	1989	Ferreira de Castro E	Portugal	1	334-39	
234	95220565	1	63	Suicide during pregnancy and its neglect as a component of maternal mortality	Int J of Gynaecol & Obstetrics	1994	Frautschi S	International	1	275-84	
2143	92022727	1	63	Suicide in the elderly	Southern Medical Journal	1992	Galanos AN	USA	1	331	CM on 592
183	90020409	1	63	Certification change versus actual behavior change in teenage suicide rates, 1955-1979	Suicide and Life-Threat Behavior	1989	Gist R	USA	1	277-88	
741	88077898	2	63	Suicide, and other causes of death, following attempted suicide	British Journal of Psychiatry	1988	Hawton K	UK	1	359-66	
211	88129982	1	63	Scandinavian routines and practices in the registration of suicide	Acta Psychiatr Scand	1987	Hesso R	Nordic countries	1	17-21	
256	91361353	1	63	Medical examiners and manner of death	Suicide and Life-Threat behavior	1991	Jarvis GK	Canada	1	115-33	
210	88100743	1	63	Improving the validity and reliability of medical-legal certifications of suicide	Suicide and Life-Threat behavior	1987	Jobes DA	USA	1	310-25	
40	97104588	1	63	Improving procedures for recording suicide statistics	Irish Medical Journal	1996	Kelleher MJ	UK	1	14-15	
3005			63	Suicide in Cork and Ireland	British J of Psychiatry	1990	Kelleher MJ	Ireland	1	533-38	
324	89045028	1	63	Miscounting suicides	Suicide and Life-Threat behavior	1988	Kleck G	USA	1	219-36	
325	88129983	1	63	Sources of error in registering suicide	Acta Psychiatr Scand	1987	Kolmos L	Nordic countries	1	22-43	
586	92101293	1	63	Reply to Kim Smith, PhD, on "Teen suicide and changing cause-of-death certification, 1953-19	Suicide and Life-Threat behavior	1991	Males M	USA	1	402-05	CM on 754
587	92101283	1	63	Teen suicide and changing cause-of-death certification, 1953-1987	Suicide and Life-Threat behavior	1991	Males M	USA	1	245-59	CM : 586
3014			63	Trends in suicide rate for England and Wales 19875-80	British J of Psychiatry	1984	McClure GMG	UK	1	119-26	
301	85260263	1	63	The reliability of reported suicide mortality statistics: an experience from Belgium	International J of Epidemiol	1985	Moens GFG	Belgium	1	272-75	
3006			63	Validity of death certificates for injury-related causes of death	American J of Epidemiol	1989	Moyer LA	USA	1	1024-32	
3015			63	The "undetermined" ruling: A medicolegal dilemma	J of Forensic Sciences	1979(?)	Murphy GK	USA	1	483-91	
39	97245079	1	63	Changes in classification of suicide in England and Wales: time trends and associations with co	Psychological Medicine	1997	Neeleman J	UK	1	467-72	
375	97068232	1	63	Suicide as a crime in the UK: legal history, international comparisons and present implications	Acta Psychiatr Scand	1996	Neeleman J	UK	1	252-57	
268	89222976	1	63	A consideration of the validity and reliability of suicide mortality data	Suicide and Life-Threat behavior	1989	O'Carrol PW	USA	1	01-16	
3002			63	The limitations of official suicide statistics	British J of Psychiatry	1995	O'Donnell I	UK	1	458-61	
145	94206602	1	63	Suicide in North and West Devon: a comparative study using coroner's inquest records	J of Public Health Medicine	1993	Pearson VAH	UK	1	320-26	
146	94143921	1	63	Adequacy of official suicide statistics for scientific research and public Policy	Suicide and Life-Threat behavior	1993	Phillips DP	USA	1	307-19	
363	88252834	2	63	Social construction or causal ascription: distinguishing suicide from undetermined deaths	Soc Psychiatry Epidemiol	1988	Platt S	UK	1	217-21	

717	85222835	1	63	The difference between date of suicidal act and recorded death certificate date in 204 consecu	American J of Public Health	1985	Rich CL	USA	1	778-79	
3040			63	Homicide, suicide, motor vehicle crash, and fall mortality: United States' Experience in compara	American J of Public Health	1989	Rockett IRH	USA	1	1396-400	
3016			63	A further investigation of differences in the suicide rates of England and Wales and of Scotland	British J of Psychiatry	1975	Ross O	UK	1	575-82	
2144			63	Validity and reliability of trends in suicide statistics	Wld Hlth statist. Quart.	1983	Sainsbury P	UK	1	339-48	
3000			63	The accuracy of officially reported suicide statistics for purposes of epidemiological research	J of Epid Community Health	1982	Sainsbury P	International	1	43-48	
38	97321333	1	63	Coroner's verdicts in the elderly: a suicide or an open verdict ?	International J Geriatric Psychiatr	1997	Salib E	UK	1	481-83	
29	97267053	1	63	Perspective: suicide in Europe	Suicide and Life-Threat behavior	1997	Schmidtke A	Europe	1	127-36	
754	92011401	2	63	Comments on"Teen suicide and changing cause of death certification, 1953-1987"	Suicide and Life-Threat behavior	1991	Smith K	USA	1	260-62	CM on 58 / CM : 586
318	91183392	1	63	The adequacy of suicide statistics for use in epidemiology and public health	Canadian J of Public Health	1991	Speechley M	Canada	1	38-42	
195	90000088	1	63	On suicide statistics	Artic Med Res	1989	Thorslund J	Greenland	1	124-30	
1067/538	93171796	1	63	On the influence of data source in aggregated data studies: a comparative study of suicide info	J of Epid Community Health	1993	Van de Voorde H	Belgium	1	73-75	
170	91134297	1	63	Do statistics lie ? Suicide in Kildare - and in Ireland	Psychological Medicine	1990	Walsh D	Ireland	1	867-71	
186	89070449	1	63	Operational criteria for determining suicide	MMWR	1988	(MMWR)	USA	1	773-74/79-80	
203	89081419	1	63	Leads from the MMWR. Operational critera for determining suicide	JAMA	1989	(JAMA)	USA	1	360 ; 366	

HOMICIDES, ASSAULT - Eurostat shortlist n° 64

N°	Base Nr	Base	Path.	Title	Journal	Year	Author	Country	Lg	Pages	Relation
657	89047970	1	64	The accuracy of industry data from death certificates for workplace homicide victims	American J of Public Health	1988	Davis H	USA	1	1579-81	
1037/623	90119887	1	64	Misclassification of childhood homicide on death certificates	American J of Public Health	1990	Lapidus GD	USA	1	213-14	
608	910181860	1	64	Comparing death certificate data with FBI crime reporting statistics on U.S. homicides	Public Health Reports	1990	Rokaw WM	USA	1	447-55	
724	89097270	2	64	Comparability and utility of national homicide data from death certificates and police records	Statistics in Medicine	1989	Rokaw WM	USA	1	390	

EVENTS OF UNDETERMINED INTENT - Eurostat shortlist n° 65 (no article)

III.2 ANALYSIS ON SPECIFIC CAUSES OF DEATH

The aim of this section was to provide, for each group of pathologies selected, an analysis based on an overview of the Eurostat mortality statistics, a summary of European experts opinions and the synthesis of methods, results and recommendations drawn from the studies published.

These analyses must be considered as a first tool for the users of statistics, enabling them to be aware and to take in account on thheir analysis of certain quality or comparability problems linked to the specific causes of death analysed. The four articles written by researchers from the co-ordination team and external contributors partly follow the same framework. This framework can be considered as a basic methods for future works on other pathologies.

III.2.1 METHODOLOGY

Selection of the causes of death to investigate in priority

The selection of causes of death to be specifically investigated was motivated by criteria such as particular suspected biases, discrepancies in establishing the underlying cause of death, and the importance of the pathology in terms of public health. 14 causes of death from the Eurostat short list have been first selected with experts from the Steering Group in Stockholm meeting and the Plenary Group in Paris meeting. At the end, the number of causes of death is still 14 but they are not exactly the same as some changes occurred within the advancement of the work.

Table 1 **Causes of death specifically investigated**

Cause of death	European short list number	ICD-9 Code	ICD-10 Code
Suicide and controversial diseases			
Suicide and intentional self harm	63	E950-E959	X60-X84
Events of undetermined intent	65	E980-E989	Y10-Y34
Unknown and unspecified causes	57	798.1-9,799	R96-R99
Cardiovascular diseases	**33**	**390-459**	**I00-I99**
Ischaemic heart diseases	34	410-414	I20-I25
Cerebrovascular diseases	36	430-438	I60-I69
Other heart diseases	35	420-423, 425-429	I30-I33, I39-I52
Pulmonary diseases			
Neoplasm of larynx , trachea,/bronchus/lung	15	161-162	C32-C34
Diseases of the respiratory system	37	460-519	J00-J99
Influenza	38	487	J10-J11
Pneumonia	39	480-486	J12-J18
Chronic lower respiratory diseases	40	490-494,496	J40-J47
of which asthma	41	493	J45-J46
Neoplasm of breast	**17**	**174-175**	**C50**

Pathologies have been added because of their close link (competing causes of death) with those analysed: Diseases of the respiratory system (Influenza, Pneumonia, Chronic lower respiratory diseases), Cardiovascular diseases (Other heart diseases). Some others primarily selected have not been analysed because of lack of time or lack of materials (few published results): Malignant neoplasm of liver, Malignant neoplasm of prostate, Diabetes, Alcohol abuse (including alcoholic psychosis), Chronic liver disease, Unknown and unspecified and Transport accidents.

Three types of material

Three types of materials have been used: European causes of death statistics, questionnaire to experts from European countries, and extraction of the literature review.

European statistics on cause of death

Mortality data published by Eurostat was available for the year 1994 (1993 for Belgium), according to the 65 causes of death on the Short list. This data has been mainly analysed from maps representing the variation between countries with regard to the European overall rates.

CHRONIC LOWER RESPIRATORY DISEASES OF WHICH

ASTHMA

Male

Female

Country	Male			Female		
	death rate **	number of deaths	number / all cause number ***	death rate **	number of deaths	number / all cause number ***
Austria	4,6	177	0,5	2,6	174	0,4
Belgium****	5,5	186	0,3	2,7	286	0,4
Denmark	5,9	116	0,4	3,6	136	0,4
Finland	1,6	58	0,2	1,9	69	0,3
France	2,8	832	0,3	2,3	1 104	0,4
Germany	7,2	2 865	0,7	4,0	2 710	0,6
Greece	0,9	55	0,1	0,4	34	0,1
Ireland	2,6	59	0,2	2,6	50	0,3
Italy	2,2	740	0,3	1,3	672	0,2
Luxembourg	5,8	12	0,6	5,5	18	1,0
Netherlands	0,4	29	0,0	0,3	25	0,0
Portugal	3,2	153	0,3	1,9	128	0,3
Spain	1,9	401	0,2	1,9	562	0,4
Sweden	2,2	125	0,3	2,5	192	0,4
United Kingdom	2,3	693	0,2	2,3	982	0,3
Europe-EU	3,5	6 471	0,4	2,4	7 062	0,4
Iceland	4,1	5	0,8	3,5	7	0,9
Norway	6,6	162	0,7	4,5	168	0,8
Switzerland	2,9	112	0,4	2,9	121	0,4

Variation of the country death rates according to the European overall rate (1994)*

-50 % -20 % +20 % +50 %

Eurostat short list: n 41

* age standardized death rate (ref population: WHO European population)
cv: variation UK:
(r UK - r European-EU) x 100 / r European-EU

** standardized death rate for 100 000

*** (number for the specific cause / all cause number) x 100

**** 1993

Data source : Eurostat

Questionnaire Part 2

This questionnaire focused on opinions from experts from European countries on the quality and international comparability of mortality data for the selected pathologies.

For each group of the 14 pathologies primarily selected, 8 'closed' questions and 6 'open' have been completed. Experts were asked to give their opinion about biases in their national mortality data for each specific disease, and to propose recommendations to improve the quality and comparability of the data.

This questionnaire was complex to answer and did not bring as much information as we expected sending it. It has been answered by 13 out of 21.

1. Would you say that <u>in your country</u> published statistics on this cause of death (see map on left page) are?

RELIABLE (no biases)
FAIRLY RELIABLE (few biases) ❑
NOT VERY RELIABLE (some biases) ❑
NOT RELIABLE (many biases) ❑

2. If biases do exist (on the basis of the underlying cause published), in what direction?

UNDER ESTIMATION ❑ OVER ESTIMATION ❑

3. Indicate the proportion (if you can)?

0 to 15 % ❑
15 to 30 % ❑
more than 30 % ❑

4. If there is an under estimation, which other causes of death compensate for it?

.....
.....

5. If there is an over estimation, which other causes of death compensate for it?

.....
.....

6. Do you think that age influences these biases?

YES ❑ NO ❑

7. Which age group do you think is the most affected by biases?

0 TO 25 ❑ 25 TO 65 ❑ > 65 ❑

8. Do you think that these biases are due to?

MEDICAL CERTIFICATION ❑
CODING RULES ❑
OTHER REASONS ❑

9. Could you briefly explain the main reasons of biases?

.....
.....

10. Given that other countries remove stable, do you think that correction of these biases could change markedly the rank/colour of your country (see map) in Europe?

YES ❑ NO ❑

11. Are your answers to Questions 1 to 5 based on?

PERSONAL OPINION ❑
COLLECTIVE OPINION ❑
SPECIFIC STUDIES ❑

12. If your answers are based on specific studies, can you quote and briefly describe them?

.....
.....

13. What would you recommend to improve the reliability of this cause of death statistic in your country?

.....
.....

14. ANY OTHER COMMENTS:

.....
.....

Published studies data base

168 papers out of the 532 available in the final database were focused on the 4 groups of pathologies selected: 53 for suicide and controversial cases, 64 for cardiovascular diseases, 45 for pulmonary diseases (including cancer of larynx and trachea/brocus/lung) and 6 for breast cancer. All papers available for each group of pathologies have been analysed, and grouped according to the methods of investigation used in the studies reported by the concerned papers. Two main methodological approaches have been identified: studies based on the evaluation of individual cause of death certificates (measure of validity), and studies based on the analysis of vital statistics (taking in account competing causes).

III.2.2 POTENTIAL BIASES AND METHODS OF MEASURE

Biases can affect either the cause of death certification process or the medical codification process. These biases can lead to underestimation or overestimation of the death rate of a specific cause of death. However, the presence of various biases in opposite directions can also lead to a balanced misclassification ending in a correct average rate, in spite of errors on the individual cause of death certificates.

A. POTENTIAL CERTIFICATION AND CODIFICATION BIASES

A.1 POTENTIAL CERTIFICATION BIASES

Comparability biases in the certification process can result from various sources: causes of death certification processes, diagnosis methods, certification 'process-understanding' and certifier training. Cultural context and confidentiality rules can also have a large impact on certification practices.

Differences in the death certification procedures

In most European countries, it is the attending physician who is responsible for the certification of the cause of death. However, in case of violent or unexplained death, the certification process might vary largely according to countries.

i) In the British Isles, in case of violent or unexplained death, a coroner must carry out an inquest. It is a legal obligation. All cause of death certificates issued by the coroner take into account the results from this inquest.

ii) In Finland, all sudden, unexplained deaths, accidental deaths, suicide and violent deaths must be examined medicolegally (autopsy). The death certificate is received and inspected by a forensic specialist. Once approved, the death certificate will be sent to the National Death Register. If not approved, the death certificate is sent back to the physician for more accurate information.

iii) In some other countries, as in France, the attending physician is free to certify directly the cause of death or to ask for more specialised techniques. There is no legal obligation for this request. When the attending physician requests a specific investigation, it is a 'Legal Medical Institute' which carries out the inquiry, determines the cause of death (mainly after autopsy) and forwards it to the service in charge of the codification of deaths.

In either case, comparability biases might be due to: i) differences in the frequency of further investigations between countries, ii) the lack of efficiency in the circulation of information, particularly on the way back to the statistics office, iii) law obligation or not..

Differences in the diagnostic methods

Apart from the differences related to the registration process, when comparing data from different countries, biases might be due to discrepancies in the use of invasive diagnostic methods such as autopsy. The autopsy rates vary largely between countries, from 7 to 38% of all deaths (*WHO 1998*). For instance, in cases of sudden death in a country such as Sweden, the autopsy rate is over 90%. In other countries such as Belgium, the practice of autopsy is markedly less frequent. Here, autopsy is performed only for in-patients, must be requested by the clinician, and must be accepted by the relatives (*Vivario 1992*).

Differences in the certification process-understanding and training

Biases may also be due to differences in physician's training and skills for cause of death certification. The attending physician is usually in a better position than any other individual to make a judgement as to which of the conditions led directly to death, and to state the antecedent condition which gave rise to this cause. But, certain studies suggested that physician's skills and habits in causes of death certification varied widely (*Sorlie 1987*).

The cause of death certification as an epidemiological information source' is still not sufficiently integrated in medical school curriculum or in advanced medical courses. Most physicians fill in the cause of death certificates as best that they can. But, for some physicians, the death certificate is still mainly considered as a legal or administrative document, and not as an important epidemiological information. On the other hand, a region such as Catalonia has close links between the hospitals, the University and the Causes of death statistics Office with positive consequences on the quality of certification.

Differences in cultural and confidentiality habits

The accuracy of cause of death determined by the attending physician decreases when the certifier can't remain neutral in some situations. The medical certification of causes of death might also depend on the cultural and religious context of a specific country. For example, suicide was unacceptable for Christian followers until recently. The certifiers/physicians can also be strongly influenced by the confidentiality rules in force, or attached to the processing of information on individual death certificates. For instance the easy access to the cause of death data for the justice, family of the deceased or the insurance companies, influence directly the reliability of the cause of death determined by the physician.

A.2 POTENTIAL CODIFICATION BIASES

The biases in codification may be considered as becoming minor in comparison to those of medical certification. Generally, the rule surrounding the choice of the underlying cause of death by the coders is precise in the International Classification of Diseases (ICD) that is used by all countries. Discrepancies in the underlying cause of death assigned to a similar case by the coders may be due to:

i) Human error

In the case of manual coding, the most frequent errors occur in the selection of the underlying cause of death.

ii) The use at the same time of different revisions of ICD between countries

The various periods of implementation of ICD amongst the European countries may induce discrepancies linked with revisions themselves.

However, the automatic coding systems that are more and more frequently applied (especially in moving into ICD-10), will contribute to improve the harmonization of the selection of the underlying cause, and reduce the 'manual coding' errors.

B. MEASURE OF THE VALIDITY AND RELIABILITY

According to results from the literature review, two approaches may be broadly distinguished in measuring the biases. The assessment of the ''validity' of the cause of death entered on a specific death certificate ('cases' analysis), and the assessment of the 'reliability' of the aggregated data broken down by sex, age, country, etc (i.e. level of the stability of biases).

B.1 MEASURE OF THE VALIDITY (GOLD STANDARD METHODS)

The 'validity' of a specific cause of death certified may be defined as the level of its agreement with a 'gold standard' certification. Validity can be measured by the percentage of true positives, true negatives or both true positives and true negatives. These types of indicators might be obtained by comparison of the underlying cause of death entered by certifiers in 'routine' activities on a death certificate, with the underlying cause of death determined by a reference certification (gold standard). This 'reference certification' (gold standard) is determined by experts who can use various additional sources (autopsy, independent register, hospital records, and specific inquiries).

Some studies are based on the certification of the same clinical cases (case histories). A random sample of certifiers/doctors is asked to complete death certificates for a limited number of clinical cases (with a defined underlying cause of death reference). These kinds of studies that compare the certification for identical cases are useful because they permit a direct measurement of the variability in the certification process. This variability may be measured according to country, to individual characteristics of the certifiers or of the deceased person. However, there are limitations in using these types of results. Firstly, the number of cases considered is usually limited, and can't allow the generalisation of the results. Secondly, the determination of the 'gold standard' is not a simple concept and may itself be dependent on the 'medical' context of a specific country.

A parallel method to measure directly the variability in the coding process is to perform a 'double coding' exercises. The underlying causes of death selected by routine coders are compared with a gold standard codification (expert nosologist's selection).

The following table (Table 2) presents the usual indicators permitting to measure validity.

Tab 2. Indicators of validity

Cause of death entered on death certificates	Gold Standard		
	Cause x	Not cause x	Total
Cause x	a	b	a+b
Not cause x	c	d	c+d
Total	a+c	b+d	a+b+c+d

Sensitivity = a/(a+c)
Specificity = d/(b+d)
Positive predictive value = a/(a+b)
Negative predictive value = d/(c+d)
Pred value = (a+d) / (a+b+c+d
According to type of investigation, the Predictive value is also called Efficiency, Completeness, Correctness or Agreement by some authors.

When the sensitivity and the specificity are close to 100%, the overall validity of cause of death certificates may be considered as high. When the sensitivity is high and the specificity is low, there is an overestimation of the cause of death. When sensitivity is low and specificity is high, there is an underestimation. When sensitivity and specificity are both low, there is an overall misclassification (the resulting directions of biases in mortality might be variable).

B.2 MEASURE OF THE RELIABILITY OF VITAL STATISTICS

The 'reliability' of vital statistics may be defined as a measure of the stability of biases over time, between countries or according to socio-demographic characteristics.
Studies, which investigate the reliability of vital statistics consider generally aggregated data. These studies proceed frequently in analysis of trends in vital statistics from competing causes of death. Competing causes of death are a group of causes of death for which the true codes can be confused with one another because of specific habits or errors in the certification process. For instance, the competing cause of death for suicide might be accidents or undetermined causes. Likewise competing cause of death for Ischaemic Heart Diseases could be sudden and unknown deaths. Frequently authors analyse joint trends in/or between countries vital statistics from the considered competing cause of death.

The reliability of a cause of death can also be investigated by joint analysis of trends in mortality, and non-mortality indicators as incidence, and survival rates. Because of the questionable link between incidence and mortality for a definite pathology, these types of investigation are complex.
Some other studies investigate the reliability of causes of death statistics by analysing corresponding trends in specific investigation methods (e.g. trends in autopsy rates).

III.2.3 SUICIDE AND CONTROVERSIAL CASES

International cause of death data serves as a primary source of epidemiological information on suicide. It may be utilised in descriptive analysis, etiological research as well as an element of evaluation of public health prevention policies. Various specialists such as statisticians, epidemiologists, sociologists, psychologists and public health professionals have had recourse for more than hundred years to this exhaustive and easily available source of information. A number of countries have collected such data over the years, allowing temporal comparisons. Simple indicators, among them suicide figures and death rates, are commonly used in the analysis of suicide deaths and yield information on it's public health burden, groups at risk, time trends as well as international disparities.

Because of their widespread utilisation and interpretations, a great and long-standing concern has been expressed on the accuracy of suicide deaths official figures. Suicide is the most frequent cause of death implied in controversial issues surrounding validity and inter-country comparability of data, as illustrates the high number of publications on the subject. Durkheim's sociological approach based on official figures sparked a large debate on their potential in the understanding of social determinants of suicide. Since then, a large amount of literature has questioned the validity and the reliability of data, even casting doubt over it's usefulness at some points in time. Nowadays, the extent to which official figures are inaccurate remains subject to debate, as the review of recent literature shows.

The main objective of this section is to present an overview of suicide data, it's interests and limitations, as well as to formulate ensuing recommendations.

The specific objectives are :
-To overview suicide rates, rates of events of undetermined intent and aggregated data in European countries, their socio-demographic characteristics and the resulting country rankings
-To summarize the opinions on validity and reliability of suicide data, based on the results of a questionnaire sent to a panel of experts
-To overview the potential causes of biases limiting data interpretation of suicide
-To review the international literature on assessment of validity and reliability of suicide data, with a specific emphasis on interests and limitations of evaluation methods suggested by the study findings
-To formulate recommendations for the improvement of data quality

A. ANALYSIS OF EUROSTAT CAUSES OF DEATH DATA

A.1 DESCRIPTIVE EPIDEMIOLOGY OF SUICIDE WITHIN EU

Lowering the high suicide rates remains one of the actual challenges of European society. In 1994 a total of 48000 suicide deaths were recorded in the whole EU, accounting for 1 % of all deaths. This is of particular importance among youth, as illustrates the example of France, where suicide accounts for 14 % of deaths among the 15-24 years old and represents the first cause of mortality among the 25-34 year olds.

Suicide rates vary considerably amongst EU countries (Table 1). A broad categorisation of countries into 4 groups according to the overall standardised suicide rates in males can be proposed as below:

1) Highest rates (over 30 per 100000) : Finland, Austria, Luxembourg, France and Belgium
2) High rates (20 to 30 per 100000) : Switzerland, Denmark and Germany
3) Medium rates (10 to 20 per 100000) : Sweden, Ireland, Norway, Iceland, Netherlands, Spain, Portugal, UK and Italy.
4) Lowest rates(less than 10 per 100000) : Greece.

Middle and Northern countries have the highest rates, except UK with medium rates. The Southern countries record low rates, the lowest being Greece. Magnitude in variation between countries can be extremely wide, such as rates in Finland being 8 times greater than those in Greece.
The rates ranking between countries remains very similar when considering the female group or the age category 'under 65 years old' (Table 2, Map 1). Each country appears to have markedly highest suicide rates among males, the average ratio male/female being 3.2. However this varies between countries, the lowest ratio being seen in the Netherlands (2.2) compared to the highest ratios observed in Iceland, Luxembourg, Greece and Portugal (more than 4).

Most suicide deaths appear to occur before the age of 65. Males under 65 years old represent on average 75 % of all suicide deaths. The corresponding proportion for females is almost 65 % on average (Table 3).

Table 1. **Suicide rates per 100 000, by country, 1994 ***

Rank	*All ages*			*< 65 years*		
	Males	Females	Ratio M/F	Males	Females	Ratio M/F
Finland	42.3	11.4	3.7	41.8	11.5	3.6
Austria	32.2	10.4	3.1	26.6	9.2	2.9
Luxembourg	30.7	6.4	4.8		6.9	3.6
France	30.6	9.8	3.1	26.0	8.7	3.0
Belgium *	30.1	10.2	3.0	26.2	9.2	2.8
Switzerland	29.2	10.8	2.7	25.0	9.5	2.6
Denmark	24.9	16.0	2.4	21.4	8.2	2.6
Germany	21.7	7.0	3.1	18.1	5.7	3.2
Sweden	19.9	7.9	2.5	17.8	7.0	2.5
EU	18.5	5.8	3.2	15.9	5.0	3.2
Ireland	17.9	5.5	3.3	18.1	5.1	3.5
Norway	17.4	6.8	2.6	17.1	6.3	2.7
Iceland	16.4	2.9	5.7	15.5	1.8	8.6
Netherlands	14.5	6.2	2.3	12.3	5.7	2.2
Spain	12.2	3.2	3.8	9.7	2.5	3.9
Portugal	12.2	2.9	4.2	9.2	2.3	4.0
U.K.	11.4	3.0	3.8	11.1	2.8	4.0
Italy	11.0	3.2	3.4	8.7	2.6	3.3
Greece	5.1	1.2	4.3	4.3	1.0	4.3

** For Belgium year 1993*

Table 2. **Ranking of EU countries according to suicide rates, from highest to lowest rate, by age category, 1994 ***

Rank	*All ages*		*< 65 years*	
	Male	Female	Male	Female
1	Finland	Finland	Finland	Finland
2	Austria	Switzerland	Austria	Switzerland
3	Luxembourg	Austria	Belgium *	Austria
4	France	Belgium *	France	Belgium *
5	Belgium *	Denmark	Switzerland	France
6	Switzerland	France	Luxembourg	Denmark
7	Denmark	Sweden	Denmark	Sweden
8	Germany	Germany	Germany	Luxembourg
9	Sweden	Norway	Ireland	Norway
10	Ireland	Luxembourg	Sweden	Germany
11	Norway	Netherlands	Norway	Netherlands
12	Iceland	Ireland	Iceland	Ireland
13	Netherlands	Italy	Netherlands	United Kingdom
14	Portugal	Spain	United Kingdom	Italy
15	Spain	United Kingdom	Spain	Spain
16	United Kingdom	Portugal	Portugal	Portugal
17	Italy	Iceland	Italy	Iceland
18	Greece	Greece	Greece	Greece

** For Belgium year 1993*

Table 3. **Proportion of suicides before the age of 65 within Europe, according to sex, 1994 ***

Rank	*< 65 years*	
	Males	Females
Ireland	90.5	78.9
Finland	89.1	84.7
Iceland	85.7	50.0
U.K.	85.3	70.9
Norway	85.0	74.3
Netherlands	81.0	79.0
Belgium *	76.0	69.4
Germany	75.6	58.3
EU	**74.9**	**64.8**
Switzerland	74.5	68.6
Austria	74.1	65.2
Luxembourg	73.8	92.3
Denmark	73.3	59.0
France	73.1	68.2
Sweden	72.6	65.3
Greece	71.5	64.9
Spain	68.8	58.2
Italy	66.7	62.1
Portugal	65.2	58.3

** For Belgium year 1993*

A.2 DESCRIPTIVE EPIDEMIOLOGY OF EVENTS OF UNDETERMINED INTENT WITHIN THE EU

Some deaths due to events of undetermined intent might actually represent undetected true suicides. If the proportion of non-acknowledged suicides gets high, so does the proportion of events of undetermined intent, accounting for its value when analysing suicide rates. Death rates due to events of undetermined intent appear to be high. In 1994 a total of 9400 deaths coded that way were recorded. In the meantime 48000 suicides were reported.

When comparing countries a ranking appears with a North-South gradient with highest rates in Northern countries and lowest rates in Southern countries (Table 4, Map 1). This gradient is similar than the gradient in suicide rates. France and Finland remain in the category of the highest rates. Surprisingly Portugal experiences the highest rate in the male group with more than 14 per 100000. A roughly similar gradient is observed within sex categories and age groups (Tab 5, Map 1).

Within this category of deaths due to events of undetermined intent, variations in death rates magnitude are much wider than within the suicide category (for ex: rates in Finland are more than 140 greater than in those in Greece) and sex ratio (from 1.3 to 10). Nevertheless the average sex ratio for deaths due to events of undetermined intent is 2.7 compared to 3.2 for suicide deaths rates.

Table 4. **Rates of death due to event of undetermined intent per 100 000, 1994*, by country and by age** *(* For Belgium year 1993)*

Rank	*All ages*			*< 65 years*		
	Males	Females	Ratio M/F	Males	Females	Ratio M/F
Portugal	14,1	4.3	3.3	11.6	3.3	3.5
Finland	5.8	1.3	4.5	5.8	1.1	5.3
France	6.3	2.3	2.7	5.5	2.0	2.8
Sweden	6,1	2.6	2.3	6.0	2.5	2.4
Denmark	6,0	2.7	2.2	6.2	2.7	2.3
U.K.	4,9	2.0	2.5	4.8	1.9	2.5
Germany	3,6	1.2	3.0	3.3	1.0	3.3
Belgium *	3,5	1.4	2.5	2.9	1.3	-
E.U	3,5	1.3	2.7	3.2	1.1	2.9
Iceland	3,0	0.0	-	3.4	0	-
Norway	3,0	0.3	10.0	0.9	0.2	4.5
Switzerland	1,8	0.7	2.6	1.6	0.7	2.6
Luxembourg	1,3	1.0	1.3	1.5	1.1	1.4
Austria	0,9	0.5	1.8	0.9	0.5	-
Ireland	0,7	0.2	3.5	0.7	0.2	3.5
Italy	0,7	0.2	3.5	0.5	0.1	5.0
Netherlands	0,7	0.2	3.5	0.7	0.2	3.5
Spain	0,5	0.2	2.5	0.4	0.1	4.0
Greece	0,1	0.0	-	0.1	0	-

Table 5. **Ranking of EU countries according to rates of death due to event of undetermined intent, from highest to lowest rate, by age, 1994 *** *(* For Belgium year 1993)*

Rank	*All ages*		*<65 years*	
	Male	Female	Male	Female
1	Portugal	Portugal	Portugal	Portugal
2	France	Denmark	Denmark	Denmark
3	Sweden	Sweden	Sweden	Sweden
4	Denmark	France	Finland	France
5	Finland	United Kingdom	France	United Kingdom
6	United Kingdom	Belgium *	United Kingdom	Belgium *
7	Germany	Finland	Iceland	Finland
8	Belgium *	Germany	Germany	Luxembourg
9	Iceland	Luxembourg	Belgium *	Germany
10	Norway	Switzerland	Switzerland	Switzerland
11	Switzerland	Austria	Luxembourg	Austria
12	Luxembourg	Norway	Austria	Norway
13	Austria	Ireland	Norway	Ireland
14	Ireland	Italy	Ireland	Netherlands
15	Italy	Netherlands	Netherlands	Italy
16	Netherlands	Spain	Italy	Spain
17	Spain	Iceland	Spain	Iceland
18	Greece	Greece	Greece	Greece

A.3 COMBINING SUICIDE DATA WITH DATA OF EVENTS OF UNDETERMINED INTENT

Given the frequent link between suicide and events of undetermined intent, analysing both variables as a unique aggregated variable might be of interest in order to set a corrected approach towards suicide deaths in EU countries.

The country ranking (when combining suicide and events of undetermined intent) does not change much and looks roughly the same as when suicide only is considered (Table 6, Table 7, Map 1).

The North-South gradient remains, and countries can be broadly categorised in similar groups as in section 1.1. The exception being Portugal, which ranks much higher when combining both causes than when considering suicide alone (because of its surprising high rates of events of undetermined intent).

Finally the magnitude of variation in death rates and sex ratio, as well as distribution according to sex category and age group roughly present similar characteristics as when considering suicide only (Table 6, Table 7).

Table 6. **Death rates by suicide and event of undetermined intent, per 100 000 inhabitants, 1994 , by country and by age** *(*for Belgium year 1993*)

Rank	*All ages*			*< 65 years*		
	Males	Females	Ratio	Males	Females	Ratio
Finland	48.1	12.7	3.8	47.6	12.6	3.8
France	36.9	12.1	3.0	31.5	10.7	3.0
Belgium *	33.6	11.6	2.9	29.1	10.5	2.8
Austria	33.1	10.9	3.0	27.5	9.7	2.8
Luxembourg	32.0	7.4	4.3	26.0	8.0	3.2
Switzerland	31.0	11.5	2.7	26.6	10.2	2.6
Denmark	30.9	12.9	2.4	27.6	10.9	2.5
Portugal	26.3	7.2	3.7	20.8	5.6	3.7
Sweden	26.0	10.5	2.5	23.8	9.5	2.5
Germany	25.3	8.2	3.1	21.4	6.7	3.2
E.U	22.0	3.1	3.1	19.1	6.1	3.1
Norway	20.4	7.1	2.9	18.0	6.5	2.8
Iceland	19.4	2.9	6.7	18.9	1.8	10.5
Ireland	18.6	5.7	3.3	18.8	5.3	3.5
U.K.	16.3	5.0	3.3	15.9	4.7	3.4
Netherlands	15.2	6.4	2.4	13.0	5.9	2.2
Spain	12.7	3.4	3.7	10.1	2.6	3.9
Italy	11.7	3.4	3.4	9.2	2.7	3.4
Greece	5.2	1.2	4.3	4.4	1.0	4.4

Male SUICIDE *(Eurostat short list n 63)* *Female*

UNDETERMINED INTENT *(Eurostat short list n 65)*

SUICIDE + UNDETERMINED *(n 63 + n 65)*

Variation of the country standardized (for 100 000)
death rates according to the European overall rate (1994)

Table 7. **In 1994* :a) Country ranking by rates of suicide, events of undetermined intent, of suicides aggregated with events of undetermined intent / b) Sex ratio of suicides and events of undetermined intent by country / c) Proportion of males > 65 years old victims of suicides and events of undetermined intent.**

Country	*Ranking number a)*			*Sex Ratio b)*		*% Males > 65 years c)*	
	Suicide in males	Undetermined in males	Suicide & Undetermined, in males	Suicide	Undetermined	Suicide	Undetermined
Finland	1	5	1	3.7	4.5	89	89
Austria	2	12	4	3.1	1.8	74	89
Luxembourg	3	11	5	4.8	-	74	100
France	4	2	2	3.1	2.7	73	75
Belgium *	5	8	3	3.0	2.5	76	72
Switzerland	6	10	6	2.7	2.6	74	78
Denmark	7	4	7	2.4	2.2	73	91
Germany	8	7	10	3.1	3.0	76	83
Sweden	9	3	9	2.5	2.3	73	85
Ireland	10	14	12	3.3	3.5	90	91
Norway	11	13	13	2.6	2.7	85	100
Iceland	12	9	11	5.7	-	86	100
Netherlands	13	14	15	2.3	3.5	81	88
Portugal	14	1	8	4.2	3.3	65	71
Spain	15	17	16	3.8	2.5	69	72
UK	16	6	14	3.8	2.5	85	86
Italy	17	14	17	3.4	3.5	67	58
Greece	18	18	18	4.3	-	72	86

(For Belgium year 1993)*

In Conclusion

Most suicides happen before the age of 65. Their occurrence is of particular concern regarding youth. A male over mortality is observed everywhere in Europe, with an average ratio male/female of 3.2. A clear North-South gradient does exists in suicides with highest rates being in Northern countries. Combining data on suicide and on events of undetermined intent suggests a similar ranking in countries. Exception being for Portugal, that shows low rates of suicide but high rates of the combined data, due to high rates of events of undetermined intent.

The example of Portugal illustrates the underlying complexity in the interpretation of official data. One might well question the reasons for such a difference. Indeed we can easily point out at least two major issues: are suicide data really measuring what they purport to measure, that is are they valid? Might we be therefore allowed to compare such data at an international level - are they comparable?

These two issues will then be looked at thoroughly in the literature review.

B. RESULTS OF THE QUESTIONNAIRE

A panel of experts was consulted through a questionnaire-based survey. Out of 21 experts , 13 have responded to the questionnaire, which resulted in a non-representative panel.

9 experts expressed the opinion that suicide death data was reliable, 11 said that data on death due to events of undetermined intent was reliable. 6 experts think that suicide death data is underestimated. 4 experts think that deaths due to events of undetermined intent are overestimated, 2 of them that they are underestimated. Most of them thought the major source of biases was due to misclassification at the certification stage.

Although these results have to be taken cautiously, they emphasise the existence of a strong complexity when analysing and interpreting suicide, as mentioned previously.

Table 8. **Results of the questionnaire-based opinions from a panel of experts about quality of data, for suicides and events of undetermined intent**

Research question	*Answer*	*Number of experts, by answer*	
		Suicide	*Events of undetermined intent*
Reliability	Reliable	5	5
	Fairly reliable	4	6
	Not (very) reliable	1	0
	Unknown	1	0
	No response	2	2
Direction of biases	Underestimation	6	2
	Overestimation	0	4
	Unknown	1	0
	No response	2	2
	Not requested	4	5
Proportion of biases if underestimation	0-15%	6	1
	No response	2	3
	Not requested	5	9
Proportion of biases if overestimation	0-15%	0	2
	Unknown	0	1
	No response	2	4
	Not requested	11	6
Influence of age on biases	Yes	2	1
	No	1	0
	Unknown	4	4
	No response	1	3
	Not requested	5	5
The most affected age group by biases	0-25 years	1	0
	> 65 years	3	1
	Not response	1	3
	Not requested	8	9
Sources of biases	Medical certification	6	6
	Coding rules	0	2
	Other reasons	6	3
	No response	2	1
	Not requested	4	5
Change of rank of the country if correction	Yes	0	1
	No	5	5
	Unknown	1	0
	No response	3	3
	Not requested	4	4
Answer based on	Personal opinion	4	5
	Collective opinion	5	6
	Specific studies	5	1
	No response	2	2

C. ANALYSIS OF THE LITERATURE REVIEW

C.1 POTENTIAL SOURCES OF BIASES

The introduction of biases may occur at the codification process or at the certification process. As a result of the coding rules of the International Classification of Diseases (ICD), biases regarding suicide may be minimised at the codification stage.

The complexity of the certification stage as well as it's major impact on quality and comparability of data unveil the needs to primarily focus on this procedure. Because of its variability between countries and between certifiers (*Atkinson M.W.* 1975, *Barraclough B.M.* 1970), it might be a major source of biases. Because of its impact on quality of data, one might question how to improve it. Thus a series of consequent questions arise : what are the potential sources of biases and what is

their likely impact? What are the methods that allow them to be identified? What are the methods that permit to assess their magnitude and impact ?

Through a literature review this section will examine the available knowledge on potential causes of certification biases as well as their impact on suicide data.
Before reviewing the potential biases it appears relevant to recall the current case definition for a suicide death.

Case definition of suicide
Suicide is easy to define as a concept (*O'Caroll P.W.* 1989). However the case definition of suicide used in epidemiology and proposed by WHO presents some limitations. According to WHO guidelines (*Rosenberg M .L.* 1988) a suicidal act may be defined as a « self-injury with varying degrees of lethal intent » and suicide may be defined as « a suicidal act with a fatal outcome ».
Such a definition is inherently difficult to use in practice, for it implies that the death be established as both self-inflicted and intentional (MMWR 1989).

Biases introduced at this stage might influence estimates in both ways. In the case of a true suicide, if evidence of self-infliction and intent are not collected, the death certificate will mention a distinct cause of death from suicide. Underreporting and, as a result, underestimation, may occur in official suicide rates. This might frequently be the case in such cases as drowning, from which evidence of intent and self-infliction is scarcely uncovered .
Conversely collecting evidence of self-infliction will in most cases conclude as to a suicide. In some rare cases however, one might think about a possible over reporting. Examples such as murders masked into suicides, or hanging from which one may strongly assume the intent of the deceased, might occur. In practice, this might be negligible because these rare events might not account for many deaths. But there is potential for over reporting, therefore overestimation.

Underestimation might therefore be the most common direction of certification biases. Here, the concept of validity of data, that is how accurate the data is and whether it really does measure what it purports to measure, is essential. The larger the underestimation is, the less valid the data is.

Having a proper understanding of the case definition of suicide may help in the study of the potential biases from the literature review.

Types of biases
Various types of biases have been identified in the literature review. Given the complexity of the certification process, the following biases will be listed according to their likely impact on data, from important to minor impact.
The type of certifier, whether this is a coroner or a medically qualified person appears to have a major impact when comparing data between countries. Applying or not a strict case definition of suicide will alter the validity of data. Various cultural legal and religious contexts might also influence validity and comparability. The role of forensic institutes also appears as non negligible.

Biases due to distinct types of certifiers
The role of the justice department in the certification process of suicidal deaths varies according to country and appears more important in some countries than others. Indeed, the person assigned to certify a suicide differs widely within the EU, ranging from a legal officer exclusively (UK, Ireland) to any medically qualified practitioner (France, Germany).

Coroners in UK and Ireland are the primary persons to decide whether there is intent and self-infliction or not.
In Ireland the Coroners Act assigns the coroner to ascertain the cause of death by holding an inquest upon a deceased person ,

«… if he is of the opinion that the death may have occurred in a violent or unnatural manner or suddenly or from unknown causes, or in a place or circumstances that under provisions contained in the Act require that an inquest be held. » (Coroners act in Connoly J.F. 1995*)*

Besides this, a verdict of suicide is only justified in law if the evidence shows beyond all reasonable doubt that, a) the deceased was responsible for the act which led to his/her death, and b) that he/she intended that act should have that income. The handbook for coroners in UK states that « suicide should never be presumed but must be based upon some evidence that the deceased intended to take his/her own life ».

When there is insufficient evidence of intent, the cause of death may be classified as an open verdict. And when there is insufficient evidence of self-infliction it may be classified as misadventure or an accident. Whatever the coroner's verdict may be, it can also be challenged in higher courts.

In some other European countries, doctors may certify suicidal deaths without any referral to legal authorities. In France for instance the medical practitioner is in charge of the certification and is the primary decision-maker as for requesting any forensic assistance or not.

Thus in short in the United Kingdom:

1) Suicide rates are based upon verdicts returned at inquest by coroners or their jury (*O'Donnel I.* 1995),

2) The case definition has to be strictly applied, i.e. evidence beyond any reasonable doubt must be collected that death was self-inflicted and that the deceased intended to end his/her life.

This can have 2 distinct types of impact.

An impact on estimates: in the UK this stringent case definition can lead to an underestimation of the true suicide rates and to registration of potential true suicides towards «open verdicts» or «misadventures or accidents». The ratio between open verdicts and suicides is likely to be indicative of underreporting of suicides when it does increase.

An impact on comparability: in the UK and Ireland coroners will indicate a suicide only in the presence of proof of intent (evidence beyond any reasonable doubt), whereas in other countries non-coroners certifiers might well base their diagnosis on the balance of probabilities (*Atkinson M.W.* 1975). In one hand case definition is thus strictly applied, whereas on the other, it is not strictly applied. Thus data to be compared will not represent the same concept, and comparability will lower.

Biases induced when collecting evidence of intent

As said above, the case definition of suicide is difficult to apply in practice, for it implies that the death be established as both self-inflicted and intentional. The practical problems faced by certifiers, especially those who will have time constraints, might therefore be how to collect evidence of intent and self-infliction, as illustrated by the case of drowning. Some modes of deaths are themselves sufficient proof of evidence of intent, as hanging, limiting biases at the certification stage (*Platt S.* 1988).

Underestimation may thus occur, rather than overestimation that, if occurred, would mean evidence of intent was gathered in a case of non-suicide . If the magnitude of underestimation due to these biases was most likely to be similar everywhere, comparability would therefore be improved.

Collecting evidence of intent through autopsies might as well result in comparability biases when one country performs more autopsies than others. This may for example be the case in Austria, characterised by a high proportion of autopsies when compared to Germany.

Biases induced by personal characteristics of certifiers

Besides the biases induced by the type of certifiers, personal and subjective judgement may occur resulting in considerable variations on the cause of death, specially in the absence of operational criteria to apply the case definition. As in the case of coroners, some will indicate a suicide only in the presence of proof of intent, some will make their opinion on the basis of the balance of probabilities -probability criterion- (*Kolmos L.* 1987). This is well described by various authors (*Salib E.* 1997, *Pearson V.A.H.* 1993, *Jarvis G.K.* 1991). Some even report variations in certification according to the socio-economic characteristics of the deceased. Jarvis shows that the proportion of certified suicide increases with the certifier's age, when he/she has a non-religious background and when the deceased is a female (*Jarvis G.K.* 1991).

The impact of this potential bias is more difficult to evaluate. The magnitude of the underestimation might vary according to whether the certifiers have similar characteristics. Those who tend to underestimate little might compensate those who tend to underestimate more. The resulting magnitude of impact will thus depend on the proportion of certifiers belonging to one of these groups. Comparability will also be subject to whether certifiers have the same characteristics.

In a similar way the level of awareness of the certifier as to what cause could mask a suicide represents a potential bias. As in the following example; a death on the road involving one person only is rarely investigated as a possible cause of suicide. The impact of this bias will be underestimation. If one supposes a similar level of awareness among certifiers comparability might not be affected.

Biases due to lack of feedback information from forensic institutes

In some countries forensic institutes in charge of the certification may not send back the resulting cause of death to the institute responsible for the codification. A number of deaths for which no accurate additional information or no information at all can be obtained will thus be coded wrongly as deaths due to unknown cause or ill defined cause. This leads to underreporting and consequent underestimation of suicide, which might however be assessed by looking at the proportion of deaths due to unprecise or unknown causes. In addition, some variations may occur in the organisation of legal certification systems between countries and in the amount of feedback information given to the codification institute.

Biases due to cultural, religious and legal contexts

In some cases there may be some resistance towards ascertaining suicide as cause of death. Denying a true suicide for cultural, religious, legal or political reasons may not be rare. The social or religious stigma attached to the relatives may prompt the certifier's reluctance to ascertain suicide. Similarly, legal or insurance-related complications faced by relatives after the death might influence the certifier's choice. From the relative's point of view, the same reasons might encourage them to conceal a suicide to the certifier (*Atkinson M.W.* 1975).

This was shown in areas where Catholicism predominates. Suicide rates appear to be low compared to high rates of events of undetermined intent whereas the opposite is observed where protestant areas. The underlying reason is that victims of suicide are unlikely to benefit from religious funerals in some catholic areas. However a number of investigations suggests the effects of religious beliefs on the attitude of officials may be less relevant than their influence on the occurrence of suicidal behaviour (*Sainsbury P.* 1983).

Although decriminalisation of suicide has been legally achieved, however lately, in the UK and Ireland, social decriminalisation of suicidal behaviour has not been achieved (*Neeleman J.* 1996).

Finally few studies have evaluated how insurance premiums can influence the certification process. However suicide is most of the time a cause of death that excludes further payments from insurance companies so is likely to influence the choice of cause of death, and an underestimation of suicide.

C.2 METHODS TO ANALYSE THE QUALITY OF DATA

As seen above, potential biases limiting the validity and the comparability of suicide data are various. Below is a review of a few methods found in the literature focusing on how to assess certification biases. Such specific methods as re-examination of cause of death and ascertainment of similar case histories by distinct certifiers have been less applied than the more practical analysis of concurrent causes of death. They differ in their advantages and limitations.

Retrospective re-examination of cause of death

The feasibility of re-examining causes of death retrospectively is of great interest. Indeed selected dubious cases are thus reviewed in the light of comprehensive and detailed information on the deceased. A «gold standard» reference to define suicide is formerly developed (*Connoly J.F.* 1995). Cases who meet perfectly the definition of the gold standard are considered true suicides. Cases are thus investigated in the light of such information as mode of death, presence or history of psychiatric or physical illness, social or interpersonal precipitants and whether or not the deceased expressed any intent of suicide. This information is gathered from distinct sources such as key informants (coroner, pathologist, General Practitioners) or medical records (medical notes, forensic reports, results from autopsy, police reports, toxicological and histological data). The diagnosis of suicide is then appraised from the accumulated information obtained.

Figures obtained by this «gold standard» reference method are then compared to those obtained from primary death certificates.

At that stage one may verify whether there is a significant difference between these figures and determine direction and magnitude of biases. This gives a rough idea on how valid the data is.

Figures obtained allow to calculate indicators such as proportion of false positives (deaths falsely labelled as suicides) and false negatives (true suicides falsely labelled as other causes), as well as predictive value. The occurrence of false negatives in comparison with false positives is more frequent. Indeed a high number of false positives would imply that a number of accidents, natural deaths or homicides would have occurred with evidence of intent and self-infliction, which in reality may be a scarce event.

In conclusion this method is useful to appraise certification procedures. Although it does not appear to yield much information about the nature of the potential biases, quite accurate information on their direction and their magnitude may be obtained to assess the validity. Its weakness lies in the difficulty of having a gold standard reference, concept uneasy to apply to suicide.

Few authors have carried out such retrospective investigations on potential suicides (*Phillips D.P.* 1993, *Moyer L.A.* 1989, *Walsh D.* 1990, *Thorslund J.* 1989, *O'Donnel I.* 1995), the results of which will be reviewed in a further section.

Ascertainment of similar cases by a sample of certifiers

This method is based on the certification of similar cases by certifiers from different countries or within a country. Few authors have focused on this type of study.

The primary objective is to assess how variable the certification may be, depending on the certifier's socio-demographic characteristics such as age, sex, or place of residence. Characteristics of the deceased have also been studied.

As previously mentioned, Jarvis has shown that the proportion of certified suicides increases with the age of the certifier, when he/she has a non-religious background and when the deceased is a female (*Jarvis G.K.* 1991). He also shows that verdicts of suicide are closely similar when repeated

by certifiers having the same characteristics, or when the deceased presents the same characteristics. This is the concept of reliability of the method. From this concept can be inferred the concept of predictability of verdicts when facing similar characteristics, either from the certifier or from the deceased.

Thus this method may be useful in appraising reliability and predictability of certification according to socio-demographic characteristics of the certifier and of the deceased. It may thus be highly informative on the nature of potential biases.

Unfortunately generalisation may not be possible because of the selection of cases and their small numbers. Minimal logistic and human resources requirements also limit it's use.

In conclusion it appears that both specific methods may be complementary. One method appears to yield quite accurate information on validity of data, whereas the other one appears to be highly informative on the nature of potential biases.

One might well think about the potential of using a combination of both methods, possibly providing a comprehensive information about quality of data.

Statistical analysis of concurrent causes of deaths

Concurrent causes of death are defined as a group that might incorporate potential causes of death hiding a suicide. For example a true suicide by drowning may well be categorised as an accident, when intent and self-infliction cannot be collected. Deaths by accident are then considered as concurrent causes of suicides.

A frequent concurrent cause for suicide is represented by the controversial cases, such as violent deaths of undetermined intent, for which the certifier cannot decide between suicide or another cause of violent death. This uncertainty may arise from a lack of information on the circumstances of death, when there is lack of evidence of intent or self-infliction.

Many other types of concurrent causes of death have been identified in the case of suicide, such as specific accidents, homicides and unknown causes (*Phillips D.P.* 1993), accidental barbiturate poisoning, pedestrian deaths caused by motor vehicles or trains, deaths of drivers in single car collisions (*Kolmos L.* 1987). Natural deaths can also in theory include a number of suicides.

Misclassification and consequent underreporting will lead to lower suicide rates and proportionally higher rates of concurrent causes. Therefore, both types of data are usually analysed concomitantly. This is an easy way to get a rough idea of the magnitude of the underestimation, once a concurrent cause of death has been identified as such. In general deaths due to events of undetermined intent are widely accepted as a predominant group of concurrent causes of suicide.

This method appears to give little information by itself on the origin of biases but has the potentiality to initiate the research process on it. Indeed having identified a concurrent cause of death might well call for more information.
On the other hand it appears to be the primary method on which to rely when suspecting wrong estimates. Once concurrent causes of death have been identified, one might confirm or invalidate the hypothesis of underestimation. For instance a low proportion of suicide combined with a high proportion of events of undetermined intent might well indicate the existence of an underestimation, the magnitude of which might be roughly inferred from the proportion of concurrent causes.

To increase the power of this method, one can look at aggregated data, such as suicide combined with deaths due to concurrent causes. The effects of this might be to compensate known or unknown biases and to make data comparable. Indeed data on concurrent causes of death, when aggregated, might compensate differences in suicide rates between countries (suicides, controversial

cases, accident cases, natural deaths with undetermined causes of death), which improves comparability (*Kolmos L.* 1987).

Nevertheless when aggregating data one should focus on causes of death for which the mode may be clearly unequivocal. Besides, accidents where suicide can be excluded as an alternative manner of death are not considered. As such the whole group of traffic accidents is generally omitted from the material, even though there is little doubt that a number of cases of true suicides are categorised in "alone accidents".

Similarly, one can also compare suicide rates to any other cause according to the mode of death (such as hanging, drowning or shooting) considered as potential concurrent cause (*Moens G.F.J.* 1985). Moreover suicides rates may also be compared to morbidity data, such as depression rates or alcoholism rates in multiple-cause analysis (*Bille-Brahe U.* 1997).

Also of interest would be to study the trends in suicide data of concurrent causes and of aggregated data and to compare them. Biases might be identified when looking at differences or even reversals of trends.

Finally similar socio-economic characteristics are usually identified within the various data sets of suicide, concurrent causes and aggregated data, adding to the evidence for the correlation between suicide and the concurrent cause. Trends in socio-economic characteristics may also be reliably studied.

If time trends of suicide data, of socio-demographic characteristics of suicide and of concurrent data are similar over time, and even if there is an underestimation, this validates the only use of suicide data as a reliable indicator at the interpretation stage. It shows that biases remain stable over time, which ensures the reliability of data. This represents a very powerful concept and method that should be systematically used at the analysis stage.

This method of concurrent causes of death is implemented at the data analysis stage, which explains its practicability as well as the high number of studies found in the literature. It also appears to be the primary method to suspect wrong estimates. Although it may not provide either accurate estimation of the underrepport or much information on the nature of potential biases, its potential for hypothesis generation is of great interest in the decision to carry out further specific studies.

D. RESULTS

After having focused on what methods may be used when looking at the quality of suicide data, what are their values and their limitations, one might look at how far the studies based on this have been conclusive.

Specific studies show the impact of certification procedures

Controversial results arise about the impact of certification procedures on the quality of data. Whereas some authors conclude to a large underestimation and lack of validity of data (*Clarke Finnegan M.* 1983, *Connoly J.F.* 1995, *O'Donnel L.* 1995), some conclude to a satisfying validity (*Allebeck P.* 1991, *Moyer L.A.* 1989, *Ross O.* 1975, *Thorslund J.* 1989). Whereas WHO concludes in 1974 that data is not sufficiently reliable for use in epidemiological and socio-demographic research (*WHO* 1974), Sainsbury and Atkinson point out that the underlying reasons for the differences observed in the WHO study might not only be certification biases (*Atkinson M.W.* 1975, *Sainsbury P.* 1983).

These controversial results illustrate the complexity of the certification procedures with all sorts of biases that may interfere with it. The impact of biases might be limited in some cases whereas in some other cases one might observe a large underestimation, depending on the type of bias identified by authors.

Studies on concurrent causes of death often confirm the ranking between countries.
Concurrent causes of death methods yield valuable findings. Country ranking, trends over time and social determinants of suicide are valuable results, though the nature of biases may not be inferred.

Concurrent causes for suicides found in the literature are predominantly deaths due to events of undetermined intent, certain types of accidents and deaths due to unknown origin.
Suicide rates ranking and corrected suicide rates ranking adjusted for concurrent causes have been compared in EU. Findings indicate that the observed rankings of countries do not change radically (*Barraclough B.M.* 1970, *Barraclough B.M.* 1973, *Lester D.* 1992). This correlation suggests that differences in practices are not sufficient to explain inter-country variations. Lester even argues that the consistent relative ranking of national suicide rates support the validity of official suicide statistics (*Lester D.* 1992).
Furthermore, some studies (*Sainsbury P.* 1982, *Whitlock F.A.* 1981) demonstrate that the ranking of suicide rates for immigrant groups has a high correlation with the ranking of the suicide rates in their country of origin. They therefore concluded that the differences between individual countries with regards to registration procedures enabled invalidation of international suicide statistics.
Finally Sainsbury concludes that the error variation in the reporting of suicide statistics is randomised in such a way as not to invalidate comparisons made between different suicide rates, especially between nations (*Sainsbury P.* 1982, *Sainsbury P.* 1983).

In the light of these findings, there seems to be a consensual opinion based on the consistency of country ranking that supports the idea of reliability of aggregated data.
Studying changes in certification practices provides valuable information on potential errors. Indeed modifications in practices in various countries may induce or not changes in suicide rates, noticeable when looking at trends. In some cases new certification practices have caused trends changes (*Ferreira De Castro E.* 1989, *Giertsen G.C.* 1993, *Gist R.* 1989, *Kelleher M.J.* 1996, *Males M.* 1991, *Neeleman J.* 1997, *Walsh D.* 1990), whereas in other cases trends remained identical (*Cantor C.H.* 1990, *McClure G.M.G.* 1984). The proportion of concurrent causes is then of value for it may tend to change inversely and proportionally to the change in suicide rates, whereas the proportion of aggregated data remains unchanged over time. Reliability may then be improved when looking at trends of aggregated data.

Finally some authors stress that it may be possible to characterise populations at risk and to analyse suicide determinants without the knowledge of all suicides, that is even when there is an underestimation, provided that biases are stable (*O'Carroll P.W.* 1989). Similarly Sainsbury argues although misreporting exists it has little impact on social determinants of suicide (*Sainsbury P.* 1982, *Sainsbury P.* 1983).
In addition time trends of the main socio-demographic characteristics such as sex and region may as well be reliably studied.

Conclusions and recommendations
Within European countries wide variations in suicide rates can be observed. A north-south gradient with higher rates in Northern Europe than in Southern Europe is noticeable. Naturally one might question to what extent this reflects true differences or the existence of biases, that is how valid, reliable and comparable the data are.

The purpose of this section was to review the state of knowledge on these issues as well on the methods currently used to assess the potential biases that may occur at the certification stage.

Several methods studying these issues have been utilised and studies based on these have been carried out.

Besides illustrating the complex process of certification and the existence of many potential biases, this literature review suggests an ubiquitous underestimation of suicide and a variable validity of data within European countries. However it generally supports the idea that despite underestimation, this data bears sufficient reliability to study country ranking, time trends, socio-demographic characterisation of at risk groups as well as determinants of suicide.

Besides these findings, this review suggests that the methods used to assess certification biases have a potential for being part of a methodology of evaluation of the data quality. Indeed, they seem to present such characteristics that, combined together in a defined manner and used for determined purposes, would yield a comprehensive information on the quality of data by country, which might be used to enhance the power of interpretation. Naturally more research would be needed to ascertain this, which might be part of the recommendations.
Primary data has formerly been ameliorated by the coding rules of the International Classification of Diseases. However the complex process of certification and the inherent biases emphasize the need to focus recommendations on the certification.
Recommendations to improve validity and homogeneity of suicide death certification have been formulated by many authors (*Moyer L.A.* 1989, *Jobes D.A.* 1987, *Connoly J.F.* 1995). Recommended interventions are the following ones: a common case definition between coroners and physicians, implementation of psychological autopsies, training of certifiers on equivocal cases, addition of evidence of patient's intent, review of amended certificates, labelling incomplete cases as pending and centralising the current vital statistics system. Batten includes the knowledge of mental status of the deceased (*Batten P.J.* 1988). Jarvis recommends more frequent specific studies such as case histories (*Jarvis G.K.* 1991). Psychological autopsies could as well complete corps autopsies. A guideline for certifiers and specific criteria to look for when facing dubious cases of suicide could be developed and produced. A Eurpean working group including key actors such as coroners, medical examiners, statisticians and PH agencies could be conducted to decide on proposed recommendations, as NCHS did in the USA (MMWR 1988).

Lastly, this report should be regarded in the light of a question of importance. Is current knowledge based on suicide data sufficient enough for policy makers to carry out public health interventions against suicide? To what extent the status quo regarding preventative strategies may have been maintained by the problems surrounding the validity of suicide data? Unless more research aimed at studying such questions is carried out, the issue of quality of suicide data might remain in a state of unanswered matters.

Annexes

Table 9. ***Synoptic table of the studied literature about methods to assess quality of suicide data***

Author	**Year**	**Country**	**Source**	**Method**	**Main results**
Schmidtke A.	1997	Europe	Vital statistics	Comments – hypotheses – literature review	
Salib E.	1997	UK-North Cheshire	Sample of deaths > 65 yrs	Ratio "suicide/open verdict" according to various variables	3 explicative variables
Neeleman J.	1997	England & Wales (EW)	Vital statistics 1974-1991	Trends of ratio "suicide/open verdict "according to various variables	Ratio increases Ratio higher in young, in women, for drowning, for jumping
Kelleher M.J.	1996	England & Wales and Ireland	Vital statistics 1976-1992	Trends in the ratio "suicide/open verdict"	Ratio increases in EW and decreases in Ireland
Pearson VAH	1993	England & Wales-Devon	Vital statistics 1988-1990	Ratio "suicide/open verdict"	Geographical variation
Phillips D.P.	1993	US - California	Vital statistics 1966-1990	Mortality peaks at symbolic ages	Peaks observed for 5 causes of death (suicides misallocated)
Walsh D.	1990	Ireland-Kildare	Vital statistics 1968-1987	Trends in underreport Re-examination of the cases Vs a	Suicide rates truly increased

				gold standard	Accuracy of statistics
Gist R.	1989	USA	Vital statistics 1955-1979 → firearm suicides and accidental deaths among 15-19 yrs	Modelling ratio suicide/accident	True change associated with existence of an artefact to explain the rise
MMWR	1988	USA		Criteria to determine suicide	
Thorslund J.	1989	Denmark-Greenland	Vital statistics 1977-1987	Re-examination of controversial cases against gold standard	Official statistics generally reliable
Jobes D.A.	1987	USA		Sources of error - Recommendations	
Hesso R.	1987	Scandinavian countries		Qualitative study of distinct registration system	The differences cannot explain the lower suicide rates in Norway
Jarvis G.K.	1991	Canada	6 Experimental cases histories	Variation in suicide certification according to the characteristics of the medical examiner and deceased	Variation with age and religion of medical examiner and with deceased gender
Cantor C.H.	1990	Australian	Vital statistics 1968-1985	Ratio "suicide/open verdict" according to regions	True rise in young male suicides
Moens G.F.G.	1985	Belgium	Vital statistics 1968-1981	Trends and geographical differences in suicide related causes	True rise in suicide rates
Speechley M.	1991	Canada	Vital statistics 1950-1982	Trends of suicide Vs trends of suicides & undetermined	True rise in suicide rates
Kleck G.	1988	USA	Vital statistics 1980	Level of suicide related causes	Few underreporting
Kolmos L.	1987	Scandinavian countries	Vital statistics 1980	Rates by country and by age of suicide Vs competing causes	True differences in suicide rates
Giertsen J.C.	1993	Norway	Vital statistics 1960-1989		Rise explained by changes in registration procedures
Bille-Brahe U.	1997	Denmark	Vital statistics 1972-1993	Multiple causes analysis	
Platt S.	1988	Scotland	Vital statistics 1968-1983	Ratio "suicide/open verdict" according to various variables	Explaining variable = mode of death
Neeleman J.	1996	European Union (EU) countries		Legal procedures for suicide in EU	Differences between EU countries
Connoly J.F.	1995	Ireland	220 cases of deaths 1978-1992	Re-examination of cases Vs a gold standard	Large underreporting of suicides
Males M.	1991	USA	Vital statistics 1953-1987 among 15-24 yrs	Trends of suicide Vs trends of suicides & accidents	Rise explained by changes in registration procedures
Batten P.J.	1988	USA		Multiple causes analysis	
Allebeck P.	1991	Sweden	Cohort of young males conscripted to military service 1969-1983	Re-examination of the cases Vs a gold standard	Suicide correctly classified - agreement of 90%
Van de Voorde H.	1993	Belgium	Vital statistics Vs judicial files 1981-1984	Matching two sources	Distinct epidemiological pictures of suicide mortality
Sainsbury P.	1982	International	Vital statistics		Reliability of differences
O'Donnell I.	1995	UK	242 cases of deaths occurred on the railways "Probable suicides"	Re-examination of cases Vs a gold standard (witnesses statement)	Underreporting Marked variation between coroners
Moyer L.A.	1989	USA	Cohort of Veterans from the Army 1965-1983	Re-examination of cases Vs a gold standard	Suicide correctly classified - agreement in 90% of cases
Ferreira de Castro E.	1989	Portugal	Vital statistics 1971-1985	Trends of suicide Vs of suicides & controversial cases, homicides	Rise in suicide explained by changes in

					registration procedures
Atkinson M.W.	1975	England & Wales	40 cases histories	Cross national certification	Large variations
Clarke-Finnegan M.	1983	Ireland	410 deaths 1978	Re-examination of cases Vs a gold standard	Large underreporting
Mc Clure G.M.G.	1984	England & Wales (EW)	Vital statistics 1975-1980	Trends of suicide Vs controversial cases, accidents	True rise in suicide rates
Ross O.	1975	EW and Scotland	Sample of cases	Cross-certification by coroners	Reliability of differences

References

Allebeck P, Allgulander C, Henningsohn L, et al. Causes of death in a cohort of 50 465 young men-validity of recorded suicide as underlying cause of death. Scand J Soc Med 1991;19(4):242-47.

Allebeck P, Allgulander C, Fisher LD. Predictors of completed suicide in a cohort of 50465 young men: role of personality and deviant behaviour. BMJ 1988;297:176-78.

Atkinson MW, Kessel N, Dalgaard JB. The comparability of suicide rates. British Journal of Psychiatry 1975;127:247-56.

Barraclough B.M. The effect that coroners have on the suicide rate and the open verdict. In Psychiatric Epidemiology. *Ed Hare HE, Wing JK*. Oxford University Press, 1970:361-5.

Barraclough B.M. National differences in suicide rates. *Brit J Psychiat* 1973;122:95-106.

Batten PJ, Hicks LJ. The use of mental status in death certification of suicide. The American Journal of Forensic Medicine and Pathology 1988;9(3):203-06.

Bille-Brahe U. Death diagnoses among suicides: an overview based on official Danish records, 1972-93. Nord J Psychiatry 1997;51(5):339-49.

Blain PA, Donaldson LJ. The reporting of in-patient suicides: identifying the problem. Public Health 1995;109(4):293-301.

Cantor CH, Dunne MP. Australian suicide data and the use of "undetermined" death category (1968-1985). Australian and New Zealand Journal of Psychiatry 1990;24:381-84.

Casey DA. Suicide in the elderly: a two-year study of data from death certificates. (see comment:Galanos AN;1992). Southern Medical Journal 1991;84(10):1185-87.

Charlton J. Trends and patterns in suicide in England and Wales. International Journal of Epidemiology 1995;24(3,suppl 1):S45-52.

Clarke-Finnegan M, Fahy TJ. Suicide rates in Ireland. Psychological Medicine 1983;13:385-91.

Connolly JF, Cullen A. Under-reporting of suicide in an Irish county. Crisis 1995;16(1):34-38.

Farberow NL, MacKinnon DR, Nelson FL. Suicide: who's counting? Public Health Reports 1977;92(3):223-32.

Farberow NL, Neuringer C. The social scientist as coroner's deputy. Journal of Forensic Sciences 1971;16(1):15-39.

Farmer RDT. Assessing the epidemiology of suicide and parasuicide. British Journal of Psychiatry 1988;153:16-20.

Ferreira de Castro E, Pimenta F, Martins I. The truth about suicide in Portugal. Acta Psychiatr Scand 1989;80:334-39.

Frautschi S, Cerulli A, Maine D. Suicide during pregnancy and its neglect as a component of maternal mortality. International Journal of Gynaecology & Obstetrics 1994;47(3):275-84.

Galanos AN. Suicide in the elderly. (comment on: Casey DA;1991). Southern Medical Journal 1992;85(3):331.

GIERTSEN J.C. Reliability of Norwegian suicide statistics. Nord Med 1983 ; 58-59.

Gist R., Welch QB. Certification change versus actual behaviour change in teenage suicide rates,1955-1979. Suicide and Life-Threatening Behaviour 1989;19(3)277-88.

Hawton K, Fagg J. Suicide, and other causes of death, following attempted suicide. British Journal of Psychiatry 1988; 152:359-66.

Hesso R. Scandinavian routines and practices in the registration of suicide. Acta psychiatr. scand. 1987; suppl 336,76:17-21.

Jarvis GK, Boldt M, Butt J. Medical examiners and manner of death. Suicide and Life-Threatening Behaviour 1991;21(2):115-33.

Jobes DA, Berman AL, Josselson AR. Improving the validity and reliability of medical-legal certifications of suicide. Suicide and Life-Threatening Behaviour 1987;17(4):310-25.

Kelleher MJ, Corcoran P, Keeley HS, et al. Improving procedures for recording suicide statistics. Irish Medical Journal 1996;89(1):14-15.

Kelleher MJ, Daly M. Suicide in Cork and Ireland. British Journal of Psychiatry 1990;157:533-38.

Kleck G. Miscounting suicides. Suicide and Life-Threatening Behaviour 1988;18(3):219-36.

Kolmos L, Bach E. Sources of error in registering suicide. Acta psychiatr. scand. 1987;336(76):22-43.

Lester D. Miscounting suicides. *Acta Psychiatr Scand* 1992;85:15-19.

Males M. Reply to Kim Smith, PhD, on "Teen suicide and changing cause of death certification, 1953-1987" (*SLTB*, 21-3). (comment on: Smith K;1991). Suicide and Life-Threatening Behaviour 1991;21(4):402-05.

Males M. Teen suicide and changing cause-of-death certification, 1953-1987. (see comments: Smith K;1991). Suicide and Life-Threatening Behaviour 1991;21(3):245-59.

McClure GMG. Trends in suicide rate for England and Wales 1975-80. British Journal of Psychiatry 1984;144:119-26.

Moens GFG. The reliability of reported suicide mortality statistics: an experience from Belgium. International Journal of Epidemiology 1985;14(2):272-75.

Moyer LA, Boyle CA, Pollock DA. Validity of death certificates for injury-related causes of death. American Journal of Epidemiology 1989;130(5):1024-32.

Murphy GK. The "undetermined" ruling: a medico legal dilemma. Journal of Forensic Sciences 1978(?);483-91.

Neeleman J, Wessely S. Changes in classification of suicide in England and Wales: time trends and associations with coroners' professional backgrounds. Psychological Medicine 1997;27:467-72.

Neeleman J. Suicide as a crime in the UK:legal history, international comparisons and present implications. Acta Psychiatr Scand 1996;94(4):252-57.

O'Carroll PW. A consideration of the validity and reliability of suicide mortality data. Suicide and Life-Threatening Behaviour 1989;19(1):1-16.

O'Donnell I, Farmer R. The limitations of official suicide statistics. British Journal of Psychiatry 1995;166:458-61.

Pearson VAH. Suicide in North and West Devon: a comparative study using Coroner's inquest records. Journal of Public Health Medicine 1993;15(4):320-26.

Phillips DP, Ruth TE. Adequacy of official suicide statistics for scientific research and public policy. Suicide and Life-Threatening Behaviour 1993;23(4):307-19.

Platt S, Backett S, Kreitman N. Social construction or causal ascription: distinguishing suicide from undetermined deaths. Soc Psychiatry Epidemiol 1988;23(4):217-21.

Rich CL, Young D, Fowler RC, et al. The difference between date of suicidal act and recorded death certificate date in 204 consecutive suicides. AJPH 1985;75(7):778-79.

Rockett IRH, Smith GS. Homicide, suicide, motor vehicle crash, and fall mortality: United States' experience in comparative perspective. AJPH 1989;79(10):1396-400.

Rosenberg M.L. Operational criteria for the determination of suicide. *Journal of Forensic Sciences* 1988;32:1445-48.

Ross O, Kreitman N. A further investigation of differences in the suicide rates of England and Wales and of Scotland. British Journal of Psychiatry 1975;127:575-82.

Sainsbury P, Jenkins JS. The accuracy of officially reported suicide statistics for purposes of epidemiological research. Journal of Epidemiology and Community Health 1982;36:43-48.

Sainsbury P. Validity and reliability of trends in suicide statistics. Wld Hlth statist. Quart. 1983;36:339-48.

Salib E. Coroner's verdicts in the elderly: a suicide or an open verdict? International Journal of Geriatric Psychiatry 1997;12:481-3.

Schmidtke A. Perspective: Suicide in Europe. Suicide and Life-Threatening Behaviour 1997;27(1):127-36.

Smith K. Comments on "Teen suicide and changing cause-of-death certification, 1953-1987". (comment on: Males M;1991). Suicide and Life-Threatening Behaviour 1991;21(3):260-62.

Speechley M, Stavraky KM. The adequacy of suicide statistics for use in Epidemiology and public health. Canadian Journal of Public Health 1991;82(1):38-42.

Thorslund J, Misfeldt J. On suicide statistics. Arct Med Res 1989;48:124-30.

Van de Voorde H, Hooft P, Mulkers U. On the influence of data source in aggregated data studies: a comparative study of suicide information based on death certificates and judicial files. Journal of Epidemiology and Community Health 1993;47(1):73-75.

Walsh D, Cullen A, Cullivan R, et al. Do statistics lie? Suicide in Kildare-and in Ireland. Psychological Medicine 1990;20:867-71.

Whitlock F.A. Migration and suicide. *Med J Australia* 1981;2:840-8.

Leads from the MMWR-Operational criteria for determining suicide. JAMA 1989;261(3):360,366.

Operational criteria for determining suicide. Morbidity and Mortality Weekly Report 1988;37(50):773-74,779-80.

WHO. Suicide and attempted suicide, Public Health paper, 58, Geneva, 1974.

III.2.4 CARDIOVASCULAR DISEASES

Large disparities in the level of death rates from cardiovascular diseases amongst developed countries have been recorded since the sixties. Many authors have questioned the sources of these disparities. Issues such as 'differences in risk factors', and 'differences in medical care' have been investigated. At the same time, the quality and the comparability of data collected from cardiovascular disease death certificates have been questioned. But these types of methodological explorations have been less frequently carried out. In the following text, we review the published studies on the quality of cause of death data for cardiovascular diseases, compare the methods of investigation and summarize the conclusions from the main published studies. Most of these analyses have been undertaken at a national or local level.

A. ANALYSIS OF EUROSTAT CAUSES OF DEATH DATA

Leading cause of death in Europe, but wide disparities in death rates between countries.

In spite of a decrease over the recent decades, cardiovascular diseases remain the leading cause of death in Europe. For the year 1994, a total of 1 600 000 deaths were recorded in all European Union countries, representing 43% of all deaths, just before cancer, which represents 27% of the total mortality. The death rates vary considerably amongst the EU countries. They may be broadly classified in 3 groups according to the overall standardised death rates from cardiovascular diseases for males (Tab 1):

1. High level (over 400 per 100,000): Ireland, Finland, Austria, Germany, Netherlands, Portugal, the UK and Denmark.
2. Mean level (between 300 and 400): Sweden, Norway, Luxembourg, Greece, Iceland, Belgium, Italy and Switzerland.
3. Low level (less than 200): Spain and France.

This classification does not outline any clear geographical gradient. The rank of the countries does not differ markedly according to sex or age groups.

More disparities for ischaemic than for cerebrovascular disease

Ischaemic heart diseases represent 40% of all cardiovascular disease, and cerebrovascular diseases 30%. In contrast to overall cardiovascular diseases, the distribution in death rates from these specific subcategories draws net gradients. But these gradients differ markedly according to the category considered (Fig 1, 2 & Map 1).

Ischaemic heart diseases (IHD) death rates are higher in northern and middle eastern European Union countries and lower in southern European Union countries, especially in France.

With the exception of two countries (Portugal and Greece) which record particularly high rates, the European death rates from cerebrovascular diseases are closer than ischaemic heart disease. Portugal records more than 1,4 times the European overall cerebrovascular diseases death rates. Paradoxically, Spain, its neighbouring country, ranks medium. The lowest rates are observed in France, which is at

Fig1. **Distribution of cardiovascular death rates according to Ischaemic Heart Disease death rates (males)***

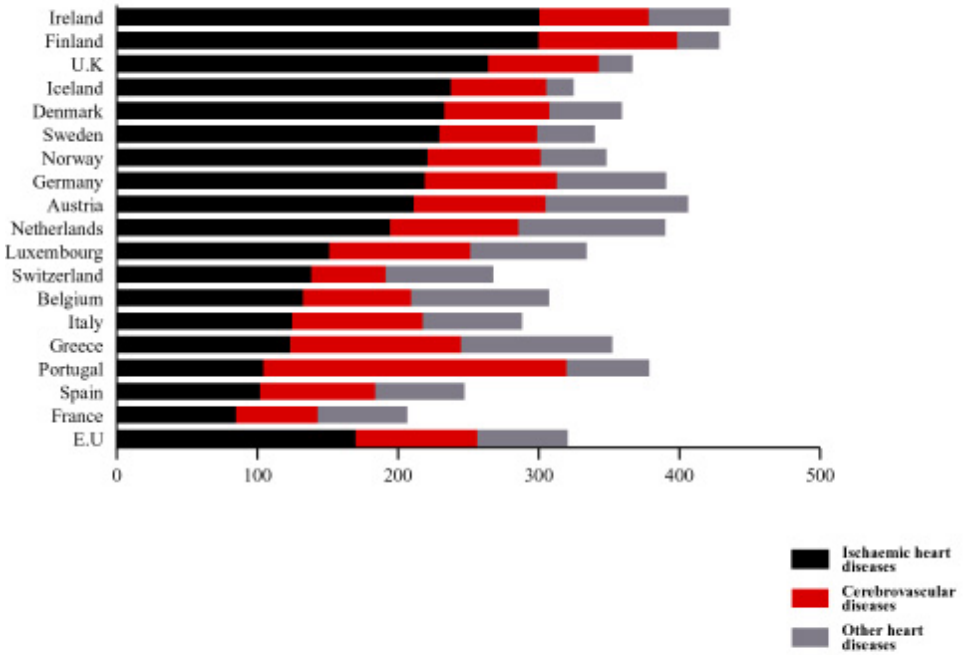
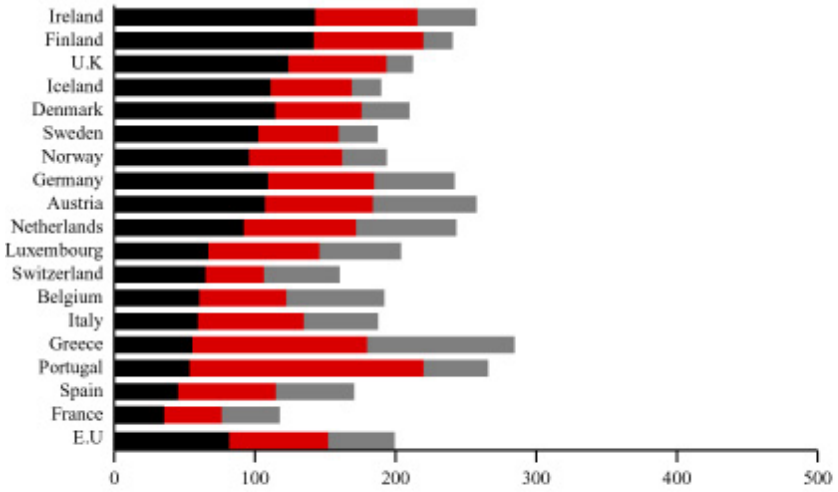
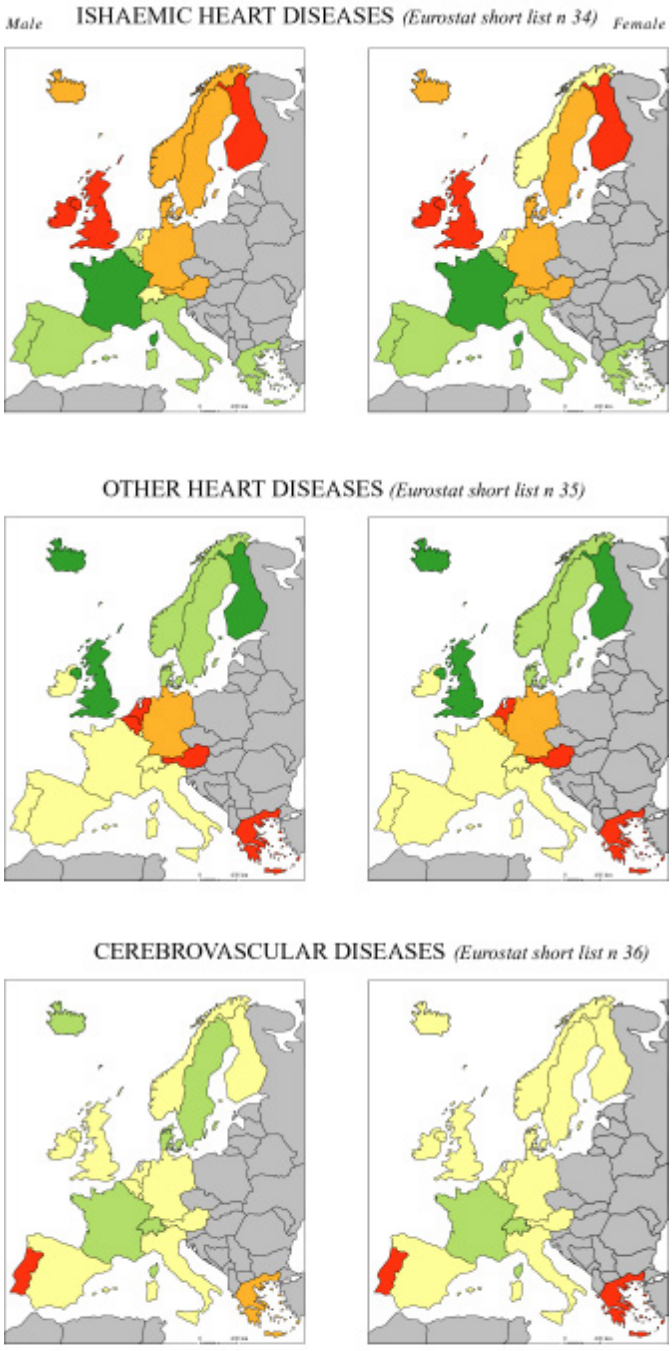


Fig2. **Distribution of cardiovascular death rates according to Ischaemic Heart Disease death rates (females)***



*Standardized death rate for 100.000



the bottom of the list of all European Union countries for both ischaemic heart disease and cerebrovascular diseases.

Why an opposite gradient for ischaemic heart disease and other heart disease?

For many countries, the level of death rates from ischaemic heart disease is in reverse order than that of 'Other Heart Diseases' (Tab 2). For example, the three countries on the bottom of the 'Other Heart Diseases' scale (Finland, the UK and Iceland) rank on the top of the 'Ischaemic Heart Diseases' scale. A similar situation is observed, in reverse order, for the countries that are on the bottom of the 'Ischaemic Heart Diseases' scale such as Greece and France. Greece is on the top of the 'Other Heart Diseases' scale, and France is in the middle despite its' overall low mortality rates from cardiovascular diseases. On the whole, death rates from 'Other Heart Diseases' are relatively low in the northern countries, and slightly higher in the southern countries. This is the opposite of the variation of death rates from 'Ischaemic Heart Diseases'. The ratio Other Heart Diseases / Ischaemic Heart Diseases for males is 1/10 in the country which records the most IHD (Finland), and 10/10 in the country which record the least IHD (France). Because they are competing diseases, this reversed variation of two categories of cardiovascular diseases, may be a questioning argument about the homogeneity of the certification of cause of death data from cardiovascular diseases.

Table 1 **Standardised death rates from cardiovascular diseases by country, year 1994***

Country	All ages			0-64 years		
	Males	Females	Ratio M/F	Males	Females	Ratio M/F
Ireland	480.3	291.6	1.6	115.5	40.0	2.9
Finland	466.1	269.1	1.7	120.6	31.0	3.9
Austria	464.4	305.7	1.5	100.4	34.1	2.9
Germany	451.3	288.5	1.5	99.2	34.5	2.9
Netherlands	444.0	277.7	1.6	80.9	30.2	2.7
Portugal	421.4	301.2	1.4	81.4	34.6	2.3
U.K.	415.1	244.9	1.7	98.3	37.2	2.6
Denmark	408.8	242.4	1.7	88.3	32.8	2.7
Sweden	390.2	222.3	1.7	77.3	25.7	3.0
Norway	389.4	219.1	1.7	83.3	27.3	3.0
Luxembourg	383.8	238.0	1.6	86.6	27.8	3.1
Greece	377.7	304.7	1.2	88.6	30.3	2.9
EU	**370.9**	**236.3**	**1.5**	**82.4**	**28.8**	**2.8**
Iceland	369.0	209.3	1.7	74.8	27.0	2.7
Belgium	350.6	221.3	1.6	75.2	28.4	2.6
Italy	341.3	229.6	1.5	69.7	25.2	2.7
Switzerland	305.1	188.1	1.6	59.6	19.9	3.0
Spain	292.1	206.4	1.4	68.8	22.4	3.0
France	252.2	146.4	1.7	55.9	17.4	3.2

* Decreasing death rates for males in all age groups - Year 1994 except Belgium (1993)

Higher sex ratio for premature mortality (<65years)

For all cardiovascular diseases the all ages sex ratio is 1.5 (for 250 deaths from cardiovascular diseases, 150 are males and 100 are females). The northern and central European countries including France record the highest sex ratio, and the southern countries (Greece, Spain, Portugal) the lowest. The sex ratio is higher for ischaemic heart diseases (2) than for cerebrovascular diseases (1.2).

The sex ratio is larger in the 0-64 age group (2.8) for all circulatory diseases, and markedly higher for ischaemic heart diseases in the same age group (4.4).

Table 2 **Classification of the countries according to death rates by subcategories of cardiovascular diseases (males-all ages)**

Rank	All cardiovascular	IHD	CVD	Other
1	Ireland	Finland	Portugal	Greece
2	Finland	Ireland	Greece	Netherlands
3	Austria	U.K.	Luxembourg	Austria
4	Germany	Iceland	Finland	Belgium
5	Netherlands	Denmark	Germany	Luxembourg
6	Portugal	Sweden	Austria	Germany
7	U.K.	Norway	Italy	Switzerland
8	Denmark	Germany	Netherlands	Italy
9	Sweden	Austria	Spain	France
10	Norway	Netherlands	Norway	Spain
11	Luxembourg	Luxembourg	U.K.	Portugal
12	Greece	Switzerland	Ireland	Ireland
13	Iceland	Belgium	Belgium	Denmark
14	Belgium	Italy	Denmark	Norway
15	Italy	Greece	Sweden	Sweden
16	Switzerland	Portugal	Iceland	Finland
17	Spain	Spain	France	U.K.
18	France	France	Switzerland	Iceland

B. RESULTS OF THE QUESTIONNAIRE

Two subcategories of cardiovascular diseases were specifically investigated through the questionnaire to members states (Ischaemic Heart Diseases and Cardiovascular Diseases).

Ischaemic heart diseases

Amongst the 13 respondents, 12 consider the cause of death statistics from ischaemic heart disease as reliable in their country (5 fairly reliable). The possible declared biases affecting cause of death statistics from ischaemic heart disease are various. According to the country's experts, deaths from ischaemic heart disease may be either overestimated or underestimated. Two experts indicated that the ischaemic heart disease biases are around 15%, but they didn't indicate the direction of biases. Those were considered as possible misclassifications in both directions. Depending on the countries, the cause of death from ischaemic heart disease can be wrongly classified as unknown and unspecified cause of death, as for cerebrovascular or other diseases. On the other hand, cause of death from malignant neoplasm, diabetes, liver cancer associated with cardiac disease may be wrongly certified as ischaemic heart disease. Respondents declared that biases affecting ischaemic heart disease statistics might be due to incomplete or imprecise information on death certificates. The quoted reasons are i) lack of training to fill out the death certificates, ii) lack of information about the context of the death (i.e. deaths occurring in the emergency medical service), iii) limited number of autopsies performed or delay in the feedback of post mortem examination results. The

accuracy of ischaemic heart diseases medical certification decreases with advancing age or in case of multiple chronic diseases (comorbidity).

Table 3 **Opinions from experts concerning the reliability of cause of death data from Ischaemic Heart Diseases and Cerebrovascular Diseases in their country**

Opinion on cause of death data		Number of responding countries/regions : 13	
		Ischaemic Heart Diseases	Cerebrovascular Diseases
Reliability	Reliable	7	10
	Fairly reliable	5	1
	Not (very) reliable	0	1
	Unknown	1	1
Direction of biases	Underestimation	4	1
	Overestimation	3	2
	Unknown	1	1
	Not requested	5	9
Proportion of biases if underestimation	0-15%	3	0
	15-30%	1	0
	More than 30%	0	0
	No response	0	1
	Not requested	9	12
Proportion of biases if overestimation	0-15%	3	1
	15-30%	0	2
	More than 30%	0	0
	Not requested	10	10
Influence of age on biases	Yes	7	4
	Unknown	0	1
	No	0	0
	No response	1	0
	Not requested	5	8
The most affected age group by biases	0-25 years	0	0
	25 to 65 years	2	0
	> 65 years	7	5
	No response	5	8
	Not requested	5	8
Sources of biases	Medical certification	6	4
	Coding rules	1	0
	Other reasons	2	1
	Unknown	1	1
	Not requested	5	8
Change of rank of the country if correction	Yes	1	0
	No	6	5
	No response	2	2
	Not requested	4	6
Answer based on	Personal opinion	3	4
	Collective opinion	5	5
	Specific studies	7	2
	No response	0	3

Cerebrovascular diseases

Amongst the 13 respondents, 10 consider that the certification for cerebrovascular diseases is sufficiently reliable in their countries. Two respondents said that cerebrovascular diseases figures are overestimated, one said that they are underestimated and one stated that the direction of biases remains uncertain. Cause of death from sudden death, cardiac arrest, dementia, cancer or unknown cause of death may be wrongly certified as cerebrovascular diseases. Cases of IHD may also be classified as Cerebrovascular Diseases. As is the case of IHD, the accuracy of medical certification

decreases with advancing age and inversely with the number of diseases associated. Errors in cerebrovascular diseases medical certification (misclassification, under/overestimation) may be due to the lack of autopsies or to the lack of return of information after autopsy.

C. ANALYSIS OF THE LITERATURE REVIEW

Interest in the quality and reliability of causes of death statistics from cardiovascular diseases has risen since the early sixties.

This was prompted by the dramatic decline in time trends, and by the large variations between countries in mortality rates from cardiovascular diseases, especially from ischaemic heart diseases. Methodological studies have been performed in order to verify the reality of this decline and/of these large discrepancies between countries.

Table 4 **Studies on quality and comparability of cause of death data from cardiovascular diseases**

COD*	Author	Date	Country	Source	Methods	Size if (sample)
ALL	Lahti	1998	Finland	Vital stat	Trends in competing diseases (autopsy rates)	
ALL	Vivario	1992	Belgium	Sample	Gold standard (autopsy)	251
ALL	Szczesniewska	1990	Poland	Sample	Gold standard (register)	2585
ALL	Hasuo	1988	Japan	Sample	Gold Standard (autopsy)	864
CVD	Reggio	1995	Italy	Sample	Gold standard **	193
CVD	Douglas	1993	USA	Vital stat	Trends in competing diseases (autopsy rates)	
CVD	Hiroyasu	1990	USA	Sample	Gold standard**	408
CVD	Garland	1989	USA	Sample	Gold standard**	500
CVD	Björkelund	1988	Sweden	Sample	Gold standard **	146
CVD	Hedley	1985	UK	Sample	Gold standard (autopsy)	120
IHD	Mähönen	1999	Finland	Sample	Gold standard **	4 835
IHD	Iribarren	1998	USA	Sample	Gold standard**	254
IHD	De Henauw	1997	Belgium	Sample	Gold standard (register)	1 675
IHD	Ambach	1995	Austria	Sample	Gold standard (autopsy)	1 595
IHD	Walsh	1992	Australia	Sample	Gold standard**	729
IHD	Nuttens	1990	France	Sample	Gold standard**	330
IHD	Guibert	1989	Canada	Sample	Gold standard (double coding)	2 400
IHD	Rodney	1988	New Zealand	Sample	Gold standard (register)	876
IHD	Sundman	1988	Sweden	Sample	Gold standard**	385
IHD	Sorlie	1987	USA	Sample	Gold standard (double coding)	1 029
IHD	Shimamoto	1987	Japan	Sample	Gold standard**	210
IHD	Folsom	1987	USA	Sample	Gold standard**	413
IHD	Leitch	1987	New Zealand	Sample of doctor	Gold standard (cases history) (double coding)	627
IHD	Martin	1987	Australia	Sample	Gold standard**	3081
IHD	Rosalind	1986	UK	Sample	Gold standard**	993
IHD	MacIlwaine	1985	UK	Sample	Gold standard	1 654
IHD	Koskenvuo	1985	Finland	Sample	Gold standard (hospital records)	7 447
				Vital stat	Trends in incidence & survival rates	

* Papers ranked according to the subcategory of disease and the decreasing year of publication
COD: Cause of death;
ALL: All cardiovascular diseases;
CVD: Cardiovascular Diseases;
IHD: Ischaemic Heart Disease

** Various types of sources for the establishment of the gold standard

The limited number of studies undertaken in view of the large number of deaths due to cardiovascular diseases

Deaths from cardiovascular diseases represent more than half of all causes of death. In comparison to other diseases investigated, the corresponding number of scientific papers published on the quality and comparability of the data is relatively low. For instance, the number of papers concerning suicide is equivalent to that of cardiovascular diseases, whereas the number of deaths due to cardiovascular diseases is more than 30 times higher.

On the whole, 40 published papers were selected. 27 studies were directly carried out on the quality or the comparability of cause of death statistics from cardiovascular diseases, 17 concerning ischaemic heart diseases, 6 cerebrovascular diseases and 4 all cardiovascular diseases. The other 13 papers consisted of comments but not on specific investigations.

The medical certification more frequently investigated than the coding process.

Out of the 27 studies selected, 17 concern exclusively medical certification, 1 the coding process and 9 both medical certification and coding. 24 papers are based on the assessment of the cause of death listed on individual death certificates and are then concerned with validity evaluation of cause of death certification. 2 are based on the analysis of vital statistics. The last one used both methods.

Amongst the 27 papers, 14 concerned European Union countries. Finland and the United Kingdom are at the top of the list. We did not find any centralised European union study, which investigated the comparability of the data between countries as a whole.

C.1 METHODS OF INVESTIGATION

Investigation of the validity of data, based on the assessment of individual cause of death certificates

The validity of medical certification from cardiovascular diseases has been investigated by comparing the underlying cause of death entered by the certifier on the death certificate with various other sources:

- autopsy results' (Austria, Belgium, the UK, and Japan).
- hospital records (Finland).
- morbidity registers such as MONICA (Finland, Belgium, Poland, and New Zealand).
- various types of source (Australia, France, Italy, Japan, Sweden, the UK and the USA). On the basis of various information, a group of experts determines the underlying cause of death to use as reference (gold standard).

The validity of the cause of death certification process has also been investigated by analysis of the variation between states of the underlying cause of death assigned by a random sample of doctors to a same set of clinical case histories. But these types of studies are rare (Australia, and New Zealand).

The comparability of the coding process has been investigated by double coding exercises in Canada, USA-Maryland, Australia and New Zealand (comparison of codes assigned by routine coders with those attributed by expert's nosologist).

Investigation of the reliability of data, based on the analysis of vital statistics

The studies that investigated the reliability of causes of death statistics from cardiovascular diseases, on the basis of analysis of aggregated data are very few. The only studies found have proceeded by analysis of:

- Trends in autopsy rates from all causes of death compared with those from ischaemic heart diseases or Cerebrovascular Diseases (Finland, and the USA).
- Trends in incidence and survival rates compared with trends in mortality rates (Finland).

C.2 RESULTS

Most of the studies which investigated the quality of cause of death data from cardiovascular diseases by the various methods described above, concluded that this data has globally an acceptable quality throughout the European Union countries.

C.2.1 STUDIES BASED ON THE ASSESSMENT OF INDIVIDUAL DEATH CERTIFICATES

Studies based on the evaluation of individual death certificates conclude generally to a good validity of the information provided by these certificates (relatively high sensibility and specificity).

Comparison of death certificates with autopsy results

A sufficient validity of causes of death certificates has been concluded from the studies based on comparison of the underlying cause of death listed on the death certificate and the one determined after autopsy. In Belgium (*Vivario 1992*), a study which compared the clinical diagnosis before and after autopsy in case of adult sudden death showed a correctness rate (predictive value) of 83% for Cerebrovascular Diseases and of 62% Ischaemic Heart Diseases. A study performed in Austria (*Ambach 1995*), suggested that the number of myocardial infarction clinically based is about 15% higher than that obtained by autopsy. The positive predictive value of the underlying cause of death clinically based was 72%. In Japan (*Hasuo 1988)*, the clinical diagnosis for cardiovascular diseases

in death certificates were compared to the diagnosis made at the autopsy. The correctness (predictive value) reaches 84% for cerebral stroke, and 66% for cardiac diseases.

A study performed in the UK on strokes (*Hedley 1985*) investigated the causes of death entered on death certificates after autopsy (full autopsy findings, and pathologists' opinions). The causes of death mentioned after autopsy were frequently mentioned in the death certificate. The most frequent discrepancies between death certificate and the pathologists' opinions concerned the relegation of hypertension from part I (due to) to part II of the death certificate (other significant conditions contributing to death).

Comparison of death certificates with hospital data records

A study comparing the causes of death entered on the death certificates with hospital records performed in Finland (*Koskenvuo 1985*) showed a good validity for Ischaemic Heart Diseases diagnoses. The correctness rate (predictive value) was 90%.

Comparison of death certificates with morbidity register information

Investigation of the validity of death certificates based on information from morbidity registers has been performed in Poland, Finland, Belgium, and New Zealand. Globally, results from this type of exercise showed a good validity of the death certificates.

In Poland (*Sczesniewska 1990*), the death certificate records from the Central Statistical Office has been compared with data from the register of Myocardial Infarction and Strokes (1984-1986). The completeness (predictive value) of the Central Statistical Office data with respect to the register data approached 90%.

A study performed in Finland (*Mähönen 1999*), investigated the underlying cause of death from routine mortality statistics for suspect coronary deaths (1983-1992). This study concluded that the Finnish routine mortality statistics for Ischaemic Heart Diseases are reasonably valid and can be used to assess trends in IHD mortality (the sensitivity was 95%, the specificity 72%, and the positive predictive value 98%).

A similar conclusion has been suggested in a study performed in New Zealand (*Rodney 1988)*, which investigated the Ischaemic Heart Diseases (IHD) official statistics' from 876 death certificates. In this study, the sensitivity and the positive predictive value were close to 90%, but the specificity was lower (50%).

One study outlined serious biases in the certification process, when considering subcategories of Ischaemic Heart Diseases. This study performed in Belgium (*De Henauw 1997*) compared 1675 cases of Acute Myocardial Infarction recorded in the WHO-MONICA register and records from death certificates during 1983-1991 in the age group 25-69 years in two geographical areas. The sensitivity of death certificates from Ischaemic Heart Disease was 73 %, but only 49% when the

Acute Myocardial Infarction (ICD9: 410) was considered separately. However, we must bear in mind that our investigation is focused on quality and comparability of mortality data for the main groups of pathologies, according to the Eurostat short list of 65 causes of death.

Comparison of death certificates with various sources

Acceptable validity of cause of death certificates has been generally suggested by authors, who compared the underlying cause of death entered on the death certificate to that determined by experts from various types of source.

A study performed in France (*Nuttens 1990*), compared the underlying cause of death from 330 death certificates possibly due to IHD, with the underlying cause of death assigned by 2 experts for the town of Lille. These experts assigned the cause of death after an inquiry using the various sources of information (medical information relevant from certifying doctors, hospital files, emergency doctor's files, and autopsy results). The authors concluded that IHD death certificates in France are sufficiently valid for epidemiological purposes (sensitivity: 78% and specificity: 96%).

A similar conclusion has also been reported following another study performed in Belfast *(UK, MacIlwaine 1985*). The underlying cause of death from 1654 death certificates (all age groups) possibly[1] due to IHD were compared with the underlying cause of death determined after further investigation. The number of deaths recorded as being due to IHD was found to be substantially accurate (sensitivity: 89% and specificity: 67%). Another study performed in England and Scotland (*Rosalind 1986*), investigated 993 IHD death certificates from patients who had died under the age of 60 years during 1980 and 1981. The positive predictive value was globally high (80%), but higher in England and Wales than in Scotland.

In Sweden (*Sundman 1988*), a study compared the routinely assigned IHD underlying cause of death from death certificates, with those determined by two physicians after review of medical records and other relevant material (hospital and district physician records, reports from clinical or medicolegal autopsies). The sensitivity of IHD death certificates was very high (95%). Another study (*Björkelund 1988*) analysed 146 death certificates of women who died from Cerebrovascular Disease in Strömstad between 1969-1978. The positive predictive value of the death certificates was 83% (87% before 75 years). This study showed that, in spite of a low Cerebrovascular autopsy rates (11%), a large majority of the death certificates had been correctly certified.

In the USA (*Folsom 1987*), an out-of-hospital IHD death study analysed a total of 413 death certificates supposed to concern mostly IHD or Cerebrovascular Diseases[2]. The findings suggest

[1] ICD9 codes: 410-414, 427, 428, 429, 250,0, 436.0

[2] ICD9 codes: 342, 402, 410-415, 420, 422, 425-441, 480-492, 496, 518, 780-781, 784-786, 798-799

that the validity of death certificates for out-of-hospital IHD is high in the USA (sensitivity: 90%, specificity: 82%). Another study (*Iribarren 1998*) assessed the validity of 254 death certificates' diagnosis of out-of-hospital sudden cardiac death. The underlying cause of death entered on the death certificates were compared with that assigned after a specific inquiry (review of the death certificate itself, clinical records, autopsy reports and informant interviews). When the cardiac arrest (ICD9: 427.5) and the Ischaemic Heart Diseases were grouped, the sensitivity reached 87%, and the specificity 66%.

A high standard of death certificates in USA has been suggested by another study (*Hiroyasu 1990*), which investigated the in-hospital deaths of possible stroke (positive predictive value: 98%). Another study (*Garland 1989*) showed that the Cerebrovascular Diseases false negative was low. In that study, which covered the period between 1950-1970, 500 death certificates were analysed for the 10-65 years age group. In the 10-65 years group, the highest sensitivity was 72% for subarachnoïd haemorrhage. The lower sensitivities were recorded for cerebral haemorrhage and infarctive stroke. Analysis of death certificates attributed to causes other than strokes showed that only 2-3% of such deaths appeared to have been due to strokes. In the children group (under 10 years), a large proportion of the cerebrovascular deaths, which occurred was attributed to birth trauma, congenital defects, or genetic predisposition.

In Japan (*Shimamoto 1987*), all cases[3] in which the underlying cause of death was Myocardial Infarction, Acute Heart Failure, Heart Failure or hypertension were investigated in two rural areas and two urban areas between 1981 and 1984. The conclusion was that the number of Myocardial Infarction deaths was not significantly underestimated from death certificates.

In Western Australia (*Martin 1987*), the underlying cause of death from Ischaemic Heart Disease (IHD) was analysed in view of the death certificate itself, hospital records, autopsies and private doctors or police records. It showed a high standard of IHD death certificates (sensitivity: 98%, positive predictive value: 92%), but the specificity was lower. Results from a similar study performed in Tasmania[4] (*Walsh 1992*) for persons aged 25-74 suggested that the Ischaemic Heart Diseases data was sufficiently accurate (sensitivity: 94%, positive predictive value: 90%, specificity: 59%).

In a study performed in Sicily (*Reggio 1995*), 193 death certificates on which Cerebrovascular Diseases were reported as initial, intermediate or terminal cause of death had been re-evaluated. If the diagnosis of stroke was considered globally, the false negatives reached 24%. But the total

[3] Review of medical records, interviews with patient's families

[4] Tasmania is a south Australian Island isolated by the Bass Strait

number of confirmed strokes was reasonably close to the number of deaths with an initial cerebrovascular cause.

The variability of medical certification of cause of death for Ischaemic Heart Diseases has also been investigated in Australia and New Zealand (*Leitch 1987*), by analysis of the variation between states of the underlying cause of death assigned by a random sample of doctors to a same set of clinical case histories (627 doctors completed death certificates for 10 case histories). This study showed a large variability in the entering of diagnosis in parts I and II of the death certificate (sensitivity varied between 37% and 99%).

The validity of the coding process has been investigated by double coding exercises in a study performed in Canada (*Guibert 1989*). This study assessed the impact of geographic and time variation in the coding of cause of death. A set of 600 death certificates for the years 1970 and 1984 was obtained from each of the two provinces: Nova Scotia (with the highest IHD mortality rates), and Saskatchewan (with the lowest IHD mortality rates). The comparison of results didn't show significant discrepancies in the coding process. The conclusion was that the variation of death certificate coding over time and geographic regions does not contribute to the explanation of the Acute Myocardial Infarction comparative mortality decline. This study also investigated coding changes due to the introduction of the Ninth revision of ICD. The conclusion was that the decline of Acute Myocardial Infarction mortality was not explained by change in the ICD revisions. However, these findings ran against the results of a study performed in USA-Maryland (*Sorlie 1986*). This study suggested that the exceptionally large decline in the number of deaths from IHD in Maryland was in part attributable to the change in the classification procedures moving from ICD8 to ICD9.

C.2.2 STUDIES BASED ON THE ANALYSIS OF VITAL STATISTICS

Studies based on the analysis of vital statistics and not on individual case assessment are rare (only 3 out of 27). Two of them investigated the trends in autopsy rates and the other one investigated the trends in incidence and survival rates.

Analysis of trends in autopsy rates

A recent study performed in Finland (*Lahti RA 1998*), investigated trends in the quality of the medical certification process by analysis of trends in autopsy rates. In this study, trends in Ischaemic Heart Diseases' autopsy rates were compared with trends in all natural causes of death autopsy rates over the period 1974-1993. It showed that the use of autopsy in IHD-diagnostics was more frequent than that of all natural deaths. The authors concluded that the recent decline of IHD observed in Finland could not be explained by deterioration in cause of death examination practices

Another study performed in the USA (*Douglas 1993*) used the same methodology for stroke: comparison of trends in autopsy rates from all causes of death and those from strokes for the periods 1955-1958, and 1972-1988. For each period, the non-stroke deaths were more than twice as likely to be autopsied than deaths due to Cerebrovascular Disease. The decline in autopsy frequency was precipitous after 1972. The improved diagnostic techniques were cited as possible explanations for the decline in stroke autopsy frequency.

Analysis of trends in incidence and survival rates

The reliability of cause of death vital statistics from Finland has been investigated in a study (*Koskenvuo 1985)* which compared trends in incidence and survival rates from Ischaemic Heart Diseases with corresponding trends in mortality rates for the years 1972 and 1982. That study concluded to a fair reliability of vital statistics from IHD. The observed decrease in mortality from IHD was explained by both decreases in incidence and better survival.

C.2.3 STUDIES BASED ON REGIONAL AND INTERNATIONAL COMPARISIONS

Most of the studies examined before concern a sole country. Only six out of the 27 selected studies investigated the comparability of data between states inside a country or between countries themselves. Four studies investigated the comparability between areas in the same country (Sweden, Belgium, Canada, and Japan). Two investigated the variability between countries (the UK, Australia and New Zealand).

Comparability of data inside a country

A study performed in Sweden investigating data from two Swedish municipalities (*Sundman 1988*) suggested that there was a good homogeneity in the certification and coding process of death from Ischaemic Heart Diseases. A similar conclusion was drawn from a study performed in Canada (*Guibert 1989*) which investigated the geographic and time variation impact on the coding process. In Japan (*Shimamoto 1987*), a study prompted by an impression of rising trends in Myocardial Infarction incidence rates in the urban population concluded that the causes of death data was sufficiently accurate in both rural and urban areas.

In contrast, a study performed in Belgium (*De Henauw 1997*), on the comparability of mortality data between Ghent (northern Dutch speaking) and Charleroi (southern French speaking) showed a substantial difference in the certification process for cardiovascular diseases (sensitivity: 68% in Ghent and 77% in Charleroi).

Comparability of data between countries

A study performed in the UK (*Rosalind 1986*) investigated the variation in mortality from Ischaemic Heart Diseases between England and Scotland. The IHD death certificates in North

Staffordshire (England) and Grampian (Scotland) were compared for the years 1980 and 1981. The results suggested that the increased observed mortality rates from IHD in Scotland might be explained by variation in cause of death certification. In this study, the inaccuracies of death certificates amounts to 8% in Grampian (Scotland), compared with 4% in North Staffordshire (England).

In a study oriented to both medical certification and coding processes performed in Australia and New Zealand (*Leitch 1987*), each death certificate completed by Auckland's doctors was coded by the Australian Bureau of Statistics Centre for Auckland, and by the Federal Office of all Australian states. It outlined a large variation in the codes assigned to each case history. But these variations were not large enough to account for the variation in Ischaemic Heart Disease rates between States.

D. CONCLUSION

Cardiovascular diseases remain the leading cause of death amongst the European Union countries, and large variation exists between countries. But we did not find any study discussing the quality and the comparability of mortality data for this group of pathologies for Europe as a whole.

According to the country's experts, and based on an individual questionnaire, the national causes of death statistics from cardiovascular diseases are reliable. In addition, the synthesis of the most recent literature suggested that when the subcategories of cardiovascular diseases are sufficiently grouped (that is the case for the Eurostat Cause of Death Short List), the published mortality data might be considered as sufficiently adequate for epidemiological purposes.

However, the studies performed concerned mainly the national or local level. Then, even if the results outlined are quite important, they are not representative enough to provide either a global assessment of the quality of mortality data, or a global information on the comparability of mortality data between countries.

One of the ways to investigate the variability of cardiovascular diseases between countries would be to undertake case histories certification and bridge coding exercises between all countries. The reliability of the published mortality data may be also investigated by comparisons of trends in a selection of competing diseases (other cardiac diseases, diabetes, sudden death…), using standardised methods comparing all countries.

DISEASES OF THE CIRCULATORY SYSTEM *Eurostat shortlist n° 33*

Armstrong DL, Wing SBW, Tyroler HA. United States mortality from ill-defined causes, 1968-1988: potential effects on heart disease mortality trends. International Journal of Epidemiology 1995;24(3):522-27.

Beadenkopf WG, Abrams M, Daoud A, et al. An assessment of certain medical aspects of death certificate data for epidemiologic study of arteriosclerotic heart disease. J. chron. Dis. 1963;16:249-62.

Curb JD, Babcock C, Pressel S, et al. Nosological coding of cause of death. American Journal of Epidemiology 1983;118(1):122-28.

Davis BR, Curb JD, Tung B, et al. Standardized physician preparation of death certificates. Controlled Clinical Trials 1987;8:110-20.

Edlavitch SA, Baxter J. Comparability of mortality follow-up before and after the National Death Index. American Journal of Epidemiology 1988;127(6):1164-78.

Engel LW, Strauchen JA, Chiazze L, et al. Accuracy of death certification in an autopsied population with specific attention to malignant neoplasms and vascular diseases. American Journal of Epidemiology 1980;111(1):99-112.

Gray DP. Asymptomatic hypercholesterolaemia. (see comment:Sumner KR;1991). BMJ 1991;302:1022.

Hasuo Y, Ueda K, Kiyohara Y, et al. Accuracy of diagnosis on death certificates for underlying causes of death in a long-term autopsy-based population study in Hisayama, Japan; with special reference to cardiovascular diseases. J Clin Epidemiol 1989;42(6):577-84.

Hay DR. Autopsy and the cause of death. (comment on:Stehbens WE;1988). New Zealand Medical Journal 1989;101(859):23.

Inman WHW, Vessey MP. Investigation of deaths from pulmonary, coronary, and cerebral thrombosis and embolism in women of child-bearing age. BMJ 1968;2:193-99.

Iribarren C, Crow RS, Hannan PJ, et al. Validation of death certificate diagnosis of out-of-hospital sudden cardiac death. The American Journal of Cardiology 1998;82(1):50-53.

Jenkins M, Farnan T, Hopper IP, et al. Deaths certified as due to coronary artery disease. (comment on:Sumner KR;1991). BMJ 1991;303:53-54.

Jow-Ching-Tu E. Multiple cause-of-death analysis of hypertension-related mortality in New York State. Public Health Reports 1987;102(3):329-35.

Kuller L, Lilienfeld A, Fisher R. Quality of death certificate diagnoses of arteriosclerotic heart disease. Public Health Reports 1967; 82(4):339-46.

Liberthson RR. Sudden death from cardiac causes in children and young adults. The New England Journal of Medicine 1996;334(16):1039-44.

Moriyama IM, Dawber TR, Kannel WB. Evaluation of diagnostic information supporting medical certification of deaths from cardiovascular disease. National Cancer Institute Monograph 1963:19:405-19.

Sorlie PD, Gold EB. The effect of physician terminology preference on coronary heart disease mortality: an artifact uncovered by the 9th revision ICD. American Journal of Public Health 1987;77(2):148-52.

Stehbens WE. Coronary heart disease death certificate diagnoses. (see comment:Hay DR;1989). New Zealand Medical Journal 1988;101(859):829.

Sumner KR. Deaths certified as due to coronary artery disease.(see comment:Jenkins M;1991),(comment on:Gray DP;1991). BMJ 1991;302:1402.

Szczesniewska D, Kurjata P, Broda G, et al. Comparison of official mortality statistics with data obtained from myocardial infarction and stroke registers. Rev. Epidém. et Santé Publ. 1990;38(5-6):435-39.

Vivario M, Partoune B, Boniver J. Mort subite de l'adulte:principales causes et fiabilité du diagnostic clinique. Revue Médicale de Liège 1992;47(12):628-36.

ISCHAEMIC HEART DISEASES *Eurostat shortlist n° 34*

Ambach E, Rabl W, Unger C, et al. The inadequacy of death certificates claiming myocardial infarction without autopsy verification. Forensic Science International 1995;71(1):75-76.

Boyle CA, Dobson AJ. The accuracy of hospital records and death certificates for acute myocardial infarction. Aust NZ J Med 1995;25(4):316-23.

Burr ML. Explaining the French paradox. J Roy Soc Health 1995;115(4):217-19.

Clarke C, Marmot MG. Life style and national and international trends in coronary heart disease mortality. Postgraduate Medical Journal 1984;60:3-8.

Cleland JGF, Erhardt L, Hall AS, et al. Validation of primary and secondary outcomes and classification of mode of death among patients with clinical evidence of herat failure after a myocardial infarction:a report from the acute infarction ramipril efficacy (AIRE) study investigators. Journal of Cardiovascular Pharmacology 1993;22(suppl 9):S22-27.

De Henauw S, de Smet P, Aelvoet W, et al. Misclassification of coronary heart disease in mortality statistics. Evidence from the WHO-MONICA Ghent-Charleroi study in Belgium. J Epidemiol Community Health 1998;52:513-19.

Dobson AJ, Gibberd RW, Leeder Sr. Death certification and coding for ischemic heart disease in Australia. (letter). American Journal of Epidemiology 1983;117(4):397-405.

Ducimetière P, Lang T, Amouyel P,et al. Why mortality from heart disease is low in France. BMJ 2000;320:249-50.

Folsom AR, Gomez-Marin O, Gillum RF, et al. Out-of-hospital coronary death in an urban population-validation of death certificate diagnosis. American Journal of Epidemiology 1987;125(6):1012-18.

Guibert RL, Wigle DT, Williams JI. Decline of acute myocardial infarction death rates not due to cause of death coding. Canadian Journal of Public Health 1989;80(6):418-22.

Jackson R, Graham P, Beaglehole R, et al. Validation of coronary heart disease death certificate diagnoses. NZ Med J 1988;101:658-60.

Knapman PA. Coroners and coronaries. (comment on:Moulton C;1991). The Lancet 1991;338(8782-83):1599.

Koskenvuo M, Kaprio J, Langinvainio H, et al. Changes in incidence and prognosis of ischaemic heart disease in Finland:a record linkage study of data on death certificates and hospital records for 1972 and 1981. BMJ 1985;290(6484):1773-75.

Lahti RA, Sarna S, Penttilä A. Exploitation of autopsy in determining natural cause of death:trends in Finland with special reference to the diagnostics of isechemic heart disease and cerebrovascular diseases in middle-aged males, 1974-1993. Forensic Science International 1998;91(2):109-21.

Leitch DGM, Heller RF, O'Connor SJ, et al. Variation in death certification of ischemic heart disease in Australia and New Zealand. Aust NZ J Med 1987;17(3):309-15.

Martin CA, Hobbs MST, Armstrong BK. Estimation of myocardial infarction mortality from routinely collected data in Western Australia. J Chron Dis 1987;40(7):661-69.

McIlwaine WJ, Donnelly MDI, Chivers AT, et al. Certification of death from ischaemic heart disease in Belfast. International Journal of Epidemiology 1985;14(4):560-65.

Moulton C, Pennycook A. Coroners, procurators fiscal, and deaths from coronary heart disease.(see comment:KnapmanPA;1991). The Lancet 1991;338(8778):1336-37.

Nuttens MC, Salomez JL, Tillard B, et al. Validité des certificats de décès pour l'étude des cardiopathies ischémiques. La Presse Médicale 1990;19(24):1143-46.

Phillips R, Carson P, Haites N, et al. Variation in mortality from ischaemic heart disease between England and Scotland. Quarterly Journal of Medicine 1987;63(241):441-48.

Sexton PT, Jamrozik K, Walsh JM. Death certification and coding for ischaemic heart disease in Tasmania. Aust NZ Med 1992;2(2):114-18.

Shimamoto T, Inada H, Doi M, et al. Recent morbidity trends in myocardial infarction in Japan:investigation of death certificates and the survival rates at coronary care units. Japanese Circulation Journal 1987;51(3):314-18.

Sorlie PD, Gold EB. Statistical consequences of varation in cause-of-death terminology for chronic ischemic heart disease. MMJ 1987;36(4):339-42.

Sorlie PD, Gold EB. The effect of physician terminology preference on coronary heart disease mortality:an artifact uncovered by the 9th Revision ICD. AJPH 1987;77(2):148-52.

Stehbens WE. Review of the validity of national coronary heart disease mortality rates. Angiology 1990;41(2):85-94.

Sundman L, Jakobsson S, Nyström L, et al. A validation of cause of death certification for ischaemic heart disease in two Swedish municipalities. Scand J Prim Health Care 1988;6:205-11.

Tunstall-Pedoe H, Kuulasmaa K, Mä hönen M, et al. Contribution of trends in survival and coronary-event rates to changes in coronary heart disease mortality:10-year results from 37 WHO MONICA project populations. The Lancet 1999; 353:1547-57.

CEREBROVASCULAR DISEASES *Eurostat shortlist n° 36*

Acheson RM, Nefzger MD, Heyman A. Mortality from stroke among U.S. veterans in Georgia and 5 western states:quality of death certification and clinical records. J Chron Dis 1973;26:405-14.

Björkelund C, Ekman H, Persson M, et al. Mortality from stroke among women in a Swedish community, Strömstad. Scand J Prim Health Care 1988;6:213-18.

Florey CV, Senter MG, Acheson RM. A study of the validity of the diagnosis of stroke in mortality data. Certificate analysis. Yale Journal of Biology and Medecine 1967;40:148-63.

Florey CV, Senter MG, Acheson RM. A study of the validity of the diagnosis of stroke in mortality data. Comparison by computer of autopsy and clinical records with death certificates. American Journal of Epidemiology 1969;89(1):15-24.

Garland FC, Lilienfeld AM, Garland CF. Declining trends in mortality from cerebrovascular disease at ages 10-65 years:a test of validity. Neuroepidemiology 1989;8(1):1-23.

Guibert RL, Wigle DT, Williams JI. Decline of acute myocardial infarction death rates not due to cause of death coding. Canadian Journal of Public Health 1989;80:418-22.

Iso H, Jacobs DR, Goldman L. Accuracy of death certificate diagnosis of intracranial hemorrhage and nonhemorrhagic stroke. American Journal of Epidemilogy 1990;132(5):993-98.

Kramer S, Diamond EL, Lilienfeld AM. Patterns of incidence and trends in diagnostic classification of cerebrovascular disease in Washington county, Maryland, 1969-1971 to 1974-1976. American Journal of Epidemiology 1982;115(3):398-411.

Kuller LH, Bolker A, Saslaw MS, et al. Nationwide cerebrovascular disease mortality study. American Journal of Epidemiology 1969;90(6):536-78.

Lanska DJ. Decline in autopsies for deaths attributed to cerebrovascular disease. Stroke 1993;24(1):71-75.

Levy D, Thom TJ. Death rates from coronary disease-progress and a puzzling paradox. The New England Journal of Medecine 1998;339(13):915-17.

Link J, Gramm HJ. Reliability of brain death diagnostics. (comment on:Paolin A;1995). Intensive Care Med 1996;22(8):836-37.

Paolin A, Manuali A, Di Paola F, et al. Reliability in diagnosis of brain death. (see comment:Link J;1996). Intensive Care Med 1995;21(8):657-62.

Peach H. Information about strokes lost between post-mortem and reported cause of death. Journal of the Royal Society of Medicine 1985;78(6):445-51.

Reggio A, Failla G, Patti F. Reliability of death certificates in the study of stroke mortality. A retrospective study in a Sicilian municipality. Ital. J. Neurol. Sci 1995;16(8):567-70.

Stehbens WE. Validity of cerebrovascular mortality rates. Angiology 1991;42(4):261-67.

III.2.5 RESPIRATORY DISEASES

In this paper respiratory diseases include :

- Malignant neoplasm of larynx and trachea/bronchus/lung (Eurostat shortlist n°15)
- Diseases of the respiratory system (Eurostat shortlist n°37)
  - influenza (n°38)
  - pneumonia (n°39)
  - chronic lower respiratory diseases (n°40)
    - of which asthma (n°41)

A. ANALYSIS OF EUROSTAT CAUSES OF DEATH DATA

Respiratory diseases are an important cause of death in many countries. In Europe 17% of deaths for males and 10% for females are related to respiratory diseases. Variations of these percentages are very important between countries for men, from 11% in Austria to 23% in Belgium, and for women, 6% in Austria to 22% in Iceland.

Important variation in death rates

Variations in death rates for respiratory diseases are very pronounced in Europe: for example, for male malignant neoplasm of larynx and trachea/bronchus/lung rates are 3 times higher in Belgium than in Sweden. The same level of differences is observed for diseases of the respiratory system between Ireland and Austria. On the whole, there is a good correlation between rates from malignant neoplasm and diseases of the respiratory system. Higher rates for men are observed in the North of Europe (UK, Ireland, Netherlands, Belgium or Luxembourg). For women, a strong opposition is noted between Northern (Iceland, Ireland, UK, Denmark, Netherlands or Belgium) and Southern countries (Spain, Portugal, Italy, Greece and France). However, with the exception of Iceland, male death rates are always higher than women's. Moreover, in many countries diseases of the respiratory system are more frequent than malignant neoplasm (except for Austria, France, Greece and Italy).

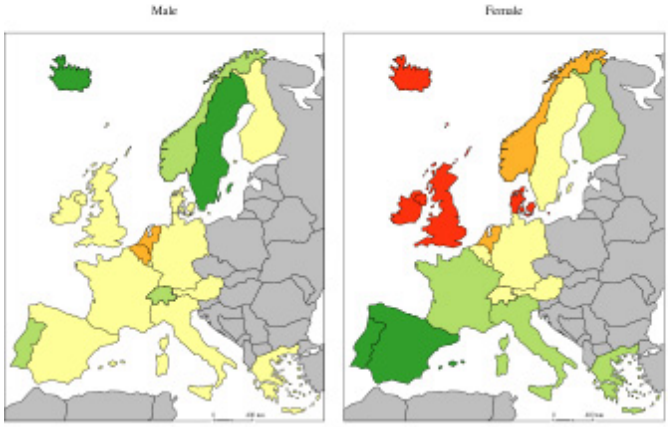
A comparison between premature death (before 65 y) and total death shows a larger frequency of premature death rates in France (not confirmed for total death rates). Opposingly, premature death rates are lower than European rates in the UK, Luxembourg and Netherlands. In the Netherlands, this situation is observed for all respiratory diseases. It would be necessary to take this into account when comparing this characteristic with other competing causes of death in order to understand more fully the origins of this situation.

Asthma shows the greatest variations

Death rates analysis for specific respiratory diseases outlined strong variations between countries. Stronger than for malignant neoplasm or general diseases of the respiratory system: rates are 8 times higher between the lowest and the highest rate for chronic respiratory diseases, 14 times for pneumonia and 18 times for asthma. This is true for both men and women.

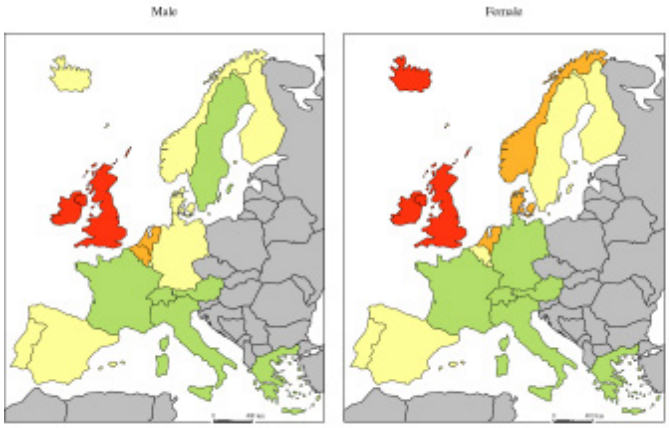
For pneumonia, rates are very high in Northern Europe and Portugal, whereas East Europe is more affected by asthma. The levels of chronic respiratory diseases are important in Ireland, UK, Belgium,

MALIGNANT NEOPLASM OF LARYNX AND TRACHEA/BRONCHUS/LUNG (a)



Country	Male			Female		
	death rate **	number of deaths	number / all cause number ***	death rate **	number of deaths	number / all cause number ***
Austria	66,1	2 463	6,7	15,3	878	2,0
Belgium****	113,6	6 059	11,2	13,8	952	1,8
Denmark	77,5	2 186	7,2	40,9	1 341	4,4
Finland	63,6	1 484	6,4	10,4	388	1,6
France	77,5	22 117	8,2	9,0	3 402	1,4
Germany	72,5	29 555	7,2	13,7	8 232	1,7
Greece	78,3	4 731	9,2	10,8	779	1,7
Ireland	78,5	1 053	6,6	28,7	557	3,7
Italy	86,8	27 985	9,8	11,8	5 104	1,9
Luxembourg	82,3	150	8,5	16,1	42	2,3
Netherlands	107,5	7 130	10,6	20,1	1 666	2,5
Portugal	48,5	2 430	4,6	7,1	472	1,0
Spain	81,0	16 375	9,1	5,8	1 546	1,0
Sweden	35,4	1 889	4,1	16,0	953	2,1
United Kingdom	78,4	24 999	8,2	30,7	13 068	4,0
Europe-EU	78,3	150 640	8,2	15,0	39 443	2,1
Iceland	38,0	45	5,0	40,7	54	6,6
Norway	48,8	1 133	5,1	19,4	515	2,4
Switzerland	68,3	2 289	7,1	14,0	629	2,0

DISEASES OF THE RESPIRATORY SYSTEM (b)



Country	Male			Female		
	death rate **	number of deaths	number / all cause number ***	death rate **	number of deaths	number / all cause number ***
Austria	46,8	1 755	4,7	21,9	1 714	3,8
Belgium****	118,7	6 185	11,4	40,1	3 963	7,5
Denmark	85,5	2 542	8,5	54,2	2 452	8,0
Finland	87,5	1 858	7,9	38,8	1 794	7,3
France	63,6	19 518	7,2	28,3	17 656	7,1
Germany	73,0	28 586	7,0	29,3	24 238	5,1
Greece	47,5	2 996	5,8	28,9	2 424	5,2
Ireland	151,0	2 252	13,8	80,5	2 001	14,2
Italy	62,6	20 441	7,2	23,8	13 282	4,8
Luxembourg	86,9	157	8,4	34,5	119	6,4
Netherlands	125,2	6 340	9,5	53,8	4 908	7,5
Portugal	91,2	4 197	8,0	39,1	2 868	6,1
Spain	93,0	19 063	10,6	34,2	11 792	7,4
Sweden	58,9	3 532	7,6	34,4	3 424	7,6
United Kingdom	172,9	42 081	15,9	80,0	49 060	15,2
Europe-EU	84,0	161 363	8,8	39,1	140 857	7,7
Iceland	72,2	86	9,6	71,9	127	13,5
Norway	82,4	2 088	9,4	51,5	2 354	10,7
Switzerland	68,7	2 424	7,8	27,5	2 064	6,7

Variation of the country death rates
according to the European overall rate (1994)*

-50 % -20 % +20 % +50 %

Eurostat short list: (a) n 15 (b) n 17

* age standardized death rate (ref population: WHO European population)
ex: variation UK:
(r UK - r European-EU) x 100 / r European-EU

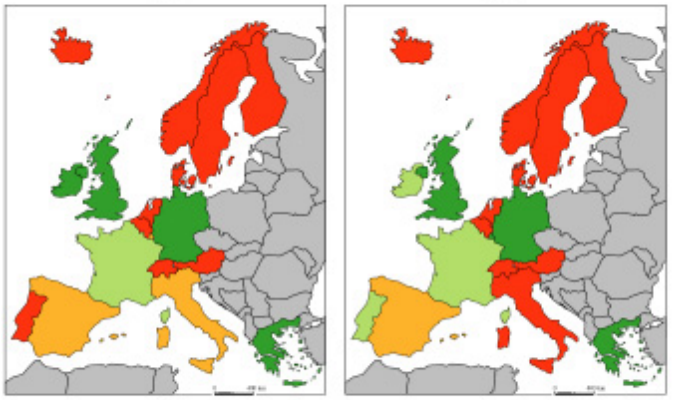
** standardized death rate for 100 000

*** (number for the specific cause / all cause number) x 100

**** 1993

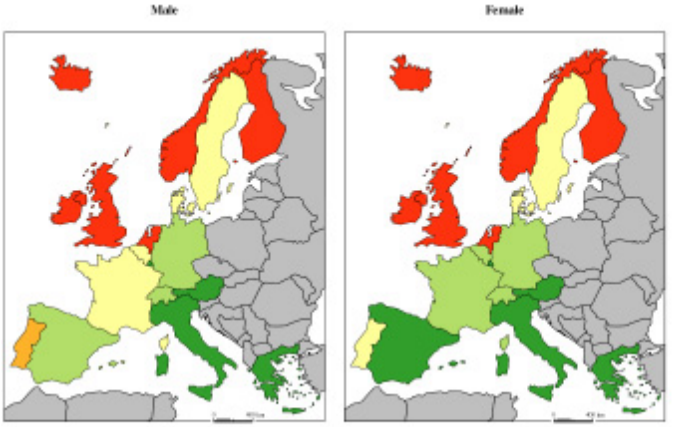
Data source : Eurostat

INFLUENZA (a)



Country	Male			Female		
	death rate **	number of deaths	number / all cause number ***	death rate **	number of deaths	number / all cause number ***
Austria	1,0	39	0,1	0,9	76	0,2
Belgium****	1,6	78	0,1	1,5	175	0,3
Denmark	1,2	38	0,1	1,0	80	0,2
Finland	1,7	52	0,1	1,5	88	0,3
France	0,4	109	0,0	0,3	223	0,1
Germany	0,2	88	0,0	0,2	182	0,0
Greece			0,0	0,0	1	0,0
Ireland	0,2	3	0,0	0,3	8	0,1
Italy	0,7	202	0,1	0,7	376	0,1
Luxembourg	0,6	1	0,1			0,0
Netherlands	1,1	56	0,1	0,9	80	0,1
Portugal	0,8	34	0,1	0,3	25	0,1
Spain	0,6	114	0,1	0,5	186	0,1
Sweden	1,3	85	0,2	1,0	111	0,2
United Kingdom	0,1	33	0,0	0,1	49	0,0
Europe-EU	**0,5**	**908**	**0,0**	**0,4**	**1 624**	**0,1**
Iceland	0,9	1	0,1	1,0	2	0,2
Norway	1,5	58	0,2	1,3	86	0,3
Switzerland	2,5	108	0,3	2,0	171	0,6

PNEUMONIA (b)



Country	Male			Female		
	death rate **	number of deaths	number / all cause number ***	death rate **	number of deaths	number / all cause number ***
Austria	13,3	494	1,3	8,6	711	1,6
Belgium****	25,9	1 289	2,4	14,0	1 483	2,8
Denmark	28,5	781	2,6	16,4	920	3,0
Finland	51,4	1 054	4,5	28,4	1 366	5,6
France	22,9	7 033	2,6	12,0	7 942	3,2
Germany	28,4	7 879	1,9	11,4	10 396	2,2
Greece	4,8	289	0,6	5,5	286	0,6
Ireland	59,7	859	5,2	46,8	1 134	7,8
Italy	10,4	3 278	1,2	6,5	3 698	1,4
Luxembourg	10,4	18	1,0	7,8	29	1,8
Netherlands	45,1	1 930	2,9	30,0	2 725	4,1
Portugal	34,6	1 543	2,9	17,7	1 312	2,8
Spain	17,4	3 474	1,9	9,1	3 185	2,0
Sweden	38,6	1 847	4,0	19,1	2 140	4,7
United Kingdom	68,5	21 179	7,0	49,8	33 264	10,3
Europe-EU	**28,2**	**52 978**	**2,9**	**18,2**	**78 593**	**3,8**
Iceland	47,5	57	6,3	36,3	73	8,9
Norway	46,3	1 174	5,3	33,6	1 661	7,6
Switzerland	22,1	897	2,9	14,0	1 145	3,7

Variation of the country death rates
according to the European overall rate (1994)*

-50 % -20 % +20 % +50 %

Eurostat short list: (a) n 38 (b) n 39

* age standardized death rate (ref population: WHO European population)
cs: variation UK:
(r UK - r European-EU) x 100 / r European-EU

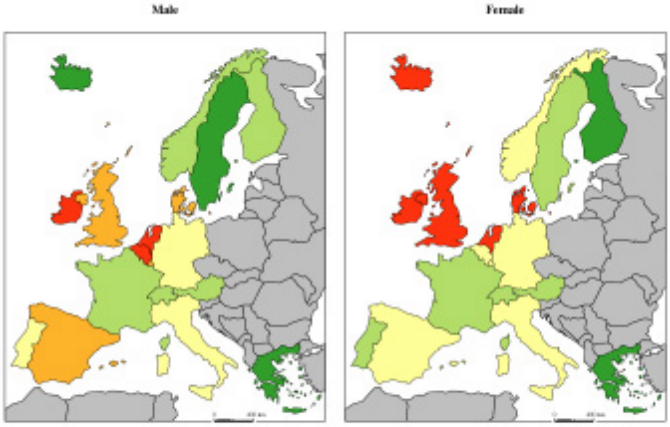
** standardized death rate for 100 000

*** (number for the specific cause / all cause number) x 100

**** 1993

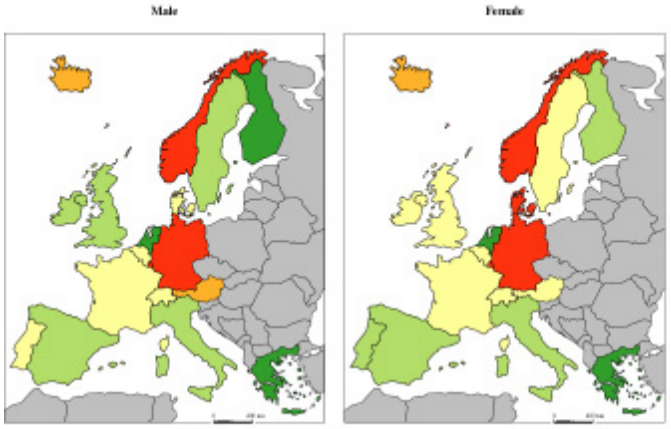
Data source : Eurostat

CHRONIC LOWER RESPIRATORY DISEASES EXCEPTED ASTHMA (a)



Country	Male			Female		
	death rate **	number of deaths	number / all cause number ***	death rate **	number of deaths	number / all cause number ***
Austria	24,9	932	2,5	8,1	635	1,5
Belgium****	66,1	3 500	6,5	14,0	1 380	2,5
Denmark	47,6	1 423	4,7	24,5	1 155	3,8
Finland	27,8	618	2,6	4,9	197	0,8
France	25,8	7 932	2,9	8,4	5 129	2,1
Germany	37,7	14 808	3,6	10,2	8 156	1,7
Greece	9,2	588	1,1	3,2	267	0,6
Ireland	70,8	1 096	6,7	29,6	652	4,5
Italy	37,7	12 414	4,4	10,2	5 880	2,2
Luxembourg	47,2	87	4,6	13,7	46	2,5
Netherlands	70,1	3 818	5,7	19,0	1 825	2,7
Portugal	32,8	1 554	3,8	9,3	780	1,5
Spain	50,2	10 468	5,8	10,4	3 676	2,3
Sweden	18,8	1 121	2,4	8,7	680	1,5
United Kingdom	50,5	16 498	5,5	21,2	10 929	3,4
Europe-EU	39,4	76 834	4,2	12,0	41 185	2,2
Iceland	16,0	19	2,1	22,4	35	4,3
Norway	24,3	626	2,8	9,8	349	1,6
Switzerland	26,9	1 068	3,4	7,2	452	1,5

CHRONIC LOWER RESPIRATORY DISEASES OF WHICH ASTHMA (b)



Country	Male			Female		
	death rate **	number of deaths	number / all cause number ***	death rate **	number of deaths	number / all cause number ***
Austria	4,6	177	0,5	2,6	174	0,4
Belgium****	3,5	186	0,3	2,7	266	0,4
Denmark	3,9	116	0,4	3,6	136	0,4
Finland	1,6	36	0,2	1,9	69	0,3
France	2,8	832	0,3	2,3	1 184	0,4
Germany	7,2	2 805	0,7	4,8	2 710	0,6
Greece	0,9	55	0,1	0,4	34	0,1
Ireland	2,6	39	0,2	2,8	93	0,5
Italy	2,2	740	0,3	1,3	672	0,2
Luxembourg	5,8	12	0,6	5,5	18	1,0
Netherlands	0,4	29	0,0	0,3	25	0,0
Portugal	3,2	153	0,3	1,9	128	0,3
Spain	1,9	401	0,2	1,9	562	0,4
Sweden	2,2	125	0,3	2,5	192	0,4
United Kingdom	2,3	680	0,2	2,3	982	0,3
Europe-EU	3,5	6 471	0,4	2,4	7 062	0,4
Iceland	4,1	5	0,6	3,5	7	0,9
Norway	6,6	162	0,7	4,5	168	0,8
Switzerland	2,9	112	0,4	2,0	121	0,4

Variation of the country death rates
according to the European overall rate (1994)*

-50 % -20 % +20 % +50 %

Eurostat short list: (a) n 40 - 41 (b) n 41

* age standardized death rate (ref population: WHO European population)
ex: variation UK:
(r UK - r European-EU) x 100 / r European-EU

** standardized death rate for 100 000

*** (number for the specific cause / all cause number) x 100

**** 1993

Data source : Eurostat

Netherlands, Denmark and Spain. As we observed for malignant neoplasm, in Iceland, chronic respiratory death rate is low for men but high for women.

The largest variation for specific respiratory diseases would be related to important differences in certification practices between certain countries. We have to verify this hypothesis but we can already observe that percentages of pneumonia and chronic respiratory diseases in all respiratory diseases vary from 30% in Greece to 95% in Ireland. Misclassification in Greece, or in Italy and Spain, could then reduce the pneumonia and chronic respiratory diseases rate, registered as other respiratory diseases. These biases have already been recognised in other studies which outline differences between England-Wales and France or Belgium (in England-Wales, the rates of chronic

lung diseases are particularly high, while in France and Belgium, there is a high frequency of non specific respiratory diseases). If this hypothesis is confirmed, it will be difficult to compare specific pneumonia and chronic respiratory diseases rates in Europe on the basis of data routines.

B. RESULTS OF THE QUESTIONNAIRE

Malignant neoplasm of larynx and trachea/bronchus/lung and asthma were specifically investigated via the questionnaire to European experts.

Malignant neoplasm of larynx and trachea/bronchus/lung

Amongst the 12 respondents, 5 consider the cause of death statistics from malignant neoplasm of larynx and trachea/bronchus/lung as reliable in their country (6 fairly reliable). According to the country's experts, deaths from malignant neoplasm of larynx and trachea/bronchus/lung may be underestimated. Only one expert declares overestimation (based on existing studies).

Biases are estimated to be around 0-15% for all countries. Misclassification concerns cardial diseases and other cancers. Respondents declared that biases might be due to incomplete or imprecise information on death certificates. The most affected age group is over 65 years, but are not said to markedly influence European mortality rates.

Asthma

Amongst the 12 respondents, 8 consider that the cause of death statistics from asthma are only fairly, or not very reliable in their countries. Two respondents said that cardiovascular disease figures are underestimated and 3 declared that they are overestimated.

In most cases there is confusion with broncho-pulmonary diseases. As for malignant neoplasm of larynx and trachea/bronchus/lung, accuracy of medical certification decreases with advancing age. Errors in medical certification (misclassification, under/overestimation) and coding rules are responsible for this bias.

Table 1 **Opinions from experts concerning the reliability of cause of death data from Malignant neoplasm of larynx and trachea/bronchus/lung and asthma.**

Opinion on cause of death data		Number of countries/regions : 12	
		Malignant neoplasm of larynx and trachea/bronchus/lung	Asthma
Reliability	Reliable	5	3
	Fairly reliable	6	6
	Not (very) reliable	1	2
	Unknown	0	0
	No response	0	1
Direction of biases	Underestimation	4	2
	Overestimation	1	3
	Unknown	0	3
	Not requested	0	3
	No response	7	1
Proportion of biases if underestimation	0-15%	4	2
	15-30%	0	0
	More than 30%	0	0
	Not requested	0	0
	No response	0	0
Proportion of biases if overestimation	0-15%	1	2
	15-30%	0	1
	More than 30%	0	0
	Not requested	0	0
	No response	0	0
Influence of age on biases	Yes	4	5
	Unknown	0	3
	No	1	0
	Not requested	0	3
	No response	7	1
The most affected age group by biases	0-25 years	0	0
	25 to 65 years	1	0
	> 65 years	3	4
	No response	0	1
	Not requested	8	7
Sources of biases	Medical certification	6	4
	Coding rules	0	2
	Other reasons	0	0
	Unknown	0	2
	Not requested	5	3
	No response	1	1
Change of rank of the country if correction	Yes	1	2
	No	6	3
	Unknown	0	3
	Not requested	4	3
	No response	1	1
Answer based on	Personal opinion	4	6
	Collective opinion	5	3
	Specific studies	1	1
	No response	2	2

C. ANALYSIS OF THE LITERATURE REVIEW

While biases potentially affect all causes of death, this can be particularly serious for diseases of the respiratory system, which are subject to great variability in certification [1]. An international study has shown that the differences observed in chronic bronchitis and in pneumonia between France and

England depend less on the differences in prevalence between the two countries than on the differences in certification practices [2].

Few studies directly examine the practices involved in certification of causes of death. Studies done generally rely on international comparisons. Comparisons within a single country are much rarer: we know of only one study, in England [3]. Accordingly, we have chosen to conduct a broader analysis of the literature about the quality, reliability and comparability of causes of death involving respiratory system diseases. This should help us to identify the elements likely to influence national mortality statistics. By respiratory diseases, we mean diseases touching the respiratory system in a broad sense, infectious (acute bronchitis, pneumonia, influenza, tuberculosis), chronic (chronic obstructive pulmonary diseases ((COPD)), asthma, pneumoconiosis) or cancerous (broncho-pulmonary cancers, mesotheliomas).

Three types of studies

We found three types of studies, each using specific methods:

-Retrospective studies of death certificates by surveys of doctors [4-13]. These studies most often submit a group of death certificates and the medical files of the deceased to a committee of medical experts. Supplemental surveys sometimes seek to reconstruct the medical history of the deceased. The objective is to draw up new death certificates and compare them with those of the physicians who formerly certified the death. This method makes it possible to access the quality of certification and determine the origin of errors. Most often, for budgetary or logistical reasons, only the “false positives” are identified: only certificates mentioning the cause under study are examined, and among them, only those in which the cause was mentioned incorrectly are counted. These surveys, nonetheless, are not intended to compare different country's practices (national and international).

- Longitudinal studies [14-20]. With this method, a cohort is followed over a period of time and health status or morbidity episodes are noted regularly. Morbidity before death is then compared with the reported cause of death. This method makes it possible to study the numerous co-morbidity factors, to understand the consistency of the certification at death in the light of the overall morbidity picture, and to assess the general relevance of death statistics for analysing the prevalence of a given type of morbidity.

- Submission of fictitious case histories to a panel of physicians [3] [4] [21-24]. Identical fictitious cases are submitted to panels of physicians practicing in different regions or different countries. The comparison of the results thus makes it possible to detect differences in practices related to certifying causes of death.

We also looked at the studies of trends in recording causes of death during bridge periods between two revisions of the International Classification of Diseases (ICD)[5] [25-30]. These successive revisions are sources of coding practice changes and may lead to reporting biases that should be measured.

The comparison of the results of each of these methods should enable us to identify the principal elements that may artificially influence mortality levels for each of the respiratory system diseases considered.

Most of the studies concentrating on asthma

Mortality from asthma has increased over the past 20 years in most developed countries. This has spurred many studies of the reliability of the statistics for this specific cause of death. The studies of asthma represent almost 2/3 of the publications on the quality of causes of death for respiratory diseases. Other types of respiratory conditions, whether chronic (chronic obstructive pulmonary) or acute (pneumonia), have been studied much less.

Generally speaking, asthma morbidity cannot be assessed from the mortality data. Longitudinal studies of subjects with confirmed asthma have shown that only 30 to 40% of the death certificates of those who died mentioned asthma [17] [18, and only 15% considered it to be the underlying cause of death.

Mortality statistics, on the other hand, tend to overestimate cases of fatal asthma. In 1984, the British Thoracic Association assessed this overestimation at 13% [4]. Subsequent surveys, based on death certificates whose validity was assessed in a follow-up examination, confirmed this overestimation. Depending on the survey, the percentage of death certificates that were coded with asthma as the underlying cause of death and were confirmed after re-examination varies from 36% to 87% [5] [8] [9] [12] [13] [17]. Only one study has concluded that death from asthma is underestimated [11]. Nonetheless the methods employed to confirm the validity of the asthma certification vary greatly from one study to another. The confirmation of asthma as the cause of death is based on a review of the medical file, by either a panel of specialists or by a single physician. A supplemental survey may sometimes asks the family or the treating medical staff questions. The thoroughness of the investigation is therefore different from one study to another; this undoubtedly explains the substantial differences between them. Moreover, although most studies examine all the certificates mentioning asthma within a district, some validity surveys have looked at death certificates of subjects with a known history of asthma, identified, for example, at hospital [11] [17]. The latter type results in an obvious selection bias, with an excess of patients with severe asthma. These surveys also report the highest percentages of confirmed asthma. Finally,

the validity or follow-up method, for obvious feasibility reasons, is most often applied only to death certificates that mention asthma. Analysis therefore includes only the “false positives”, that is, the deaths coded as asthma that are actually due to another cause; there is no information about whether deaths coded as some other disease are really caused by asthma (the 'false negatives'). Only one study has looked at 'false negatives'. Of 19 certificates mentioning asthma, 18 were confirmed; 4 cases were found among other causes of death; this finding led the authors to conclude that asthma mortality is underestimated [11]. Nonetheless, this study involved very few cases, all of them patients who had been hospitalised for asthma. Another study, which analysed all the certificates mentioning chronic obstructive pulmonary diseases, identified up to 26% as asthma cases in which the disease was not mentioned on the death certificate [12].

Other diseases of the respiratory system less studied

Other respiratory system diseases have been analysed much less often. These studies, like those for asthma, show that respiratory morbidity cannot generally be assessed from mortality statistics. A 14-year longitudinal study of obstructive pulmonary diseases in the United States was able to compare health status before death with the listed causes of death. Bronchial obstruction was mentioned on the death certificates of only 60% of those who died among patients confirmed as having it during regular surveys [15]. Another longitudinal study of people with chronic bronchitis confirmed this figure [14]. Moreover, when these diseases are specified on the death certificate, they are rarely mentioned as the underlying cause. Chronic obstructive pulmonary diseases were coded as the underlying cause of death for only 16 to 23% of patients identified with it. This percentage was lower for women than for men [14]. These low percentages are actually associated with co-morbidity, which is particularly frequent for this disease: those with severe bronchial obstruction often die of cardiac arrhythmia caused by gas exchange problems. Nonetheless, when obstruction is accompanied by an acute disease (pneumonia), the chronic disease is mentioned more often [15]. These co-morbidity issues are also the source of frequent errors in reporting chronic obstructive pulmonary diseases. A follow-up examination of death certificates that mentioned chronic obstructive pulmonary diseases showed that only 40% of the deaths coded with it were confirmed as such [12].

Nor would death certificates allow all cases of pneumonia to be identified on the basis of the sole underlying cause of death. In a longitudinal survey performed one month after hospitalisation, pneumonia was mentioned on 86% of the death certificates of patients diagnosed with it during hospitalisation; only 38% mentioned it as the underlying cause of death [18]. Similarly, of 92 cases of pulmonary embolism recognised at autopsy among patients who died in hospital, this disease was coded as the underlying cause of only 29 deaths (32%) [10]. Of patients with mesothelioma

recorded in a cancer registry, only 13% had their underlying cause of death coded as mesothelioma [16].

Finally, among respiratory diseases, only broncho-pulmonary cancers were characterised by a satisfactory concordance between mortality and morbidity information. In a longitudinal survey of an elderly population in Boston, 17% of the lung cancers identified by a registry or during hospitalisation were not mentioned on the death certificate [20]. These results are confirmed by other longitudinal studies [18] [31].

Differences in the certification process

The differences in the certification of respiratory diseases cannot be considered as the major source of the disparities in European mortality rates. A fictitious case of asthma submitted to physician panels in 8 European Community nations did reveal substantial differences in asthma certification, but these apparently were not associated with the level of asthma mortality in each country [2] [21] [24]. On the other hand, an association was found between mortality levels and the proportion of physicians entering asthma cases as chronic obstructive pulmonary diseases. This difference seems to matter mostly in the difficult cases, since the same cases were not interpreted identically everywhere [24].

The sources of these differences most often appear to involve a misdiagnosis in part I of the certificate. A missing diagnosis, an accurate diagnosis placed in part 2 or an incorrect morbid sequence cause fewer errors [23]. For example, the reliability of the certification of a fictitious case of chronic obstructive pulmonary diseases ranged from 60% in Italy to 91% in the Netherlands, but improved after subsequent ICD coding (especially in Belgium and Italy). This certification nonetheless also led to a reduction in the reliability percentages in some countries, France in particular. Substantial differences in mortality according to the category of respiratory disease have been observed between France and England: in England, mortality from acute and chronic diseases is very high, while in France, it is the 'other' diseases of the respiratory system that are more frequent. These differences reflect the way that physicians certify the deaths [2]. We cannot, however, be certain that the physicians selected in this early 1980s study, were representative of the certifying physicians in each of the 8 European Community nations they came from; all the French physicians, for example, came from only one region [22].

Many factors can play a role in differences in certification practices. The recognition of a health problem in one region may result in a tendency to code this problem more readily on the certificate of a difficult case. Farmer's lung, for example, is better recognised in Ireland, where many studies of

this disease have been conducted [22], than in some other nations. It is also better recognised by rural physicians, more sensitised to the problem than their urban colleagues.

Other differences depend on the physician's type of practice: a case of infarct in a patient with chronic obstructive bronchitis was coded as an infarct by 95% of English hospital staff physicians, while private practitioners certified chronic bronchitis more often [2]. More generally, hospital staff physicians appear to be less specific in their certification [4]. Moreover, the only study to compare death certification within a single country also found certification differences according to when the physician completed medical school [3].

Differences which change through time

Medical knowledge does indeed advance, and these advances affect both certification and coding practices, as can be seen in the current trend to the widespread use of the term; chronic obstructive pulmonary diseases [12]. Looking at the same clinical picture, physicians mention chronic obstructive pulmonary diseases more often today than asthma; this may partially explain the reduction in asthma mortality and the increase in chronic obstructive pulmonary diseases mortality in the United States during the 1980s [25]. Similarly, before 1978, chronic conditions were most often recorded as emphysema; since then they have been recorded as chronic obstructive pulmonary diseases [14]. Respiratory diseases have always raised many diagnostic problems, and coding practices have changed with our knowledge of this subject. This is also the case for asthma deaths in children, which were often coded as wheezing bronchitis before 1980 [26].

Changes in the successive revisions of the International Classification of Diseases (ICD) and the recommendations that accompanied them have also led to modifications in the coding of respiratory diseases. Deaths from bronchitis, bronchiolitis or emphysema with mention of asthma, which were coded as bronchitis for the underlying cause in the 8th revision, were thereafter coded as asthma in the 9th revision [5] [28] [32]. This modification may alone be responsible for a 30% increase in asthma deaths, a percentage that increases with age [5]. In the United States, the comparability ratio for asthma between the 8th and 9th revisions has been estimated at 0.74 [27].

Finally, the accuracy of the diagnoses varies with age: asthma diagnoses are most accurate between 5 and 34 years [26]. Diagnoses for chronic obstructive pulmonary diseases and for lung cancers are more reliable before 55 years [7] [12]. More generally the pertinence of the diagnosis varies inversely with the patient's age [21].

General influence of reporting practices on geographic disparities

Except for one British study, no report has analysed the influence that reporting of causes of death has on the geographic disparities in respiratory system mortality. Through various studies that focus on the quality and reliability of certifications, it is nonetheless possible to identify some of the elements likely to introduce bias.

We must first stress that the entire category of respiratory diseases is undoubtedly one of the disease groups most difficult to certify. The reporting of these causes of death is particularly complicated by the somewhat vague character of many of the conditions affecting the respiratory system, including an aggregate of symptoms not always well identified and definitions that remain imprecise, the natural course, the complications of many of the diseases, and the frequency of co-morbidity.

That said, we can try to draw up a list of proposals that take into account these possible biases in the light of the issues involved in a geographic approach to respiratory system diseases. Such an approach has three types of goals:

1. To compare incidence between areas. To do this, the statistics that are analysed must be comparable.
2. To be able to identify the burden of a disease on local health facilities, which necessarily involves being able to assess the number of cases of morbidity in a particular place
3. To know the health impact or seriousness of this disease, that is, the number of deaths it causes, either directly or indirectly.

The comparisons for the first point can be made with mortality data. We have nonetheless noted that there are numerous possible sources of geographic bias in cause of death reports: They stem largely from specific types of context-sensitive effects (health context, type and length of practice, sensitisation to specific problems, etc.). Without supplemental surveys, it is impossible to quantify more precisely the impact of these effects on the mortality disparities that have been observed. Some very specific causes of death require several precautions when interpreting these differences: the study of fatal asthma from a geographic perspective thus raises problems, for the errors are essentially due to poor completion of death certificates [6] [23]. The same is true for chronic bronchitis and for pneumonia.

Nonetheless the only study of coding disparities within a single country showed that these differences were minimal [3]. This analysis concerned only the major ICD categories and not specific diseases. Consolidation of causes of death into broad types of condition (chronic, acute) makes it possible to minimise the risk of bias. Analysis of the youngest age groups also seems to limit this risk.

As to the second goal of geographic studies, generally speaking, the prevalence of respiratory diseases is difficult to assess from the underlying cause-of-death data. Except for broncho-pulmonary cancers, respiratory system diseases are largely under-recorded in the mortality statistics because they frequently develop towards other clinical forms (cardiovascular diseases) and extensive co-morbidity. Thus, although the deaths directly due to asthma seem to be over-represented, they are nonetheless not necessarily a good indicator of the cases of prevalent asthma. Only broncho-pulmonary cancers are characterised by good consistency between morbidity and mortality. The use of death statistics can nonetheless give us an idea of the scale of the disparities touching one country or one particular area.

As to the third point, examination of the underlying cause of death alone does not enable us to study the impact of a specific disease affecting the respiratory system on overall mortality. When the underlying and associated causes of death are studied, we note that only a low proportion of the certificates mentioning respiratory diseases described them as the underlying cause. For example, in the United States, for the period 1979-1993, only 43% of deaths mentioning bronchial obstruction were coded with that as the underlying cause [33]. This percentage was only 50% for pulmonary fibroses during the same period [34]. It therefore seems essential to promote more multiple cause of death studies that take into account both the underlying and associated causes [35-36]. These approaches present the double advantage of improving our assessment of the prevalence of each respiratory disease (all the certificates mentioning this disease not only as underlying cause of death) and allowing us to develop disease profiles that take co-morbidity into account. It is uncertain that the morbidity sequence is the same everywhere for a given underlying disease, or even that the same associated causes are listed. Only a multiple causes approach will allow us to verify this type of hypothesis.

References

[1] Hatton F. Mortalité par maladies de l’appareil respiratoire dans dix pays d’Europe et d’Amérique du Nord (1979-1990). *Rev Mal Resp*, 1996; 13: 1-3.

[2] Kelson MC, Heller RF. The effect of death certification and coding practices on observed differences in respiratory disease mortality in 8 EEC countries. *Rev Epidemiol Sante Publ*, 1983; 31: 423-432.

423-432. Death certification by British doctors: a demographic analysis. *J Epidemiol Community Health*, 1982; 36: 146-149.

[4] British Thoracic Association. Accuracy of death certificates in bronchial asthma. *Thorax*, 1984; 39: 505-509.

[5] Stewart CJ, Nunn AJ. Are asthma mortality rates changing ? *Br J Dis Chest*, 1985; 79: 229-234.

[6] Sears MR, Rea HH, de Boer G, et al. Accuracy or certification of deaths due to asthma. A national study. *Am J Epidemiol*, 1986; 124(6): 1004-1011.

[7] Delendi M, Riboli E, Peruzzo P et al. Comparison of diagnoses of cancers of the respiratory system on death certificates and at autopsy. In Riboli M, Delendi M. *Autopsy in epidemiology and medical research*. Lyon: IARC, 1991: 55-62.

[8] Campbell DA, McLennan G, Coates JR et al. Accuracy of asthma statistics from death certificates in South Australia. *Med J Aust*, 1992; 156: 860-863.

[9] Wright SC, Evans AE, Sinnamon DG, MacMahon J. [9] Wright SC, Evans AE, Sinnamon DG, MacMahon J. *Thorax*, 1994; 49: 141-143.

[10] Morgenthaler TI, Ryu JH. Clinical characteristics of fatal pulmonary embolism in a referral hospital. *Mayo Clin Proc*, 1995; 70: 417-424.

[11] Guite HF, Burney PGJ. Accuracy of recording of deaths from asthma in the UK: the false negative rate. *Thorax*, 1996; 51: 924-928.

[12] Smyth ET, Wright SC, Evans AE et al. Death from airways obstruction: accuracy of certification in Northern Ireland. *Thorax*, 1996; 51: 293-297.

293-297. Age-dependent inaccuracy of asthma death certification in Northern England, 1991-1992. *Eur Respir J*, 199; 12: 1079-1083.

[14] Higgins MW, Keller JB. Trends in CHRONIC OBSTRUCTIVE PULMONARY DISEASES Morbidity ad Mortality in Tecumseh, Michigan. *Am Rev Respir Dis*, 1989; 140: S42-S48.

[15] Camilli AE, Robbins DR, Lebowitz MD. [15] Camilli AE, Robbins DR, Lebowitz MD. *Am J Epidemiol*, 1991; 133(8): 795-800.

[16] Davis LK, Martin TR, Kligler B. Use of death certificates for mesothelioma surveillance. *Public Health Rep*, 1992; 107(4): 481-483.

[17] Hunt LW, Silverstein MD, Reed CE et al. Accuracy of the death certificate in a population-based study of asthmatic patients. *JAMA*, 1993; 269(15): 1947-1952.

[18] Goldacre MJ. Cause-specific mortality: understanding uncertain tips of the disease iceberg. *J Epidemiol Community Health*, 1993; 47: 491-496.

[19] Nejjari C, Tessier T, Baldi P. Aspects épidémiologiques du veillissement respiratoire: apport de l'enquête PAQUID. *Rev Epidem Santé Publ*, 1997; 45: 417-428.

[20] Stang A, Glynn RJ, Gann PH et al. Cancer occurrence in the elderly: Agreement between three major data sources. *Ann Epidemiol*, 1999; 9(1): 60-67.

[21] Neukirch F, Maguin P, Perdrizet S, Pariente R. Validité des données de mortalité par maladies respiratoires en France et dans sept autres pays de la CEE. *Rev Mal Resp*, 1984; 1: 361-367.

[22] Farebrother MJB, Kelson MC, Heller RF. Death certification of farmer's lung and chronic airway diseases in different countries of the EEC. *Br J Dis Chest*, 1985; 79: 352-360.

[23] Mackenbach JP, Van Duyne WMJ, Kelson MC. Certification and coding of two underlying causes of death in the Netherlands and other countries of the European Community. *J Epidemiol Community Health*, 1987; 41: 156-160.

[24] Burney PGJ. The effect of death certification practice on recorded national asthma mortality rates. *Rev Epidemiol Sante pub*, 1989; 37: 385-389.

[25] Woolcock AJ. Worldwide differences in asthma prevalence and mortality. Why is asthma mortality so low in the USA ? *Chest*, 1986; 90(5): 40S-45S.

[26] Sears MR. Why are deaths from asthma increasing? *Eur J Respir Dis*, 1986; 69(Sup 147): 175-181.

[27] Evans R, Mullally DI, Wilson RW, et al. National trends in the morbidity and mortality of asthma in the US. Prevalence, hospitalisation and death from asthma over two decades: 1965-1984. *Chest*, 1987; 91(6): 65S-74S.

[28] Jackson R, Sears MR, Beaglehole R, Rea HH. International trends in asthma mortality: 1970 to 1985. *Chest*, 1988; 94(5): 914-919.

[29] Bouvier-Colle MH. Les différentes révisions de la CIM. In. Bouvier-Colle MH, Hatton F, Vallin J. *Mortalité et causes de décès en France*. Paris: Inserm, 1990.

[30] Juel K, Pedersen PA. Increasing asthma mortality in Denmark 1969-88 not a result of a changed coding practice. *Annals of Allergy*, 1992; 68: 180-182.

[31] Wells C, Mannimo DM. Pulmonary fibrosis and lung cancer in the United States: analysis of the multiple cause of death mortality data, 1979 through 1991. *South Med J*, 1996; 89(5): 505-510.

[32] Sears MR. Increasing asthma mortality – Fact or artifact? *J Allergy Clin Immunol*, 1988; 82(6): 957-960.

[33] Mannimo DM, Brown C, Giovino GA. Obstructive lung disease deaths in the United States from 1979 through 1993: an analysis using multiple-cause mortality data. *Am J Respir Crit Care Med*, 1997; 156: 814-818.

[34] Mannimo DM, Etzel RA, Parrish RG. Pulmonary fibrosis deaths in the United States, 1979-1991. An analysis of multiple-cause mortality data. *Am J Respir Crit Care Med*, 1996; 153: 1548-1552.

[35] Mackenbach JP, Kunst AE, Lautenbach H et al., Competing causes of death: a death certificate study. *J Clin Epidemiol*, 1997; 50(10): 1069-1077.

[36] Mackenbach JP, Kunst AE, Lautenbach H, et al. Gains in life expectancy after elimination of major causes of death: revised estimates taking into account the effect of competing causes. *J Epidemiol Community Health*, 1999; 53: 32-37.

III.2.6 BREAST CANCER (MALIGNANT NEOPLASM OF BREAST)

A. ANALYSIS OF EUROSTAT CAUSES OF DEATH DATA

Cancer of the breast is the third commonest cause of death in females in all of the European Union countries, and the 3 EFTA countries. In 1994, cancer of the breast contributed to 4% of all the female deaths and was exceeded only by ischaemic heart and cerebrovascular diseases (16% and 14% respectively). For deaths in the under 65 years category, this sequence is reversed. Cancer of the breast is the leading cause of death in females under 65 years and in 1994 it contributed to 12% of all the female deaths in this age category. Ischaemic heart and cerebrovascular diseases contributed to 7% and 5% respectively. However the death rates vary considerably between countries, and they can be broadly classified into three groups based on their standardised death rates (Table 1):

1. High level (over 35 per 100,000): Denmark, Ireland, Netherlands and the United Kingdom.
2. Mean level (between 25 and 35 per 100,000): Austria, Belgium, France, Germany, Italy, Luxembourg, Portugal, Spain, Iceland, Norway and Switzerland.
3. Low level (less than 25 per 100,000): Finland, Greece and Sweden.

This classification does not outline a clear gradient and does not markedly differ for premature deaths. (Table 2):

1. High level : Ireland and Netherlands.
2. Mean level : Austria, Belgium, Denmark, France, Germany, Italy, Luxembourg, Portugal, Spain, Iceland, Norway, Switzerland and the United Kingdom.
3. Low level : Finland, Greece and Sweden.

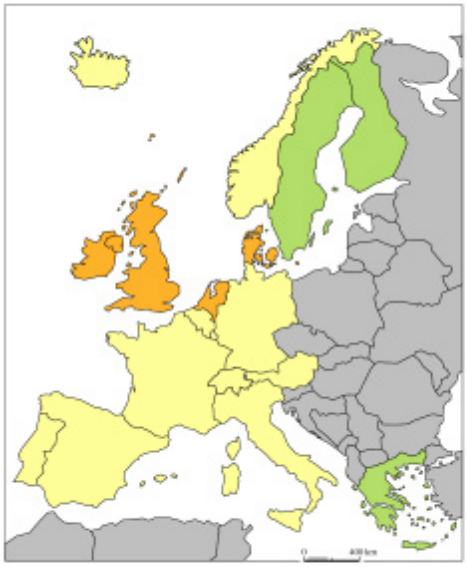
Tables 3 and 4 outline the extreme countries for deaths from all ages and the under 65 years respectively. In 1994, for deaths from all ages, Netherlands has the highest rate, and Finland the least with 23 per 100,000. For the under 65 years deaths, Ireland leads with 25 per 100,000 and Finland and Sweden have the least deaths with 15 per 100,000.

Table 1 **Variation of the standardised death rates according to the European overall rate 1994 all ages**

- 20%	Average	+ 20%
Finland	Austria	Denmark
Greece	Belgium	Ireland
Sweden	France	Netherlands
	Germany	United Kingdom
	Italy	
	Luxembourg	
	Portugal	
	Spain	
	Iceland	
	Norway	
	Switzerland	

MALIGNANT NEOPLASM OF BREAST (a)

Female



Variation of the country death rates
according to the European overall rate (1994)*

-50 % -20 % +20 % +50 %

Country	Female		
	death rate **	number of deaths	number / all cause number ***
Austria	31,1	1 728	4,0
Belgium****	35,0	2 379	4,5
Denmark	37,3	1 274	4,2
Finland	23,2	760	3,1
France	28,6	10 783	4,3
Germany	31,3	18 356	3,9
Greece	23,3	1 507	3,2
Ireland	37,4	648	4,4
Italy	28,7	11 343	4,2
Luxembourg	33,9	89	4,8
Netherlands	41,7	3 555	5,4
Portugal	25,0	1 484	3,1
Spain	24,6	5 864	3,7
Sweden	23,8	1 461	3,2
United Kingdom	36,7	14 401	4,4
Europe-EU	30,5	75 632	4,1
Iceland	32,1	38	4,6
Norway	28,7	816	3,8
Switzerland	32,4	1 595	5,2

Data source : Eurostat

(a) Eurostat short list: n 17

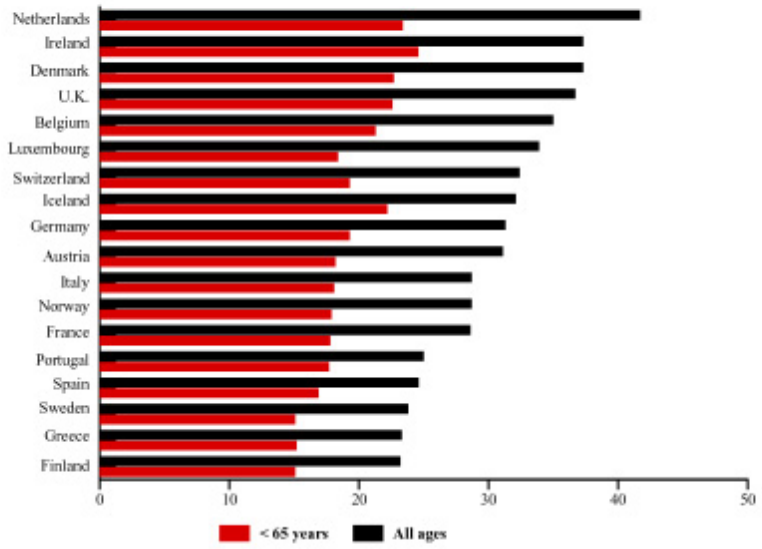
* age standardized death rate (ref population: WHO European population)
ex: variation UK:
(r UK - r European-EU) x 100 / r European-EU

** standardized death rate for 100 000

*** (number for the specific cause / all cause number) x 100

**** 1993

Fig 1. **Distribution of malignant neoplasm of breast death rates according to the European overall rates (1994)***



*standardized death rate for 100.000

Table 2 **Variation of the standardised death rates according to the European overall rate 1994 for < 65 years**

- 20%	Average	+ 20%
Finland	Austria	Ireland
Greece	Belgium	Netherlands
Sweden	Denmark	
	France	
	Germany	
	Italy	
	Luxembourg	
	Portugal	
	Spain	
	Iceland	
	Norway	
	Switzerland	
	United kingdom	

Table 3 **1994 all ages**

Country	Death rate per 100,000	Number of deaths	% of total deaths
Netherlands	41.7	3555	5.4
EU average	30.5	75632	4.1
Finland	23.2	760	3.1

Table 4 **Breast cancer deaths 1994 for < 65 years**

Country	Death rate per 100,000	Number of deaths	% of total deaths
Ireland	24.6	297	13.3
EU average	19.1	30395	12.2
Finland	15.1	331	10.2
Sweden	15.1	548	10.6

B. RESULTS OF THE QUESTIONNAIRE

11 experts (out of 13 respondents) consider the cause of death statistics from breast cancer as reliable in their country and two as fairly reliable. An underestimation of breast cancer deaths of 0 -15% is notified in Austria and Germany.

Three experts have mentionned studies that also concluded to an underestimation of breast cancer as the underlying cause of death (between 5 to 10%) but these results are not considered as sufficiently documented.

The reliability statement was based on specific studies in Sweden and Iceland. In other countries, the answers are based on personal or collective opinions.

One country (Austria) indicated that the over 65 years age group is mainly affected by biases.

For the experts who have notified the existence of biases, the medical certification is the main reason for this, but coding is signaled as an additional problem.

Table 1 **Opinions from experts concerning the reliability of cause of death data from breast cancer in their country**

Opinion on cause of death data		Number of responding countries/regions : 13
Reliability	Reliable	11
	Fairly reliable	2
Direction of biases	Underestimation	2
	Not requested	11
Proportion of biases if underestimation	0-15%	2
	Not requested	11
Proportion of biases if overestimation	Not requested	13
Influence of age on biases	Yes	1
	No	1
	No response	1
	Not requested	10
The most affected age group by biases	> 65 years	1
	No response	1
	Not requested	11
Sources of biases	Medical certification	3
	Not requested	10
Change of rank of the country if correction	No	4
	Not requested	9
Answer based on	Personal opinion	5
	Collective opinion	4
	Specific studies	3
	No response	2

C. ANALYSIS OF THE LITERATURE REVIEW

Background

Six basic scientific papers were selected for review regarding the comparability of causes of death data.

One of these articles (study 2) was summarised but excluded from results since it concerned time trends only. 3 papers were based on Sweden and 2 on the UK. Each included the comparison of the underlying cause of death from the national statistical office with that produced by review of clinical care records. The death certificates were obtained for all except study 5. The study population varied from 1296 to 2631 in study 1, 928 in 3, 193 in 4, 484 in 5 and 1296 in 6.

The 5 studies under review involved practically the same method of investigation of the underlying cause of death. However not all included a review of deaths from an unknown primary e.g. study 5, 6 and study 3 included these but the extent of checking them is variable. Study 3 also has the disadvantage that the assessors were not blinded to the source of the case because of resource problems thus biases may be present. Not all studies defined what determines breast cancer to be considered as an underlying cause of death (study 1 and 4) and those that had, were different. Study 3 defined breast

cancer as underlying cause of death "if in the opinion of the assessor, the patient would not have died when she did, had she not received a diagnosis of breast cancer. We did not specify the evidence required." In study 5 "if disseminated disease was present, the clinical death cause diagnosis was considered to be breast carcinoma irrespective of whether other potentially life-threatening diseases were also present. Local recurrence of cancer on the chest wall without evidence of further dissemination was considered contributory cause of death." Study 6 applied WHO guidelines whereby the underlying cause of death is the disease that started the chain of events that led to death. "Breast cancer present at death was registered in patients obviously dying with remaining cancer and in whom there was no evidence of another primary malignancy. If death occurred within 30 days from the primary operation or later because of obvious complications of treatment, the patient was registered as dead with breast cancer as the underlying cause of death. Violent deaths including suicide were registered as underlying cause of death even in patients with generalised or loco-regionally remaining breast cancer."

Finally, in study 4, due to logistic reasons the original sample was reduced from 309 to 200 by omitting (in general) every third patient.

Results

All studies concluded that the official statistics showed an underestimation of deaths from breast cancer. However, this underestimation was very slight. The UK studies showed an average underestimate of 2% (one study showed 0.3%, the other 4%) while two of the three Swedish studies showed an average underestimation of 3% (one study showed an average underestimation of 4%, ranging from 0.8% to 6%, while the other 2%). The third Swedish study showed that prior to 1981 there was an overestimation of 5%. This involved the guidance to coders to select breast cancer as the underlying cause of death even if it is in Part II of the death certificate in preference to some selected causes like bronchopneumonia.

Types of errors

Inaccuracies in registration figures – mistaken diagnosis or patients escaping registration. Inaccuracies in figures for deaths - errors in the cause of death certification can lead to under/over estimation of deaths from breast cancer. This can arise from illegible writing, mistakes e.g. carcinoma bronchus instead of carcinoma breast, the association between breast cancer and other diseases such as other primary malignancies. Adverse effects of surgery, radiation therapy and chemotherapy could also increase the intercurrent mortality.

Inaccuracies due to coding system – Part I / Part II differences and their interpretation such as WHO rule 3.

Conclusion

It must be emphasised that in general the accuracy of the statistics at the national offices is very good. However, all studies showed a slight underestimation of breast cancer deaths. This means that when comparisons are being made, the official mortality rates issued for these two countries are underestimating the real rate by about 3%. It would be beneficial to carry out a study on the accuracy of diagnosis in death certification in all member states such that the level of over/under-estimation can be determined and allow real comparisons to be made.

On the other hand initiatives regarding these inaccuracies may be initiated. Eurostat could assume this responsibility and prepare a plan to be implemented in all member states so as to decrease as much as possible any errors. (e.g. A comprehensive education pack for all certifying doctors, a programme of continuing medical education, an exchange of information with the certifying doctors when they send an incorrect death certificate.)

With regards to the changes in time trends due to changes in coding rules, it is advisable to study multiple causes of death coding and to calculate the ratio of multiple cause of death rate and underlying cause rate by year of death. This will highlight the systematic bias caused by the change in coding policy. Thus it is important for all countries to keep multiple causes of death in their databases.

Finally, two points must be emphasised. One is the bias towards entering breast cancer in Part II of the death certificate in cases with clinical cure even if cure was confirmed at autopsy. This bias is probably caused by a wish to supply the National Cancer Registry with the necessary information to calculate survival rates and maybe also information on non-reported incident cases. The other point is the practice to upgrade a malignant diagnosis entered in part II of the death certificate to become registered as underlying cause of death. The education programme mentioned above is the only way to create awareness of these problems and their avoidance in the future.

Studies

(1) Garne JP, Aspegren K, Balldin G. Breast cancer as cause of death. A study over the validity of the officially registered cause of death in 2 631 breast cancer patients dying in Malmö, Sweden 1964-1992. *Acta Oncologica 1996*

(2) Robertson C, Boyle P. Statistical modelling of breast cancer incidence and mortality rates in Scotland. *British Journal of Cancer 1997*

(3) Chamberlain J, Coleman D, Ellman R,et al. Verification of the cause of death in the trial of early detection of breast cancer.UK trial of early detection of breast cancer group. *British Journal of Cancer 199*1

(4) Brinkley D, Haybittle JL, Ralderson MR. Death certification in cancer of the breast. *British Medical Journal 1984*

(5) Rutqvist LE. Validity of certified causes of death in breast carcinoma patients - *Acta Radiologica Oncology 1985*

(6) Nyström L, Larsson LG, Rutqvist LE, et al. Determination of cause of death among breast cancer cases in the Swedish randomized mammography screening trials. A comparison between official statistics and validation by an endpoint committee. - *Acta Oncologica* 1995

Appendices

Study 1: Garne JP, Aspegren K, Balldin G. Breast cancer as cause of death. A study over the validity of the officially registered cause of death in 2 631 breast cancer patients dying in Malmö, Sweden 1964-1992. Acta Oncologica 1996

The aim of this paper was to study the validity of the National Cause of Death Registry as regards breast cancer as cause of death, in Malmo - Sweden, 1964-1992.

Methods

The study group included all patients registered with breast cancer as cause of death a the Cause of Death Registry as well as patients from an incidence series of breast cancer dying within the period whether from breast cancer or not.

During 1961 -1991 invasive breast cancer was diagnosed in 4389 women in Malmo. 7 patients emigrated and 2522 died. Of these 2460 died as residents in Malmo. 171 women were added, as they died in Malmo within the study period but where diagnosed either before 1961 or outside Malmo or diagnosis on the death certificate was incorrect. Thus, the study group comprised to 631 patients dying in Malmo 1964 - 1992 with a previous diagnosis of breast cancer or with breast cancer registered as cause of death at the Cause of Death Registry.

For each deceased patient the last available clinical records were sought for together with autopsy records, clinical or forensic. If necessary, records were obtained from other hospitals or at nursing homes, etc. In each case it was decided by one of the authors whether or not breast cancer was the underlying cause of death.

All cases with a mismatch between data from the present revision and data from the Cause of Death Registry regarding breast cancer as underlying or contributory cause of death were selected for further study and death certificates were procured in these cases.

To illustrate the influence of changes in coding policies over time in another way we calculated the following age-standardised death rates based on Causes of Death Registry data for Malmo: UCR = Underlying cause rate, i.e. death rate for patients registered with breast cancer as underlying cause of death, and MCR = Multiple cause rate, i.e. death rate for patients registered with breast cancer as underlying or contributing cause of death. The ratio MCR/UC was calculated for each year. Age-standardisation was done according to the Swedish national census of 1970.

Results

Discordance between our data and the Cause of Death Register was found in 184 cases (7%). In 63 cases (2%) discordance concerned breast cancer as contributing cause of death and in 121 cases (5%) breast cancer as underlying cause of death.

There was a tendency towards a higher age at death in the discordant cases than in the total study-population.

In 40 cases breast cancer was under-registered and in 81 cases over-registered as underlying cause of death.

We calculated age-standardised breast cancer mortality rates for these two periods and found that the discordant cases caused a spurious decrease in mortality of 5% in the official data.

Discussion

Other researchers have found good precision of diagnosis in malignant cases overall (1.2), but reservations must be made in breast cancer taking into account the high cure-rates and long survival even in some fatal cases, which may cause a bias in determining cause of death in non-autopsied cases.

We found discordance in 5% of cases concerning underlying cause of death. The imprecision was greatest in patients older than 70 years of age at death, which can reflect either a low interest in correctly establishing the cause of death in elderly persons or, more likely, the existence of more competing causes of death with increasing age.

The discordant cases caused an overestimation of the age-standardised specific breast cancer death rate in the order of 5% before 1981. Our results were produced through the cumbersome method of scrutinising each case individually. By applying the indirect method of comparing the ratio between multiple and underlying cause rate between periods it is possible by using available registry data to get an impression of the systematic bias caused by the change in coding policy. The change demonstrated in this way is, however, not as easy to interpret in quantitative terms as that demonstrated by the direct method.

We want to emphasise two findings from our study. One is the bias towards entering breast cancer in part II of the death certificate in cases with clinical cure even if cure was confirmed at autopsy. This bias is probably caused by a wish to supply the Swedish Cancer Registry with information on non-reported incident cases since this registry regularly links up with the Cause of Death Registry. The other point is the practice at the Cause of Death Registry up to 1980 to upgrade a malignant diagnosis entered in part II of the death certificate to become registered as underlying cause of death.

Study 2: Robertson C, Boyle P. Statistical modelling of breast cancer incidence and mortality rates in Scotland. British Journal of Cancer 1997

It is important to understand the mechanisms underlying changing patterns of cancer rates and this is especially appropriate when trying to understand the temporal evolution of breast cancer incidence and mortality rates. Such rates are subject to such a range of influences, such as the effects of the introduction of large-scale mammographic screening programmes and treatment advances; such influences must be taken into consideration so that a clearer understanding of underlying trends may be obtained from mathematical modelling in which incidence and mortality are considered simultaneously.

Methods

Cancer mortality and population data for Scotland are available for 5-year age groups from 1950 to 1990 from the World Health Organisation mortality database and individual records of cancer incidence are available from 1960 to 1990 (Black et al, 1995). These data give an opportunity to compare simultaneously the changes in cohort patterns in both incidence and mortality.

Using the individual records of all incident cases of breast cancer diagnosed in Scotland between 1960 and 1989, a two-way table of age group by time period was constructed using intervals of 2 years. All ages from 20 to 83 years were used giving 32 age groups. 15 time periods and 46 birth cohorts. The first cohort corresponds to those who were aged 82-83 years in 1960-62, i.e. born in 1877-80; the second cohort were aged 80-81 years in 1960-62 i.e. born in 1879-82. Thus there is some overlap of cohorts and the convention used here is to take the central two years 1878-79, 1880-81, etc. and to refer to the cohort by the first of these 2 years.

The population data are only available for 5-year age groups for each year from 1950. For the analysis using 2-year age groups and time periods, it was necessary to interpolate the populations in single years of age, and this was achieved by using a smoothed two-dimensional cubic interpolation (Akima, 1978). This is not as sophisticated as Beer's method (Shyrock et al, 1976). Used by Tarone and Chu (1996), as it does not guarantee that the 5-year totals are preserved. As a check on the interpolation, the 5-year totals based on the interpolation were compared with the data. However, the differences are small and unlikely to lead to any great bias, as the number of incidence cases is small relative to the population sizes, which range from 208000 among 20-24 year olds to 70000 in the 80-84 age group in 1989.

For the analysis of mortality data, the standard 5-year age groups and time periods were used. In this instance, there are 13 age groups from 20-24 to 80-84, eight time periods from 1950-1989 and hence 20 cohorts, denoted by their mod years: 1870, 1875, etc. The parameters of the age-period-cohort model were estimated using a generalised linear model with binomial errors and a logistic link.

Results

The age-period-cohort model of the incidence rates had a deviance of 513 and 389 degrees of freedom. Residual analysis revealed that the lack of fit was associated with overdispersion. The model for the mortality rates had a deviance of 65 on 66 degrees of freedom. For incidence, there was evidence of significant non-linear period of cohort effects were significant.

Discussion

When our analysis is compared with the recent analysis of data from the USA and Japan by Tarone and Chu (1996), it is clear that there are similar changes in the cohort trends in the mortality rates around 1925 in Scotland, the USA and Japan. There is a decrease in the slope observed in all three countries. However, it is interesting that this same pattern of reduction is not observed in the Scottish incidence data. Rather than showing a clear difference in the eras before and after 1925, examination of the Scottish incidence and mortality data shows evidence of a decrease in the cohort trends associated with those born after the Second World War compared with those born before. This trend can also be seen in the younger cohorts of the USA mortality data (Tarone and Chu 1996; Figure 1), but it is not present in the Japanese data in which a small increase is suggested; this could be due in some small part to the westernization of the Japanese diet subsequent to 1945 (Boyle et al, 1993). The increase in birth cohort mortality around the turn of the century is present in all three countries.

Study 3: Chamberlain J, Coleman D, Ellman R, et al. Verification of the cause of death in the trial of early detection of breast cancer. UK trial of early detection of breast cancer group. British Journal of Cancer 1991

This paper is involved with evaluating the performance of breast cancer screening.

Methods

Eight districts participated in this study: Edinburgh, Guilford had breast screening, Huddersfield and Nottingham had education in breast self examination, Oxford, Bristol, Southmead, Dundee and Stoke had no special intervention (comparison group).

99% of females in Trial of Early Detection of Breast Cancer were found in the NHS Central Registries (NHSCR). For these the Scottish General Registry Office and the NHSCR for England and Wales sent the TEDBC, death certificates with ICD-coded underlying causes of death stating cancer of the breast in part 1 or part 2 or with unknown primary neoplasm in part 1. They also sent cancer registration notifications. Local research staff in the eight districts were asked to find case notes of all cases of breast cancer except for those diagnosed prior to entry into the trial. These were then reviewed by a designated local doctor with a second review by a medically qualified coordinating assessor (CCA). When the CCA disagreed with the local doctor, the problem was discussed between them, the former however having the final decision.

Results

990 females died before 1988 with first mention of breast cancer on death certificate or with a known diagnosis since entry. No death certificates were submitted by NHSCR for 2% (17) of the cases. The NHSCR sent 84% (832) registrations while 15%(145) were submitted by local trial staff. For the remaining 1% (14)*, the date of death was assumed to be the date of diagnosis. Case notes for 928 (94%) of the 990 females were found. Over half of the 62 not found resulted from staffing difficulties in a single center. For the rest, reasons included, records destroyed, lost or stored inaccessible.

The extent of disagreement between the assessors' opinion and the death certificate on whether or not breast cancer was the underlying cause of death was 6% of the reviewed cases. However, the disagreement for death certificates with underlying

cause of death of breast cancer was 3%, for those with no mention of breast cancer was 12% and 66% for those where breast cancer was mentioned but not coded as underlying cause of death.

Conclusions

The proportion of deaths with probable errors was 6% in this study whereas Brinkley et al. (1984) initially found 9% disagreement but was reduced to 4% after exclusion of cases where there was room for uncertainty.

Study 4: Brinkley D, Haybittle JL, Ralderson MR. Death certification in cancer of the breast. British Medical Journal 1984

Methods

The Cambridge Cancer Registry aims to register all cases of cancer in its area (Registration started in 1960 and records are filed by year of registration).

309 patients were identified with cancer of the breast that died in 1980. For logistic reasons the study was carried out on 200 patients omitting, one every third patient on the list. From these, seven were excluded. One had no death certificate, two were duplicates and four no clinical notes were available.

The remaining 193 patients were classified their cause of death according to the clinical notes or registry cards into three categories: (I) ca breast; (ii) another cause but with overt signs of ca breast; (iii) another cause with no overt signs of ca breast.

Results

Initial comparison between the cause of death entered on the death certificate with the classification derived from the records resulted in 9% (17) disagreement.

When discrepancies occurred the records were reviewed to access the strength of the evidence that had led to a classification different from that given on the death certificate.

After review only six certificates were wrongly coded as due to another cause but where definitely due to ca breast.

Conclusions

The overall prevalence of error is 3% and the deaths of the cancer of the breast were underestimated by 4%. This is similar to the 6% by Heasman and Lipworth (1966).

Study 5: Rutqvist LE. Validity of certified causes of death in breast carcinoma patients - Acta Radiologica Oncology 1985

This study was based on breast carcinoma cases reported from Stockholm County (population 1.5 million) to the Swedish Cancer Registry during 1961 - 1963 (1730 cases) and 1971-1973 (2127 cases).

Methods

Systematic samples from the 2 periods were obtained by selecting patients born on certain days of each month. More days were used for the former period in order to get two samples of approximately equal size. For statistical reasons, the samples from the age group >69 years were increased as a preliminary analysis showed that the survival of the 1971 - 73 sample deviated from that of the total series. Thus the total number of patients were 414 for 1961-63 and 444 for 1971-73. The number of excluded cases was 22 (5%) and 34 (8%) in the two samples respectively. The most common errors were either registration of local recurrences or distant metastases as new primary malignancy or of in situ carcinomas as invasive cancers. Remaining for analysis were thus 392 and 410 cases.

Follow up data was obtained from the Swedish Registry of Causes of Death. Data were available on deaths before Jan 1st 1980. In the selected case material, 502 deaths occurred this date; 304 in the 1961-63 sample, and 198 in the 1971-73 sample. One patient in each sample was excluded because no official diagnosis was registered.

Clinical data on the deceased cases were obtained from hospital records, general practitioners, pathology reports, autopsies and other relevant sources. Some cases had to be excluded because clinical data were unavailable or so scanty that evaluation of the cause of death was not possible. The final number of deaths included in this study was 484 (96% of the total deaths), 292 from the 1961-63 sample, and 192 from the 1971-73 sample.

The aim of the investigation was to access the certified underlying cause of death correctly indicated the presence or absence of recurrent breast carcinoma at death. If disseminated disease was present, the clinical death cause diagnosis was considered to be breast carcinoma irrespective of whether other potentially live threatening diseases were also present. Local recurrence of cancer on the chest wall without evidence of further dissemination was considered contributory cause of death. The clinical diagnosis was compared with the officially recorded causes of death.

The validity of cause of death certification might be influenced by age with possibly less accurate diagnoses among old patients. The proportion of cases with discordant diagnoses were therefore calculated separately for the two age groups < = 69 years and > 69 years.

Results

Of the total 484 deaths 280 (58%) were officially recorded as due to breast carcinoma. (underlying cause) and 204 (42%) as due to other causes. The overall proportion of cases with discordant diagnoses was 41/444 (9%). However, discordant diagnoses were significantly less frequent among patients below 70 years.

In 18 cases (weighted estimate: 5% $\pm$ 1%) of those with an official breast carcinoma diagnosis, the clinical records showed that disseminated breast carcinoma had not been present at death (Table 2). On the other hand, among those with other official diagnoses, 23 (weighted estimated: 14% $\pm$ 4%) were found to have had disseminated breast carcinoma. This difference was statistically significant ($p<0.05$). Thus, if breast carcinoma had been recorded as the underlying cause of death in all patients who had disseminated disease at death, this would have resulted in a net decrease of intercurrent deaths with 5 cases (weighted estimate : -6%) and a corresponding net increase of breast carcinoma deaths (weighted estimate: +2%).

Among those with an official diagnosis of cancer other than breast cancer, the proportion of cases with discordant diagnoses was 9/43 (weighted estimate: 24% $\pm$ 8%) and was thus higher than among those with other intercurrent diagnoses (weighted estimate: 9% $\pm$ 4%) but the difference was not significant.

The overall proportion of cases with discordant diagnoses was lower among young than among old patients. The most marked difference between the two age groups was observed for patients with an official diagnosis of breast carcinoma: the proportion of cases with discordant diagnoses among those aged below 70 years was 4/164 (2% $\pm$ 1%) whereas it was 14/116 (12% $\pm$ 3%) amend the older patients ($p<0.01$).

Discussion

The present results suggest a net overestimation of intercurrent deaths in the official statistics and a corresponding new underestimation of breast carcinoma deaths. Previous studies have shown that the recorded intercurrent mortality of breast carcinoma patients is higher than expected for an age-matched general population, both in regard to non-neoplastic diseases and to other tumours. This excess may be to some extent explained by errors in the cause of death certification. Other factors, which could explain the excess of intercurrent deaths, are the association between breast cancer and other diseases, e.g. other primary malignancies. Adverse effects of surgery, radiation therapy and chemotherapy could also increase the intercurrent mortality.

Study 6: Nyström L, Larsson LG, Rutqvist LE, et al. Determination of cause of death among breast cancer cases in the Swedish randomized mammography screening trials. A comparison between official statistics and validation by an endpoint committee. - Acta Oncologica 1995

This study is an overview of the Swedish trials and includes extensive checks of the quality of the follow-up information using the Swedish Cancer Registry and the National Cause of Death Register at Statistics Sweden. It also included an extramural blind review of the available medical documentation by an independent endpoint committee.

Methods

The cohorts. Initially, each of the five screening centres sent a magnetic tape containing information about their cohorts (personal identification number, date of randomisation and date of the first screening round of the control group) to the administrative centre of the present study at the Department of Epidemiology and Public Health in Umea. The cohorts, which consist of 282 777 women aged 40-74 years (invited group (IG) = 156 911; control group (CG) = 125 866) were linked to the six regional cancer registers to identify cases with breast cancer diagnosed between 1958 and 1989, and to the CDR to identify women who died between 1951 and 1989 and the cause of death according to Statistics Sweden. The Official Population Register at SPAR DAFA DATA AB was used to validate the information of date of death for those who died between 1981 - 1989 and to obtain information on emigration.

Deaths among the breast cancer cases. A total of 27 582 deaths occurred during the follow-up from date of randomisation through December 31, 1989. The review was restricted to those breast cancer patients who were reported to the cancer register with breast cancer after the date of randomisation and who died before January 1, 1990 according to the CDR. Patients with non-invasive breast cancer or with other malignant primary breast tumours than carcinoma (sarcoma phyllodes, other sarcomas, malignant lymphomas) were not included in this group. Cases not reported to the cancer register, but with breast cancer (ICD8 = 174) as the underlying or contributory cause of death according to the CDR, were also reviewed if death occurred after randomised but before January 1, 1988.

End Point Committee. The members of the EPC individually and independently reviewed each case to determine the underlying cause of death, whether breast cancer was present at death an if so there were loco-regional or distant metastases and whether the death was regarded as a complication to treatment of breast cancer.

Study base. A total of 1 313 women met the inclusion criteria, having died with a diagnosis of breast cancer, of which 14 were identified by the CDR only. Seventeen women were excluded by the EPC, 15 as they did not have breast carcinoma although they had been reported to the cancer register and another two as they had migrated (one to Finland and one to Poland) and could not be traced. Thus, the study base consisted of 1 296 cases.

Results

Disagreement between the members of the EPC occurred in 131 cases (10%) and in 89 (6.9%) of these there was disagreement as to whether breast cancer was or was not the underlying cause of death.

The degree of disagreement increased by age at randomisation from 5.6% in the 40-49 age group to 19% in the 70-74 age group.

IV. CONCLUSIONS

The 15 European Union countries plus two EFTA countries brought together for the first time under the project « Quality and comparability of European causes of death statistics » in the aim of improving quality and comparability of mortality data. The result is an exhaustive work achieved through a close involvement of international experts, from which the conclusions and the perspectives are summarised below.

Certification practices

- A state of knowledge of certification practices within EU countries has been achieved, making possible to outline directions for improvements and harmonization.
- A solid network of international experts has been built and the foundations to perpetuate the exchange dynamics now exist.
- 39 recommendations have been validated by the above group of experts.

These conclusions suggest perspectives :

- The current state of knowledge on certification practices could easily be disseminated as extracts, graphs and maps through the European Commission websites.
- A regular update of the emerging knowledge on certification practices should be carried out by member states. This could be performed on the occasion of the annual provision of data to Eurostat.
- The dynamics generated by this project should not be lost. The group of experts should be actively involved in the future of this project and in the follow up of the application of recommendations.
- Amongst recommendations, the provision of training course material gathered a high level of consensus among experts as to their feasibility.

Knowledge base on the 65 causes of death (Eurostat short list)

- International literature reviews on causes of death have been undertaken so that an exhaustive compilation of 532* published studies on the quality and comparability of cause of death statistics could be achieved.
- Reliable methods to improve analysis of data have been identified for four large groups of causes of death (suicide and controversial cases, cardiovascular diseases, pulmonary diseases - including lung cancer, and breast cancer). The existence of complementary methodologies to improve data analysis has been suggested regarding some causes.
- The huge amount of information produced and numerous research questions arising from this task form a sound basis from which additional investigations may be carried out.

These conclusions suggest perspectives :

- As for certification practices, the effort yielded by these literature reviews should be sustained and emerging knowledge regularly updated.
- Further investigations to apply the above identified methods to other causes of death should be carried out, and findings disseminated through the source responsible for the update of information.
- Then, in the light of these findings, the conception, production and diffusion of a dictionary on data quality through Eurostat (website) may be discussed.

*papers related to specific pathologies.

V. SUMMARY

Background. **The project "Comparability and quality improvement in European causes of death statistics in Europe" (1999-2001) has been undertaken as an initiative of the DG Sanco Health Monitoring Programme and the Eurostat Task Force on Causes of Death. Both organisations include as their primary assignment the development of useful and reliable health indicators.**

Objectives. **The objectives were :**
– to produce a precise assessment of death certification procedures in Europe with ensuing recommendations for improvement and harmonization;
– to establish an extensive knowledge database on the 65 causes of death (Eurostat Short list), from which to develop a method of analysis to be applied to a selection of pathologies.

Materials and methods **. The materials used were i) two questionnaires sent to a network of experts from 17 European countries, ii) a literature review of studies published during the past 25 years, iii) meetings and exchange of information with the experts network.**

Results **. The objectives have been achieved and yielded the following results:**
– a detailed state of current knowledge on death certification practices in 17 European countries;
– a series of 39 recommendations on certification procedures proposed by the network of experts;
– a knowledge base of 532 articles related to the 65 causes of death (Eurostat short list);
– a method of analysis tested on four groups of pathologies (suicide and controversial cases, cardiovascular diseases, respiratory diseases - including cancer of the lung, and breast cancer).

Conclusions . An important amount of information has been produced throughout the project implementation, from which the main issues surrounding certification practices and data quality have been drawn out.
It constitutes a useful and comprehensive base on which additional work can be performed.
The constitution of a dynamic network of experts and a solid database should be sustained and opportunities to pursue efforts in the future should be viewed as a priority. In particular, the recommendations on certification practices must be rapidly followed up.