



Work Package 4 Report

Inventory of the Existing Mortality Monitoring Systems in Europe

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Susanna Conti (susanna.conti@iss.it, WP4 Leader)*, Mark Kanieff*, Giada Minelli*, Grazia Rago* and the WP4 Collaborating Group (Theresa Lamagni, Olga Sadicova, Jožica Šelb, Apostolos Vantarakis)

Istituto Superiore di Sanità (ISS)
Statistics Unit
Viale Regina Elena 299
00161 Rome, Italy



**European
Commission**

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Summary

We present the results of a survey conducted by Work Package 4 (“Inventory of the existing mortality monitoring systems in Europe”) of the project "European Monitoring of Excess Mortality for Public Health Action" (EURO-MOMO), which is being conducted to develop a routine public-health mortality monitoring system for the timely detection of excess deaths related to public-health threats in Europe. The survey was conducted in 32 European countries using two questionnaires on: i) the existing and planned mortality monitoring systems; and ii) the routine collection of mortality data. Nine mortality monitoring systems were identified in 7 countries [Belgium, Germany, France (2 systems), Italy (2 systems), Portugal, Spain, and Switzerland], in addition to several systems in a pilot or planning state. Each system is described in detail, as are the procedures for collecting routine mortality data in all surveyed countries. The results will be used for the successive phases of EURO-MOMO, in particular, for identifying the minimum requirements for the planned European system and for selecting countries to include in the project’s pilot phase.

Introduction

European Monitoring of Excess Mortality for Public Health Action (EURO-MOMO) is a three-year project coordinated by the Statens Serum Institut, Denmark, and co-funded by the European Commission (EC), Directorate General for Health and Consumers (DG SANCO). The project has 22 partners from 20 European Countries. The general objective of EURO-MOMO is to develop and operate a routine public-health mortality-monitoring system for detecting and measuring, in a timely manner, the excess number of deaths related to influenza and other possible public-health threats across Europe (www.euromomo.eu).

One of the prerequisites for reaching this objective is the availability of information on existing systems for the timely monitoring of excess mortality, which is important for several reasons: i) this information (e.g., methodology and recorded variables) can be used as a model for developing the European-level system (e.g., for defining the minimum requirements of this system); along these same lines, the information on these systems’ weaknesses can be useful for avoiding problems with the European-level system; ii) the information on which resources are already available for monitoring excess mortality can be used to establish the capacity of these systems to be integrated into the European-level system, as well as for choosing suitable countries for a pilot study; and iii) the information on those countries with no existing systems can be used to determine which countries are in greatest need of the monitoring of excess mortality. It is also necessary to have information on the routine collection of mortality data at the national level. This information is important not only because it could be a determinant of which countries will be able to implement mortality monitoring but also because the procedures for collecting these data can be potentially adapted to actually perform mortality monitoring.

Obtaining this information is the responsibility of Work Package 4 (“Inventory of the existing mortality monitoring systems in Europe”). The objectives of Work Package 4 were to map: i) existing and planned systems for collecting mortality data for rapid public-health surveillance (e.g., influenza mortality data) and ii) procedures for collecting mortality data on a routine basis (i.e., data used for such purposes as demographics). The specific objectives were to determine: i) the availability of mortality data and the procedures for data collection: timeliness, coverage (national or regional), type of data, and coding systems used; and ii) the components and attributes of existing mortality monitoring systems. To this end, we conducted a survey of existing, pilot, and planned systems for mortality monitoring and, as background for the mortality monitoring systems, the routine collection of mortality data in Europe.

Methods

To meet these objectives, we performed a survey in individual European countries using two questionnaires designed specifically for this purpose: i) a questionnaire on existing and planned systems for the timely monitoring of excess mortality; and ii) a questionnaire on the routine national-level collection of mortality data. The questionnaires were developed through a series of discussions among the WP4 members, which includes experts in the field of mortality data, and other EURO-MOMO participants. The questionnaire on the routine collection of mortality data was also based on the questionnaire used by EuroStat in the report “Comparability and quality improvement in European causes of death statistics in Europe (1999-2001)”. A first draft of the questionnaires was sent to EURO-MOMO participants and modified based on their criticisms and suggestions, repeating this process until the final version was acceptable to all.

The questionnaires were intended to be completed by contact persons in 32 countries. A number of these contact persons were EURO-MOMO participants, whereas to identify the others, we relied on a variety of sources, including the EURO-MOMO participants themselves, our knowledge of existing mortality monitoring systems and their coordinators, our network of work relationships established in the past (i.e., colleagues of previous EC projects), and, for the questionnaire on the routine collection of mortality data, the list of national reference persons for EuroStat. This resulted in the creation of two separate lists, one for each questionnaire, although in some cases a single reference person completed both questionnaires.

Once we identified potential candidates, we contacted them by e-mail to request whether or not they would be available to complete the questionnaires, specifying the date that they could expect to receive them. If no response was received, we attempted to contact them again; if this attempt failed, we used the above-mentioned sources to identify someone else. For persons declining participation, we asked them to suggest another person; if they did not, again, we relied on the above-mentioned sources to identify an alternative.

The questionnaires were sent to by e-mail contact persons in the first week of September 2008, asking them to reply by the end of the month. If no response was received by that date, reminders were sent until the completed questionnaires were received. We encouraged the contact persons to contact us if they had any questions or problems with completing the questionnaire; similarly, if the responses to the questionnaires were unclear or the questionnaires were incomplete, we asked for clarifications.

Questionnaires

Questionnaire on existing and planned systems for the timely monitoring of excess mortality (Appendix 1)

In developing this questionnaire, we attempted to make it as complete as possible without making it excessively long, so as not to place an excessive burden on the contact persons. The questionnaire, which was written with Microsoft Excel, consists of 49 questions. The questionnaire covers six areas (described in detail below): 1) general characteristics of the system; 2) data collection (how and who collects the data); 3) data analysis; 4) data dissemination (how the data are disseminated or "feedback"); 5) data privacy; and 6) functioning of the system (strengths and weaknesses). To ensure that the contact person understood exactly what type of system we were investigating, the first question includes a definition of rapid mortality surveillance systems: "a system for rapidly collecting data on excess mortality for the purposes of public-health surveillance (i.e., a system existing in addition to the routine collection of data on deaths, generally performed by statistics institutes)".

1) General characteristics of the system

This area includes questions on: i) whether the system is active, in a pilot phase, or suspended, or if a system is planned for the future ii) the name of the system; iii) the institution that manages it; iv) collaborating institutions; v) funding institution; vi) the main objectives (to determine whether they coincide with those of EURO-MOMO); vii) the year it was created; viii) whether historical data are collected (and earliest year); and ix) whether data are collected continuously or only in specific cases (e.g., public-health threats).

2) Data collection

This area includes questions on: i) who provides the data directly to the system; ii) whether it is mandatory to submit mortality data to the system; iii) geographic coverage of the system (NUTS level); iv) coverage of the national population (percentage); v) whether the cause of death is recorded, and if so, whether other causes are collected; vi) version of the International Classification of Diseases (ICD) used to code the cause of death; vii) whether the data received are individual or aggregated; viii) period of aggregation (e.g., daily, weekly); ix) variables collected (e.g., gender, age, place of death); x) smallest geographic unit to which the data refer; xi) how data are submitted to the system; xii) frequency of data submission; xiii) whether the delay between the date of death and the receipt of data has been analysed and, if yes, the median and the 25th and 75th percentiles of the time elapsed; and xiv) whether other data are collected together with the mortality data (i.e., climate, influenza, other), including the type of climate and influenza data collected.

3) Data analysis

This area includes questions on: i) whether data quality control is performed and at what level (e.g., locally, centrally); ii) whether data are analysed separately by sex; iii) what measures are calculated (e.g., only absolute values, crude rates, adjusted rates), iv) whether the Standardised Mortality Ratio (SMR) is calculated; v) the types of analyses performed (e.g., time series, mathematical models taking into account other variables); and vi) a space for providing bibliographic references for the methods used.

4) Data dissemination

This area includes questions on: i) the aggregation of disseminated data in terms of time period (e.g., daily, monthly); ii) the aggregation of disseminated data in terms of geographic area (e.g., national, NUTS); iii) the form of the disseminated data (e.g., tables, graphs); iv) the means of dissemination (e.g., public or restricted website, hardcopy); and v) the frequency with which the disseminated data are updated.

5) Privacy

This area includes questions on: i) whether the data are considered to be "personal data" and subject to regulations on protecting privacy; ii) whether personal data can be legally sent to public-health institutions in other countries and, if yes, at what level of aggregation and under what conditions; and iii) whether the data are linked with other databases.

6) Functioning of the system

To have an idea of how well the system functions, we provided blank spaces for describing the strengths and weaknesses of the system.

Questionnaire on the routine national-level collection of mortality data (Appendix 2)

The questionnaire on the routine national-level collection of mortality data consisted of 28 questions, which cover four areas: 1) general characteristics of the procedures; 2) death certificate; 3) data set; and 4) data dissemination.

1) General characteristics of the procedures

This area included: i) a request for a brief description of the routine system for collecting mortality data, including a link to any existing website; we also asked the contact persons to attach data flowcharts; and ii) a question on the institution managing the system.

2) Death certificate

This area includes questions on: i) whether a single standardised death certificate is used nationwide, and, if not, how many different types of death certificates are used and in what geographic areas; and ii) whether or not a separate perinatal death certificate is used. We also asked the contact persons to send us a copy of the death certificate(s) used in their country.

3) Data set

This area includes questions on: i) the year the system began to collect data; ii) whether the specific cause of death is recorded and, if yes, whether other causes resulting in the underlying cause or other significant conditions are recorded; iii) the percentage of all death certificates with more than one diagnosis; iv) the version of the ICD used; v) whether automated procedures are used to encode the cause of death; vi) the level at which the code is assigned (e.g., locally, centrally); vii) the variables collected (e.g., gender, marital status, education); viii) whether reporting delay is analysed and, if yes, the median and 25th and 75th percentiles of the delay; ix) whether data quality control is performed and at what level (e.g., locally, centrally); x) whether the data are considered as "personal data" and thus subject to regulations for protecting privacy; xi) whether data can be legally sent to public-health institutions in other countries and at what level of aggregation and under what conditions; and xii) whether the data are linked with other databases.

4) Data dissemination

This area includes questions on: i) the year of publication of the most recent official national reported published; ii) whether the mortality data in the official national report are presented by gender, age group, and/or in the form of rates; and iii) the minimum area unit used in the official report, including the Nomenclature of Territorial Units for Statistics (NUTS).

Analysis of the responses to the questionnaires and creation of a database

All of the information was recorded in a database, which allows all of the completed questionnaires to be viewed (database available on CD, in both Acrobat and Microsoft Access). In particular, the database consists of two groups of files (one for each of the two questionnaires). For the questionnaires on systems for mortality monitoring, each of the individual files contains the answers for specific sections of the questionnaire (e.g., general characteristics, data collection, data analysis), whereas the entire questionnaire on the routine collection of mortality data is provided in a single file.

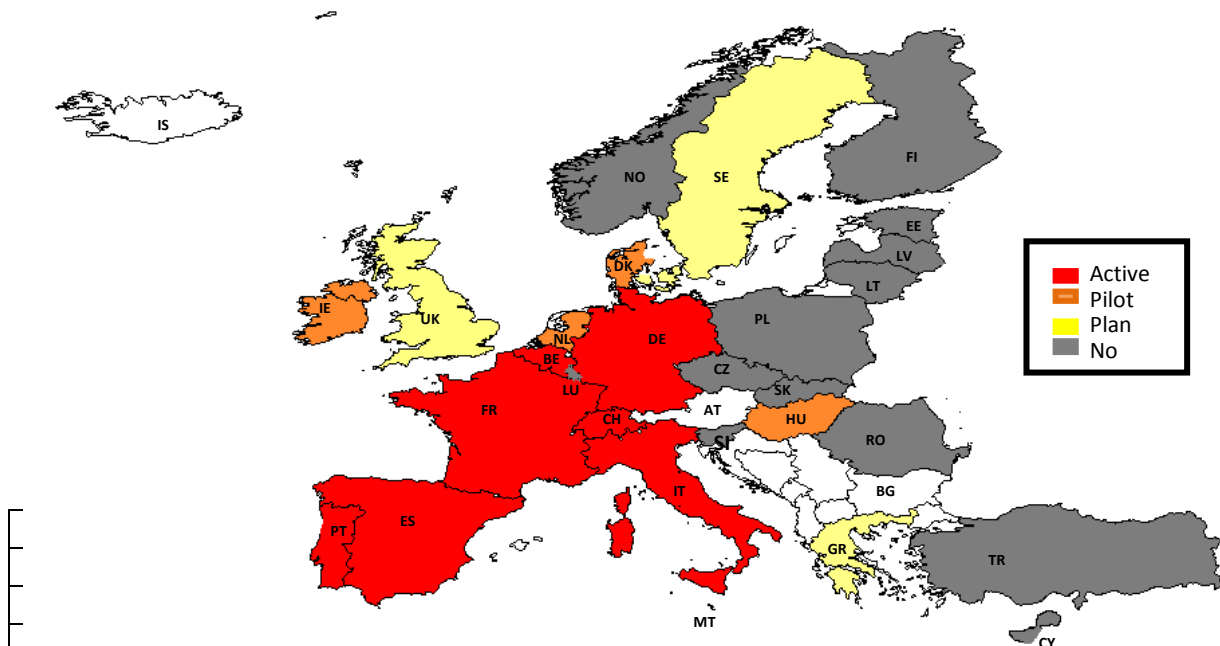
For both questionnaires, a descriptive analysis of the results was performed, using the SPSS statistical package as support. As mentioned, to ensure to the greatest extent possible that the data would be complete and accurate, we encouraged the contact persons to send us an e-mail if they had any questions or problems with completing the questionnaire. If the responses to the questionnaires were unclear or inconsistent or the questionnaires were incomplete, we asked for clarifications.

Results

Existing systems for the timely monitoring of excess mortality

Of the 32 countries surveyed, 28 completed the questionnaire on existing and planned systems for the timely monitoring of excess mortality. For the remaining four countries, we were either not able to identify a contact person, or the contact person, after having agreed to complete the questionnaire, failed to send it back to us, despite numerous attempts to contact him/her. Of the 28 responding countries, 7 have an existing mortality surveillance system (i.e., Belgium, France, Germany, Italy, Portugal, Spain, and Switzerland). However, France and Italy have two systems each, so there are a total of 9 systems (in the present report, the terms "France 1", "France 2", "Italy 1", and "Italy 2" are used to distinguish these systems). A map of Europe with indications of which countries have a mortality surveillance system is provided in Figure 1 below, and the names of the 9 existing systems are reported in Table 1.

Figure 1 - Rapid mortality surveillance systems in Europe



Germany	No official name reported
Italy ("Italy 1")	<i>Sistema Nazionale di Sorveglianza Rapida della Mortalità</i>
Italy ("Italy 2")	<i>Sorveglianza Epidemiologica Rapida della Mortalità nelle Città Capoluogo di Regione/Provincia Autonoma</i>
Portugal	No official name reported
Spain	<i>MOMO: Monitorizacion de la Mortalidad Diaria</i>
Switzerland	<i>Überwachung der Sterblichkeit (Exzessmortalität)</i>

The 9 existing systems are described in detail below, followed by a summary description of the pilot and planned systems.

General characteristics of the systems

In the questionnaire, we asked about each system's objective, to determine whether it coincided with the general objective of EURO-MOMO. The reported objectives ranged from very generic to more specific, though all of them seem to conform with EURO-MOMO. Some of the objectives specifically mention such key terms as "real-time", "rapid", "early" or "timely". The most generic objective is that reported by the system in Switzerland, whereas the most detailed objective is that of the system in Belgium.

Belgium - "1) Detection of high-mortality associated events, early identification of potential health hazards, 2) Estimation of impact of emerging health threats, 3) Recommendation of public health measures, 4) Evaluation of coordinated actions at national or European levels (e.g. influenza vaccinations, national heat plans), 5) Follow up of possible secular trends in mortality"

France 1 – “To identify a changes in mortality trends as soon as possible in order to launch an alert; to monitor the population health through the impact on mortality of a well known or correctly identified event”

France 2 – “The main objectives are to shorten the delay of medical causes of death availability and to increase the data quality.”

Germany – “To recognize and assess possible health threats with respect to excess mortality as heat waves, influenza, other epidemic occurrences”

Italy 1 – “The system is aimed to provide real time mortality data in order to identify increases in mortality associated to heat waves, for the timely activation of heat response plans. Moreover, it allows the evaluation of the impact of heat waves during summer, city-specific heat health watch warning systems (HHWWS) and prevention programs.”

Italy 2 – “To describe mortality in all age classes in the major cities in a more timely manner with respect to routine mortality data collection, so as to reveal excesses in mortality associated with specific conditions, such as heat waves, cold spells, and influenza outbreaks”

Portugal – “Daily surveillance, extreme weather impact detection or confirmation; collaboration with existing plans for heat waves”

Spain – “To detect daily unexpected excess in general mortality, short term trend upsurges in general mortality and to estimate excess mortality in periods of interest; it was initially active during summer to help reduce the impact of heat-waves on health but currently is active all the year round.”

Switzerland - "To detect spells of excess mortality"

With regard to the years in which the 9 existing systems became operational, all of the systems are fairly recent. The first system, that in Portugal, was activated in 2003, followed by: France 1, Italy 1, and Spain (2004); Belgium and Italy 2 (2005); Switzerland (2006); Germany (2007); and France 2 (2008). Some systems, when created, also began to collect historical data (i.e., data from years prior to the creation of the system). The system in Switzerland had the oldest historical data, which date back to 1969, followed by Spain (1981), Belgium (1985), Italy 1 (1995), Italy 2 (2003), and Germany (2006).

Regarding the institution/organisation that is responsible for the system, all but one are managed by either a health institute (5 of the 9 systems) or a statistics institute, and in one case, both. The one exception is the "Italy 1" system (i.e., the surveillance system for deaths related to

heat waves), which is run by the Department of Civil Protection. For some systems, another institution or institutions collaborate on management, in particular: a statistics institute for the France 1 system, a health institute for the France 2 and German systems, local registrars' offices for the Italy 2 system, and a notary and registries institute and the Ministry of Justice for the Portuguese system. Regarding funding, six of the systems receive specific funding (i.e., not part of the ordinary budget) from a public health institute (Belgium, Germany, France 1, France 2, Spain, and Italy 2), whereas funding is part of the ordinary budget for 2 systems (Portugal and Switzerland); the remaining system (Italy 1) is funded by the Department of Civil Protection.

We also collected information on whether the system was active for the entire year or only during certain periods of the year (e.g., the wintertime for influenza) or only for "emergencies". All of the systems are active year-round, except for the Italy 2 system, which monitors heat-wave related mortality from May to September.

Data collection

Data are provided by civil authorities (e.g., the General Registrars Office) for all of the systems except the France 2 system, for which health authorities/facilities provide the data. For four of the systems (Belgium, France 1, Germany, and Switzerland), it is mandatory to provide the data to the system. Regarding data submission, the means and frequency are as follows: Belgium - e-mail (weekly); France 1 - Internet (daily); France 2 - web portal (daily, in real-time: time of death + 4 hours); Germany - downloaded files submitted by the Office for Statistics (weekly); Italy 1 - e-mail and fax (daily); Italy 2 - e-mail (monthly); Portugal - e-mail (daily); Spain - e-mail (daily); and Switzerland - electronic data transfer (daily)

Regarding the geographic coverage of the data, the answers provided were as follows: Belgium, France 1, and France 2 - "Entire country"; Germany - "NUTS 1"; Italy 1 and Italy 2 - "Capital cities of Italy's 21 Regions and Autonomous Provinces"; Portugal - "Entire country" and "NUTS 1 and 2"; Spain - "NUTS 2 and 3", "Certain towns/cities", and "Climatic zones"; and Switzerland - "Entire country" and "NUTS 1". We also analysed the coverage of the systems in terms of the percentage of the national population (Table 2). Three of the systems report 100% coverage, whereas for the remaining 6 systems, coverage ranged from 1% for the France 2 system to 57% for the Spanish system. With specific regard to Germany, the system only covers the State of Hesse.

Table 2 - Coverage of the mortality surveillance system: Percentage of the national population

System	Coverage (% of national population)
Belgium	100
France 1	70
France 2	1
Germany*	7
Italy 1**	20
Italy 2	16
Portugal	100
Spain	57
Switzerland	100

*Only covers the State of Hesse

**Refers to the population aged ≥ 65 years

The smallest geographic unit to which the data received by the system refer is "town/city" for Belgium, France 1, France 2, Italy 2, Spain, and Switzerland; it is "NUTS 3" and "administrative districts" for Germany; "town/city" and "census tract for the City of Rome" for Italy 1; and "NUTS 1 and 2" for Portugal.

We also investigated whether the system records the specific cause of death; only the France 2 system, which was specifically created for this purpose, does so. This system, in addition to the underlying cause of death, records data on "Other causes resulting in the underlying cause" and "Other significant conditions". The causes of death are coded using ICD X.

For all of the systems, the data received are individual data. The specific variables collected vary among the systems (Table 3). All of them record some indication of age at death, whether it be the specific age, the age group, or the date of birth. All systems also record gender and date and place of death; three systems record the site of death (e.g., hospital, home). No one records educational level or occupation (not shown in Table), and only one system each records marital status and nationality.

Table 3 - Variables collected by the mortality surveillance systems

System	Sex	Age	Age group	Marital status	Date birth	Date death	Site death	Place death	Residence	Nationality
Belgium	X				X	X		X	X	X
France 1	X	X				X		X	X	
France 2	X				X	X	X	X	X	
Germany	X	X	X			X		X	X	
Italy 1	X				X	X	X	X	X	
Italy 2	X	X				X		X	X	
Portugal	X	X			X	X		X		
Spain	X	X		X	X	X	X	X	X	
Switzerland	X	X	X		X	X		X	X	X

Regarding the timeliness of data collection, the median time that elapses between the date of death and the date that the data are received by the surveillance system, together with the 25th and 75th percentiles, is reported in Table 4. Overall, the systems can be considered as basically rapid. The median time for the 9 systems is 3 days, with the times ranging from 4 hours (for the France 2 system, a new system based on e-death certification) to 10 days for the German system.

Table 4 - 25th, 50th, and 75th percentiles of the time between death and data receipt for the mortality surveillance systems

System	Percentile		
	25 th	50 th (median)	75 th
Belgium	5 days	8 days	11 days
France 1	Nr	Nr	Nr
France 2	Nr	4 hours	Nr
Germany	Nr	10 days	Nr
Italy 1	Nr	3 days	Nr
Italy 2	Nr	Nr	Nr
Portugal	Nr	1 day	Nr
Spain	1 day	2 days	4 days
Switzerland	4 days	6 days	8 days

nr = not reported

Regarding data on influenza and climate, 5 of the 9 systems monitor excess influenza mortality, and 7 systems collect climatic data, though the specific data vary by system (Table 5).

Table 5 - Collection of data on influenza and climate by the mortality surveillance systems

System	Influenza data	Climate data		
Belgium	X	X	Minimum temperature	X
			Maximum temperature	X
			Humidity	X
			Ozone/other particles	X
France 1*		X	Minimum temperature	X
			Maximum temperature	X
			Humidity	X
			Ozone/other particles	
France 2*		X	Minimum temperature	X
			Maximum temperature	X
			Humidity	X
			Ozone/other particles	
Germany	X	X	Minimum temperature	
			Maximum temperature	X
			Humidity	
			Ozone/other particles	X
			Other: Air pollution ozone - holidays, etc.	X
Italy 1		X	Minimum temperature	X
			Maximum temperature	X
			Humidity	X
			Ozone/other particles	
			Other: Maximum apparent temperature	X
Italy 2**	X			
Portugal				
Spain	X	X	Minimum temperature	X
			Maximum temperature	X
			Humidity	
			Ozone/other particles	
Switzerland***	X	X	Minimum temperature	X
			Maximum temperature	X
			Humidity	
			Ozone/other particles	

*Climate data for the France 1 and France 2 systems are provided by another system.

**The Italy 2 system performs a linked analysis with the data from the European Influenza Surveillance Scheme (EISS).

***For the system in Switzerland, influenza and climate data are provided by another office.

Data analysis

Data quality control is performed by six systems (i.e., Belgium, France 1, France 2, Italy 1, Portugal, and Spain), in all cases at the central level. Data are analysed separately by gender by six systems (Belgium, Italy 1, Italy 2, Portugal, Spain, and Switzerland). Regarding the calculated measures, 5 systems produce only absolute values (i.e., Germany, Italy 2, Portugal, Spain, and Switzerland). The system in Belgium produces crude rates only, whereas the France 1 and France 2 systems produce crude rates plus rates adjusted by age, and the Italy 1 system produces crude rates and rates adjusted by age and by gender. None of the systems calculate the SMR. Regarding the types of analyses performed, the system in Belgium performs time-series analyses only; the France 1 and Italy 1 systems perform times series and mathematical models taking into account other variables; and the Spain performs time series, Cusum modification algorithm, and Kriging analysis.

Data dissemination

Another important aspect of these systems is the dissemination (or feedback) of data once they have been received by the system. All of the 8 systems for which this information was available (i.e., excluding Germany) disseminate data through either a website or e-mail; in some cases, hard copy is also used (Table 6). Regarding the frequency of data dissemination, this ranges from daily (Portugal and Spain) to yearly (Switzerland).

Table 6 - Mode and frequency of data dissemination for the mortality surveillance systems

System	Mode of data dissemination	Frequency of data dissemination	Period of aggregation for disseminated data
Belgium	public website	Weekly	Daily
France 1	restricted website, e-mail, hard copy	Nr	Weekly
France 2	e-mail and hard copy	Nr	weekly ("daily if necessary")
Germany		Nr	daily, weekly
Italy 1	e-mail and hard copy	Nr	Monthly
Italy 2	public website	Every 3 months, annual report	Monthly
Portugal	e-mail	Weekdays	daily (though currently done only during summer)
Spain	e-mail	Daily report, final summary report	Daily
Switzerland	public website and hard copy	Yearly	weekly, monthly, yearly

nr = not reported

The geographic area for which the disseminated data are aggregated is as follows: Belgium - national; France 1 - national, regional, and town/city; France 2 - national, regional, and town/city; Germany - NUTS 1 and 3; Italy 1 - Town/city; Italy 2 - Town/city; Portugal - national, regional, and NUTS 1 and 2; Spain - national, regional, and town/city; and Switzerland - national and NUTS 1. The frequency with which the disseminated data are updated is: Belgium - weekly; France 1 - weekly (daily if necessary); France 2 - weekly (daily if necessary); Germany - daily and weekly; Italy 1 - monthly; Italy 2 - monthly; Portugal - daily (but only during the summer); Spain - daily; and Switzerland - weekly, monthly, and yearly.

5) Privacy

We also investigated whether or not the system collects data that can be defined as "personal" or sensitive" and are thus subject to restrictions. By "personal data", we mean data regarding an identifiable person, that is, one who can be directly or indirectly identified, in particular by reference to an identification number or to factors specific to his/her physical, physiological, mental, economic, cultural or social identity. Five of the systems (Belgium, France 1, France 2, Portugal, and Spain) reported that they collect personal data, yet none of them are authorised to provide personal data to other institutions.

6) Functioning of the system

At the end of the questionnaire, we provided blank spaces for the contact person to describe the strong points and weak points of the surveillance system, in addition to a space for additional comments. The most commonly reported strong points were: i) timeliness (or rapidity) of data collection; ii) coverage; iii) advantages of individual data, in terms of their utility in performing analyses by geographic area, age, gender, etc. and for linkage with influenza and climate data; iv) data quality; and v) low cost and ease of management of the system. The most common weak points were: i) delay (or lack of timeliness), and ii) lack of data on the cause of death.

Mortality surveillance systems in the pilot or planning phase

In addition to the 9 existing mortality surveillance systems, 6 countries reported that they have a system that is currently in the pilot phase [i.e., Denmark, Germany (Berlin), Hungary, Ireland, the Netherlands, and Scotland]. The year that the pilot phase began ranges from 1995 to 2008; no information on the pilot system in Germany (Berlin) are available. In all cases, the system is managed by a health institute. Three of the systems have national coverage (i.e., Denmark, Ireland, and the Netherlands), and three collect data for the entire year (i.e., Denmark, Ireland, and Scotland). Only the system in Hungary collects influenza data, whereas climate data is collected by the systems in Ireland and Scotland. The system in Ireland is also the only system to collect data on the specific cause of death. The median delay from the date of death to the date that the data are received by the system was reported for two countries: Denmark (3 days) and Ireland (10 weeks).

Another 3 countries have developed plans for a mortality surveillance system (i.e., Greece, Sweden, and the United Kingdom). As for the pilot systems, all of these planned systems are managed by a health institute. The Greek system is expected to become operational in 2009, whereas no information on the planned year of activation was provided for the systems in Sweden and the United Kingdom. National coverage is expected for the systems in Sweden and the United Kingdom. The system in Sweden will be operational for the entire year. This system will also collect data on climate. Only the system in the United Kingdom plans to collect influenza data, and cause of death will be recorded by the systems in Greece and the United Kingdom.

(Note: Since the performance of this survey, the authors have been informed that in England/Wales, a system for the flu-pandemic now exists and started producing reports in July 2009.)

The routine collection of national mortality data

For the questionnaire on the routine collection of national mortality data, the contact person was in most cases different from the one for the questionnaire on existing mortality surveillance systems, and most of these contact persons were associated with EuroStat. Thirty of the 32 contact persons completed the questionnaire. The main information collected on the questionnaire, by country, is summarised in the table in Appendix 3.

General characteristics

Given that the questionnaire included a blank space for describing the procedures for the routine collection of mortality data and that the descriptions provided varied to a great extent (see database), a straightforward comparison of the general characteristics is quite difficult. In any case, the fundamental information regarding these systems is covered by the other sections of the questionnaire and reported below.

Death certificate

A single standardised death certificate is used nationwide in 27 of the 30 countries surveyed. Thirteen countries reported the use of a separate perinatal death certificate.

Data set

With regard to the year in which data began to be collected, this ranged from the year 1829 to 2006. Twenty three countries collect data on the specific cause of death; of these, 20 collect data on other causes resulting in the underlying cause, and 19 collect data on other significant conditions. The percentage of all death certificates for which more than one diagnosis is reported ranges from 25% to 98%. With regard to the specific version of ICD, 2 countries use ICD IX and 25 use ICD X. Automated procedures to encode the cause of death are used by 12 countries.

With regard to the specific data collected by each system, the variables collected by each country are summarised in Table 7 below. Eleven countries also collect additional variables (designated as "other" on the questionnaire), which are specified in Table 8.

Table 7 - Variables collected as part of the routine collection of national mortality data

Country	Variable									
	Sex	Marital status	Educational level	Occupation	Date birth	Date death	Site death	Place death	Residence	Nationality
Austria	X	X			X	X	X	X	X	X
Belgium	X	X	X	X	X	X	X	X	X	X
Bulgaria	X	X			X	X	X	X	X	
Switzerland	X	X		X	X	X		X	X	X
Cyprus	X				X	X	X	X	X	X
Czech Republic	X	X	X	X	X	X	X		X	
Germany	X				X	X			X	
Estonia	X	X	X	X	X	X	X	X	X	X
Spain	X	X			X	X	X	X	X	
Finland	X	X			X	X	X	X	X	X
France	X	X		X	X	X	X	X	X	X
Greece	X	X		X	X	X	X	X	X	X
Ireland	X	X		X	X	X	X	X	X	
Italy	X	X	X		X	X	X	X	X	X
Lithuania	X	X			X	X	X	X	X	
Luxembourg	X	X		X	X	X	X	X	X	X
Latvia	X				X	X	X	X	X	
Malta	X	X		X	X	X	X	X	X	X
Norway	X	X			X	X	X	X	X	
Hungary	X	X			X	X	X	X	X	
Poland	X	X	X		X	X	X	X	X	X
Portugal	X	X	X	X	X	X	X	X	X	X
Romania	X	X	X	X	X	X	X	X	X	X
Sweden	X	X			X	X			X	X
Slovenia	X	X	X	X	X	X	X	X	X	
Slovakia	X	X			X	X	X	X	X	X
United Kingdom	X	X		X	X	X	X	X	X	
Turkey	X		X	X	X	X	X	X	X	X
Netherlands	X	X			X	X	X	X	X	X
Scotland	X					X			X	

Table 8 - Other variables collected as part of the routine collection of national mortality data

Country	Variables (designated as "Other" on the questionnaire)
Austria	religion, autopsy, maternal death
Belgium	actual occupation status, social status in last occupation, previous occupations, date of birth of surviving wife/husband, date of last marriage, living situation, time (hour

	and minutes) of death, nature of death, circumstances of death, place of accident, date and time (hour and minutes) of the accident, causes of death (up to 7), state of pregnancy, recent delivery, autopsy or other additional examinations, treating doctor or not. Occupation, circumstances of death and previous occupations will not appear in the recent datasets of the Walloon Region as they can not be processed easily (texts).The causes of death appear in the data bank as ICD-10 codes. The written text is not kept so far.
Czech Republic	Citizenship
Greece	age of wife/husband who is alive
Italy	professional or not professional condition, professional position, activity sector
Luxembourg	interval between illness begin and death, autopsy required
Malta	details of accident, if pregnant, (see death certificate)
Slovakia	information provided on copy of death certificate, not available in English
Turkey	place of injury, type of injury, maternal death, stillbirth, infant death
UK, England & Wales	other significant conditions contributing to the death but not related to the disease or condition
UK, Scotland	date of registration, site of registration

Reporting delay is analysed by 11 countries (i.e., Cyprus, France, Greece, Italy, Latvia, Malta, Slovenia, Spain, Switzerland, England & Wales, and Scotland), yet only 4 countries specified the 25th and 75th percentiles of the delay: Cyprus (3, 5.5, and 7 months, respectively); Spain (2, 1, and 4 days); Switzerland (6, 4, and 8 days); UK, England and Wales (1, 2, and 3, days); and Scotland (3, 4, and 5 days). All countries perform data quality control, which in nearly all cases is performed centrally. In 27 countries, the data collected are considered as "personal data" and thus subject to regulations for protecting privacy.

Data dissemination

The year of the most recent publication of data ranged from 2000 to 2008. Five countries reported 2008 (i.e., the current year at the time the questionnaire was received); 11 reported 2007 (i.e., the previous year, yet the most recent completed year); and 5 reported 2006. In all countries, the mortality data in the official national report are presented by gender; in 29 countries they are reported by age group; and in 26 countries they are reported in the form of rates.

Conclusions and recommendations

The results of this survey reveal that only 9 completely functional systems for the timely monitoring of mortality are currently operational in Europe, and they represent only 7 countries (out of a total of 32 countries surveyed). Furthermore, all 9 systems are in Western Europe, and the only system identified in Eastern Europe is a pilot in Hungary, emphasising the need for such systems in this area. With regard to the general characteristics of these systems, the objectives of all of them are consistent with the main objective of EURO-MOMO: "To develop and operate a routine public health mortality monitoring system aimed at detecting and measuring, on a real-time basis, excess number of deaths related to influenza and other possible public-health threats across European countries." In some cases, terms such as "real-time" and "early" are specified in the objectives, stressing the importance of timeliness, yet the exact meaning of these terms seems to vary and will have to be further evaluated in light of the requirements of a future European-wide system.

Other important general characteristics are the type of institution/organisation that is responsible for the system and the funding that the system receives. That all but one system are managed by either a health institute or a statistics institute is indicative of the type of expertise available for performing such surveillance. With regard to funding, that two thirds of the systems receive specific funding (i.e., not part of the ordinary budget) is encouraging, in that it is indicative of a country's financial resources available for surveillance. Nonetheless, both of these aspects will need to be investigated even further if the objectives of EURO-MOMO are to be successfully reached.

Two of the fundamental characteristics of a rapid mortality surveillance system are the timeliness with which data are collected and the coverage. In our survey, their importance was confirmed by the fact that they were among the main strong and weak points reported for the systems. Regarding timeliness, the minimum period reported for the 50th percentile was 4 hours, which is made possible through the use of e-death certification, though it must be considered that the national coverage of this system (France 2) is only 1%. By contrast, the greatest duration for the 50th percentile was 10 days, and although this is not excessively long, as mentioned, it will be necessary to determine whether or not it is sufficiently brief for the purposes of EURO-MOMO. Regarding coverage, of concern is the finding that only 3 of the systems reported 100% coverage, and that the next highest coverage was 57%. In the successive phase of EURO-MOMO, means of improving and maintaining high coverage will have to be thoroughly discussed, along with the extremely important issue of achieving an acceptable balance of timeliness and high coverage.

We were particularly concerned with whether or not the systems collected influenza data, in light of the potential occurrence of an influenza pandemic, as well as climate data, considering the important effects of such events as heat waves and cold spells on mortality. Only about half of the systems monitor influenza mortality, whereas the situation is more encouraging for climate data, which is collected by nearly all of the systems, although the specific climate data collected vary.

That some of the systems collect personal data gives rise to the issue of data privacy, which has become an increasingly important concern in light of the enormous progress made in information technology and the consequent ease with which data can be accessed, including personal and confidential data. Although none of the systems share personal data with other institutions, in creating a European-level system, legislation regarding the protection of data, such as "Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data", will have to be respected, as will the specific legislation in individual countries.

With regard to functioning of the systems, though the strengths and weaknesses reported for the systems could probably be expected for any surveillance system, they are important in that they provide an indication of the characteristics that, according to the contact persons, are fundamental to these systems, and, perhaps more importantly, of the characteristics that are desired yet have not been obtained. These responses will be of particular importance when attempting to establish systems (or adapt existing ones) in the EURO-MOMO system.

Although described only briefly, the information on the mortality monitoring systems in a pilot or planning phase is quite important, in that it provides indications of the current and/or future resources for excess mortality monitoring. Moreover, the fact that these systems are not yet operating to their full intended potential or are still being planned could represent an opportunity for the requirements of EURO-MOMO to be more easily integrated into these systems and perhaps make these systems more attractive for inclusion in the pilot phase..

With regard to the routine collection of national mortality data, as known, all of the countries perform such data collection, though the specific characteristics vary by country and some countries' procedures seem to be more efficient than others. Although a description of the collection of mortality data in Europe has been provided by EuroStat, and this description is much more detailed than ours, the most recent EuroStat report dates back to 2001 [i.e., "Comparability and quality improvement in European causes of death statistics in Europe (1999-2001)"]. Thus our

results constitute more updated information on these activities. The importance of this information lies in the fact that the procedures could potentially be adapted in situations requiring rapid mortality surveillance, though this would have to be thoroughly evaluated and may not always be possible. Moreover, this information could contribute to determining which countries will be able to implement mortality monitoring. However, it must also be considered that routine data collection is in many cases the responsibility of statistics institutes, whereas more than half of the 9 systems for monitoring excess mortality in our survey were run by a health institute; thus the potential for a statistics institute to run a system for monitoring excess mortality or for different institutes to collaborate must be evaluated in the individual countries.

In interpreting the results of this survey, some limitations must be considered. First of all, although we made every attempt to identify the most suitable contact person in each country, our response rate for the questionnaire on excess mortality monitoring was not 100%. Moreover, we cannot exclude the possibility that the responders may not be aware of each and every existing mortality monitoring system, though this is unlikely, given that an extensive network of healthcare professionals, including experts in death statistics and surveillance systems, was used to identify these persons. With regard to the responses to our survey, again, though we made numerous requests for clarifications of unclear questions or incomplete answers, our attempts were not always successful. Furthermore, it must also be considered that the mere fact that certain data are collected by a system is not indicative of the fact that these data are of high quality, and though most of the excess mortality monitoring systems and all of the routine procedures for collecting mortality data include data quality control, the specifics of the control procedures were not investigated.

Despite these limitations, the results of the survey provide an overall picture of excess mortality surveillance and the routine collection of mortality data in Europe. Obviously, there is room for improvement, not only for the individual systems but more importantly in terms of coverage of Europe as a whole. The results of this survey, which constitutes one of the main actions of EURO-MOMO, will be especially important for the project's successive phases. In particular, they are necessary for the activities of Work Package 5 ("Concept: Core attributes and requirements"), whose responsibilities are to identify the minimum requirements for real-time mortality monitoring at the national and international level (based on available resources and expertise) and to identify systems that could be made operational based on their feasibility, quality and suitability. The results of this survey will also be useful for Work Package 8, "Synthesis: Pilot of a consensus mortality monitoring system", in which the proposed mortality monitoring system will be tested in selected pilot sites.

References

- 1) EURO-MOMO website (www.euromomo.eu)
- 2) Eurostat website (ec.europa.eu/eurostat)
- 3) Atlas of Eurostat "Comparability and quality improvement in European causes of death statistics in Europe (1999-2001)"
- 4) Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data

Appendix 1 – Questionnaire on existing and planned systems for the timely monitoring of excess mortality

QUESTIONNAIRE ON MORTALITY SURVEILLANCE SYSTEMS			
General Characteristics of the Mortality Surveillance System			
		Yes	No
1	Does a mortality surveillance system exist in your country? (i.e., a system for rapidly collecting data on excess mortality for the purposes of public-health surveillance, in addition to the routine collection of data on deaths which is generally performed by statistics institutes)		
2	If YES, what is the current status of this system?	Yes	No
	Active		
	Pilot phase		
	Suspended (please specify the reason)		
	Other (please specify)		
		Yes	No
3	If NO, to the best of your knowledge, is a system planned? (If a system is planned, please complete the questionnaire for the planned system)		
4	What is the name of the mortality surveillance system?		
5	What institution/organisation manages the surveillance system?		
6	What other institutions/organisations collaborate on managing the surveillance system (if any)?		
7	What institution/organisation funds the surveillance system?		
8	What are the main objectives of the system? (please describe briefly)		
9	In what year did the surveillance system begin to collect data?	Year:	
10	If historical data are collected, to what year do the earliest data refer? (e.g., a system may have begun to collect data in 2001 yet may have also asked for past data, such as that for 2000)	Year:	

11	Please specify whether data is collected on an ongoing basis or only in specific cases (such as public-health threats or certain periods of the year (please write "Ongoing", "Specific" or "Period"))		
Data Collection			
12	Who provides the data directly to the surveillance system?	Yes	No
	Civil authorities (e.g., General Registrar's Office)		
	Health authorities or facilities (e.g., hospitals, clinics, local health units)		
	Other (please specify)		
		Yes	No
13	Is it mandatory to submit mortality data to the surveillance system? (i.e., in accordance with legislation or other regulations)		
14	What is the geographic coverage of the surveillance system? <i>If your country is a Member State, please specify the NUTS level [NUTS (Nomenclature of Territorial Units for Statistics) is a European classification of territorial units for statistics in Member States].</i>		
	NUTS 1: "Gewesten/Regions" in Belgium; "Länder " in Germany; "Continte", "Região dos Açores" and "Região da Madeira" in Portugal; "Scotland, Wales, Northern Ireland" and "Government Office Regions of England" in the United Kingdom.		
	NUTS 2: "Provincies/Provinces" in Belgium; "Regierungsbezirke" in Germany; "Periferies" in Greece; "Comunidades y ciudades autonomas" in Spain; "Régions" in France; "Regions" in Ireland; "Regioni" in Italy; "Provincies" in the Netherlands; "Länder" in Austria.		
	NUTS 3: "arrondissements" in Belgium; "amtskommuner" in Denmark; "Kreise/kreisfreie Städte" in Germany; "nomoi" in Greece; "provincias" in Spain; "départements" in France; "regional authority regions" in Ireland; "provincia" in Italy; "län" in Sweden; "maakunnat/landskapen" in Finland.		
		Yes	No
	Entire country		
	Certain region(s) (if NUTS is not applicable)		
	NUTS1		
	NUTS2		
	NUTS3		
	Certain town(s)/city(ies)		
	Other (please specify)		
15	With regard to the geographic divisions indicated above, what is the total coverage of the national population (in terms of percentage)?	%:	
16	Does the system collect information on the cause of death?		
17	If YES, in addition to the underlying cause of death, does the system collect information on the following causes?	Yes	No
	Other causes resulting in the underlying		
	Other significant conditions		
	Other (please specify)		
18	Which version of the International Classification of Diseases (ICD) is used to codify the cause of death?	Yes	No
	ICD IX Revision (specify the digit level __)		
	ICD X Revision (specify the digit level __)		
	Other (please specify)		
		Indiv.	Aggr.
19	Are the data that are received by the surveillance system individual or aggregated data?		

20	For what period are the data aggregated?	Yes	No
	Daily		
	Weekly		
	Monthly		
	Other (please specify)		
21	What variables are collected?	Yes	No
	Gender		
	Age		
	Age group		
	Marital status		
	Educational level		
	Occupation		
	Date of birth		
	Date of death		
	Site of death (e.g., home, hospital)		
	Place of death (e.g., city, region, other country)		
	Place of residence		
	Nationality		
	Other (please specify)		
22	What is the smallest geographic unit to which the data received by the system refer? (see explanation of NUTS above)		
		Yes	No
	Region (If NUTS is not applicable)		
	NUTS1		
	NUTS2		
	NUTS3		
	Town/city		
	Census tract		
	Other (please specify)		
23	How are the data submitted to the surveillance system?	Yes	No
	Via a web portal		
	E-mail		
	Post		
	Other (please specify)		
24	How often are the data submitted to the surveillance system?	Yes	No
	Daily		
	Weekly		
	Monthly		
	Other (please specify)		
25	Has the delay between the date of death and the date that the data are received by the surveillance system been analysed?		

26	If YES, what are the median and the 25th and 75th percentiles of the amount of time that elapses between the date of death and the date that the data are received by the surveillance system?		
		Yes	No
27	Are other data collected together with the mortality data?		
28	If yes, what data are collected?	Yes	No
	Information on climate (e.g., maximum/minimum temperature, humidity)		
	Incidence of influenza		
	Other (please specify)		
Climate Data			
Please fill out this section if data on climate are submitted to the mortality surveillance system			
29	What data on the climate are collected?	Yes	No
	Minimum temperature		
	Maximum temperature		
	Humidity		
	Ozone and other particles		
	Other (please specify)		
30	How often are the data on climate submitted to the surveillance system?	Yes	No
	Daily		
	Weekly		
	Monthly		
	Other (please specify)		
31	What is the geographic coverage of the data on climate (see explanation of NUTS above)?	Yes	No
	Entire country		
	Certain region(s) (if NUTS is not applicable)		
	NUTS1		
	NUTS2		
	NUTS3		
	Certain towns/city(ies)		
	Other (please specify)		
32	Please describe the climate data used in the mortality surveillance system, providing any information that you feel may be useful.		
Influenza Data			
Please fill out this section if data on influenza are submitted to the mortality surveillance system			
		Yes	No

33	Are the data from the mortality surveillance system used to perform a linked analysis with the data from the European Influenza Surveillance Scheme (EISS)?		
34	Do you or your institution use the influenza data that you provide to EISS?		
35	If other systems for surveying influenza exist, please describe the system briefly.		
Data Analysis			
		Yes	No
36	Is data quality control performed?		
37	If YES, please specify at what level (e.g., locally, centrally)		
		Yes	No
38	Are the data analysed separately by sex?		
39	What measures are calculated?	Yes	No
	Only absolute values		
	Crude rates		
	Rates adjusted by gender		
	Rates adjusted by age		
	Rates adjusted by other variables (please specify)		
	Standardised Mortality Ratio (SMR) (please specify here how the expected values are calculated).		
	Other (please specify)		
40	What types of analyses are performed?	Yes	No
	Time series		
	Mathematical models taking into account other variables (e.g., environmental temperature) (please specify)		
	Mathematical models correcting for underreporting		
	Other analyses (please specify)		
	Please provide bibliographic references for the methods used		
Data Dissemination			

41	In terms of the time period, at what level of aggregation are the data produced for dissemination?	Yes	No
	Daily		
	Weekly		
	Monthly		
	Yearly		
	Other (please specify) :		
42	In terms of the geographic area, at what level of aggregation are the data produced for dissemination?	Yes	No
	National level		
	Regional level		
	NUTS1		
	NUTS2		
	NUTS3		
	Town/city level		
	Other (please specify)		
43	In what form are the data disseminated?	Yes	No
	Tables		
	Graphs		
	Other (please specify)		
44	How are the data disseminated?	Yes	No
	Public website (please provide address)		
	Restricted website (please specify restriction)		
	E-mail		
	Hard copy (e.g., publications)		
	Other (please specify)		
45	How often are the disseminated data updated? (please specify for each of the categories below)	Write frequency here (e.g., weekly, monthly)	
	Public website		
	E-mail		
	Restricted website		
	Hard copy		
	Other (please specify form of dissemination)		

Privacy			
		Yes	No
46	Are the data submitted considered to be "personal data" and thus subject to regulations or laws for protecting privacy (e.g., Data Protection Acts)? (Personal data are those regarding an identifiable person, that is, one who can be directly or indirectly identified, in particular by reference to an identification number or to factors specific to his/her physical, physiological, mental, economic, cultural, or social identity)		
47	According to current legislation in your country, can the data be sent to institutions in other countries for public-health purposes?		
48	If yes, at what level of aggregation and under what conditions?		
49	Are the data used to perform a linked analysis with data from other databases? (If YES, please specify the database).		
Functioning of the Surveillance System			
To have an idea of how well the system functions, please describe what you feel are its strong points and weak points.			
Strong points			
Weak points			

Additional Comments: (Please provide any additional information that you feel is important for a complete description of the surveillance system)

Thank you very much for your kind collaboration.

Appendix 2 - Questionnaire on the routine national-level collection of mortality data

QUESTIONNAIRE: ROUTINE SYSTEMS FOR COLLECTING MORTALITY DATA			
General Characteristics of the system			
1	Please provide here a brief description of the routine system for collecting mortality data, including a link to any existing website and attaching flowcharts		
2	Institution/organisation managing the data collection system:		
Death Certificate			
3	Is a single standardised death certificate used throughout the country? (i.e., a minimum set of variables that are collected in all areas of the country, as opposed to variables that appear with different names, formats, response categories, or allowable values). If YES please send a copy of the death certificate.	Yes	No
4	If NOT, please specify how many different types of death certificates are used and in what geographic areas (e.g., there is a different type of death certificate for each of the country's regions). <i>If your country is a Member State, please specify the NUTS level [NUTS (Nomenclature of Territorial Units for Statistics) is a European classification of territorial units for statistics in Member States].</i>		
	NUTS 1: "Gewesten/Regions" in Belgium; "Länder" in Germany; "Continente", "Região dos Açores" and "Região da Madeira" in Portugal; "Scotland, Wales, Northern Ireland" and "Government Office Regions of England" in the United Kingdom.		
	NUTS 2: "Provincies/Provinces" in Belgium; "Regierungsbezirke" in Germany; "Periferies" in Greece; "Comundidades y ciudades autonomas" in Spain; "Régions" in France; "Regions" in Ireland; "Regioni" in Italy; "Provincies" in the Netherlands; "Länder" in Austria.		
	NUTS 3: "arrondissements" in Belgium; "amtskommuner" in Denmark; "Kreise/kreisfreie Städte" in Germany; "nomoi" in Greece; "provincias" in Spain; "départements" in France; "regional authority regions" in Ireland; "provincie" in Italy; "län" in Sweden; "maakunnat/landskapen" in Finland.		
		Yes	No
	Certain region(s) (if NUTS is not applicable)		
	NUTS1		
	NUTS2		
	NUTS3		
	Other (please specify)		
5	Is there a separate perinatal death certificate?		
Data Set			
6	In what year did the surveillance system begin to collect data?	Year:	
7	Does the system collect information on the specific cause of death?	Yes	No
8	If YES, in addition to the underlying cause of death, does the system collect information on the following causes?	Yes	No

	Other causes resulting in the underlying cause		
	Other significant conditions		
	Other (please specify)		
9	At the national level, what is the percentage of all death certificates for which more than one diagnosis is reported (e.g., 90%)	%:	
10	Which version of the International Classification of Diseases (ICD) is used to codify the cause of death?	Yes	No
	ICD IX Revision (specify the digit level ___)		
	ICD X Revision (specify the digit level ___)		
	Other (please specify)		
11	Are automated procedures used to encode to the cause of death?	Yes	No
12	At what level is the code assigned to the cause of death?	Yes	No
	Locally		
	Centrally		
	Other (please specify)		
13	Do the following data appear on the dataset?	Yes	No
	Gender		
	Marital status		
	Educational level		
	Occupation		
	Date of birth		
	Date of death		
	Site of death (e.g., home, hospital)		
	Place of death (e.g., city, region)		
	Place of residence		
	Nationality		
	Other (please specify)		
14	Has the delay between the date of death and the date that the data are received by the surveillance system been analysed?	Yes	No
15	If YES, what are the median and the 25th and 75th percentiles of the amount of time that elapses between the date of death and the date that the data are received by the surveillance system?		
16	Is data quality control performed?	Yes	No
17	If YES, please specify at what level (e.g., locally, centrally)		
18	Are the data that are received by the system individual or aggregated data?	Individual	Aggregated

19	Are the data submitted considered to be "personal data" and thus subject to regulations or laws for protecting privacy (e.g., Data Protection Acts)? (Personal data are those regarding an identifiable person, that is, one who can be directly or indirectly identified, in particular by reference to an identification number or to factors specific to his/her physical, physiological, mental, economic, cultural, or social identity)	Yes	No
20	According to current legislation in your country, can the data be sent to institutions in other countries for public-health purposes?	Yes	No
21	If YES, at what level of aggregation and under what conditions?		
22	Are the data linked with other databases?	Yes	No
23	If YES, please specify:		
Data Dissemination			
24	In what year was the most recent official national report published?	Year:	
25	In the official national report, are the mortality data presented by gender?	Yes	No
26	In the official national report, are the mortality data presented by age group?		
27	In the official national report, are the mortality data presented in the form of rates?		
28	In the official national report, what is the minimum area unit used? (see explanation of NUTS above)	Yes	No
	Certain region(s) (if NUTS is not applicable)		
	NUTS1		
	NUTS2		
	NUTS3		
	Other (please specify)		
Thank you very much for your kind collaboration.			

Appendix 3 - Main characteristics of the routine collection of national mortality data, by country

Country	Standardised death certificate	Separate perinatal death certificate	First year data collected	Specific cause of death collected	Death certificates with multiple diagnoses (%)	ICD version	Automated encoding of causes of death	Data quality control	Data considered as personal data	National report			
										Year of last publication	Data presented by gender	Data presented by age group	Data expressed as rates
Austria	yes	no	1970	Yes	70	ICD X	no	yes	yes	2007	yes	yes	yes
Belgium	yes	yes	1829	yes		ICD X		yes	yes	2003	yes	yes	no
Bulgaria	yes	yes	1927			ICD X	nr	yes	yes	2007	yes	yes	yes
Cyprus	yes	no	2004	yes	78	ICD X	yes	yes	yes	2006	yes	no	yes
Czech Republic	yes	no		3		ICD X	no	yes	yes	2007	yes	yes	yes
Estonia	yes	yes		yes	60	ICD X	no	yes	yes	2008	yes	yes	yes
Finland	yes	yes	1936	yes	25	ICD X	yes	yes	yes	2006	yes	yes	yes
France	yes	no	1968	yes			yes	yes	yes	2005	yes	yes	yes
Germany		yes	1950	yes	90	ICD X	yes	yes	yes	2007	yes	yes	yes
Greece	yes	no	1956	yes	90	ICD IX	no	yes	yes	2004	yes	yes	yes
Hungary	yes	yes	1970	yes	80	ICD X	yes	yes	yes	2008	yes	yes	yes
Ireland	yes	no	1864	yes	80	ICD X	yes	yes	yes	2007	yes	yes	yes
Italy	yes	yes	1887	yes	98	ICD X	yes	yes	yes	2005	yes	yes	yes
Latvia	yes	yes	1996	yes	77	ICD X	yes	yes	yes	2007	yes	yes	yes
Lithuania		yes	1993	no	90	ICD X	no	yes	yes		yes	yes	yes

Luxembourg		yes	1963	yes	91	ICD X	yes	yes	yes	2005	yes	yes	yes
Malta	yes	no	1900	yes	82	ICD X	no	yes	no	2006	yes	yes	yes
Country	Standardised death certificate	Separate perinatal death certificate	First year data collected	Specific cause of death collected	Death certificates with multiple diagnoses (%)	ICD version	Automated encoding of causes of death	Data quality control	Data considered as personal data	Year of last publication	Data presented by gender	Data presented by age group	Data expressed as rates
Netherlands	yes	nr	1901	yes	50	ICD X	no	yes	yes		yes	yes	no
Norway	yes	yes	1951	yes	73	ICD X	yes	yes	yes	2006	yes	yes	yes
Poland	yes	no		no		ICD X	no	yes	yes	2007	yes	yes	yes
Portugal	yes	nr	1955	yes	60	ICD X	no	yes	yes	2006	yes	yes	yes
Romania	yes	no	1950	yes	91	ICD X	no	yes	yes	2008	yes	yes	yes
Slovakia	yes	yes	1993	yes	90	ICD X	no	yes	yes	2007	yes	yes	yes
Slovenia	yes	no	1985	yes		ICD X	no	yes	yes	2006	yes	yes	yes
Spain	yes	no	2004	no			nr	yes	no	2007	yes	yes	yes
Sweden	yes	no	1994	yes		ICD IX	yes	yes	yes	2008	yes	yes	yes
Switzerland	yes	no	1876	yes	83%	ICD X	no	yes	yes	2008	yes	yes	"partly yes"
Turkey	yes	no	1931	yes		ICD X	no	yes	yes	2007	yes	yes	no
UK England & Wales	yes	yes	1837	yes	76	ICD X	yes	yes	yes	2007	yes	yes	yes
UK Scotland	yes	nr	2006	no			nr	yes	no	1855	yes	yes	yes