



Work Package 5 Report

Concept: Core attributes and requirements

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Executive Summary

This report presents a conceptual perspective of what must be the characteristics of a rapid European mortality monitoring system. Such perspective was obtained from scientific literature revision, from European existing field experience on mortality monitoring systems, and from potential end-users and implementers opinions and perceptions obtained from individual questionnaires and a focus group approach, on the first case, and a 1 ½ day workshop on the second.

Literature revision showed that EuroMOMO Project objective is groundbreaking since no parallel experience was found. The closest system was the North American based on 122 cities mortality data that but EuroMOMO system seems more ambitious as it aims to be more timely and prospective. In Europe only 11 mortality monitoring systems in development were found, with nine of them pertaining to 7 countries being fully operational. Otherwise, generic mortality monitoring systems are very scarce on scientific literature most referred system are disease-specific.

The European mortality monitoring system is herein defined as being the use of a common method to monitor all-causes mortality in age stratified population to determine and report European geographical mortality patterns in a timely manner. This system should have as major functions the performance of mortality observation and of support for public health decision actions. It should have the capabilities of early detect mortality related events and of identifying the respective mortality excesses, and also allow perception of time change in mortality patterns either globally, by geographical areas and by causes of death.

System minimum requirements were set as, to have the number of all-causes deaths, to have a baseline or a model for its calculation, and to have capability to breakdown information by region, age group and sex with a weekly periodicity. The number of all-causes deaths can be collected from a sampling framework only when complete data is not available.

What separated minimum requirements at national and European levels were questions of timing and of geographic level of reporting. At national level the monitoring system should collected data daily. However, for the European level, the weekly reporting was considered sufficient. Concerning the geographical aspect breakdown at country level was considered sufficient without the need of being as fine as for national level.

Mortality monitoring system identified ideal requirements focused on the need of relating mortality with clinical history. Experts considered that there should be an

epidemiological link; there should be information about the cause of death and about the deceased clinical history.

The end-users considered that mortality monitoring system construction requires substantial investments. Investment should consider nationwide management entities, owning human resources and technology, which would be responsible for overall system management supported by a shared system of information accessible and represented by institutions that are part of the system.

Risk assessment should be performed by an evaluator group, composed of elements from various institutions. That once identified a possible risk would report it to the National Health Authority. This whole system of risk assessment (from discovery to report) should involve a rapid interconnection between institutions, via computer automations, and be performed on a daily schedule.

Integration with other information systems such as heat waves surveillance systems and influenza activity monitoring was considered important and as being an additional requirement for risk assessment. In particular end-users tended to give this great importance individually, but in group discussion it did not particularly emerge as of major importance.

All experts involved in this study identified more advantages coming from creating a mortality monitoring system than disadvantages. Advantages would be to have active health monitoring, possibility of health risks early detection, of planning and implementing strategies of control and prevention. In contrast, economic and political interests underlying the implementation of the system, and the applicability of current information or costs associated with some information ignorance were identified as potential disadvantages or threats.

It was remarkable that both groups, of end-users and implementers, coming from very distinct backgrounds gave an overall common idea of what a European rapid mortality monitoring system should be, how it should function, what it should be capable of, and what its requirements should be at country and global levels. And furthermore, their perceptions and opinions were overlapping with the currently available aspects covered by literature about mortality monitoring.

1. 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).

Having the aim of conceptually looking for several solutions on mortality monitoring on the European and country level and of defining the minimum requirements to establish a feasible European mortality system, EuroMOMO Workpackage 5 (WP 5) faced the challenge of seeking out for the relevant available information and of, eventually, take a more qualitative approach gathering opinions from several experts to fulfill its objectives.

2. Methods

In this work methodology to attain main objective consisted in the reviewing of scientific literature on mortality monitoring systems, on revision and summary of presentations performed by researchers on existing and planned mortality monitoring systems, and the conduction of ad-hoc expert panel discussions to address the issue of the concept and requirements of a European mortality monitoring system. Specifically, two different panels were consulted, one that included representatives from health and civil protection authorities and health and meteorological institutes acting as potential end-users in which a focus group approach was performed, and, the other, an international experts panel of individuals involved in mortality monitoring systems representing the implementers perspective.

3. From the literature

3.1. *General considerations*

From a generic public-health point of view several articles point out that, “good public-health decision making is dependent on reliable and timely statistics in births and

deaths (including the medical causes of deaths)” (AbouZahr et al. 2007); “accurate and timely data for mortality by age, sex, and cause both nationally and subnationally are essential for the design, implementation, monitoring, and assessment of health programmes and policies” (Hill et al. 2007). In (Begg, Rao and Lopez 2005), where interest lies on the conceptual design of sample-based mortality, states that the focus must rely on “obtaining robust age-specific and sex specific estimate of important causes of death”.

These generic perspectives set upfront very generic and optimal requirement for monitoring/surveillance mortality systems. Namely, the need to have reliable and timely mortality data with the capability of disaggregation by sex, age, national and regional levels and, even more demanding, by causes of death (or at least by important causes of death).

Another important point on what mortality information can be used for mortality surveillance is made by (Begg et al. 2005). It is advocated that to have an efficient mortality monitoring/surveillance system it is not absolutely necessary to have a mortality registration system for an entire population, a sample-based mortality will be sufficient as long as it fulfils some designs requirements: 1) includes a simple measure of uncertainty; 2) prior information on the frequency of mortality by age, sex, and cause in the population; 3) and some knowledge about which causes of death are important and at what ages. The main point here is very relevant, since to do mortality monitoring one is not required to have full registration data of the entire population, it is also feasible using a population sample. The remaining requirements seem to be very demanding, but that is because the monitoring objectives are put on whole population (country or higher), specific causes of death, and calculation of age group and sex specific mortality rates. It is reasonable to assume that if not so detailed information is aimed, for instance if only identification of unexpected mortality is of interest, without the full measuring of the change in mortality these design requirements can be relaxed or even not necessary at all.

When referring to uncertainty this later reference seems to relate to cause specific estimation problems. Two situations are referred as source of uncertainty, in a thorough system and in a sample-based system. In the first it is a question of what information is available to attribute the cause of death; in the second it is a fact resulting from not observing all the population this is mainly a classic statistical problem context and it will be generically addressed when building statistical models. From this perspective for the EuroMOMO context the uncertainty measure condition or requirement can be stated on a completely different manner: when using sample-

based mortality information system it may be of importance to know which proportion of the population (or of the mortality) is being sampled and to account for the natural statistical variation.

We assume that the work (Begg et al. 2005) is referring to an annual information system, natural adaptations are necessary when thinking of thinner information grid by month, week or other.

In the EuroMOMO context it is difficult to imagine countries without a full mortality registration system, but it is very plausible that access to that data on a timely manner may be very difficult or in some cases impossible. In such cases what this latter work says and can be adapted from it, is that a sample-based mortality system is enough as long as representativeness is guaranteed and there is prior information on sampled fraction used, frequency of mortality by age, sex, and region (region is not cited on this work, cause of death, is, I am adding region since it seems relevant for EuroMOMO) in the population and some knowledge about which causes of death are important, at what ages, in what conditions (winter, summer, etc.) and when they may affect total mortality.

3.2. Surveillance/Monitoring system attributes

We couldn't actually find a straight reference listing the attributes of a monitoring system, the closest we could find were the attributes for a surveillance system (1988, German et al. 2001).

This makes us discuss whether there is a substantial difference between a surveillance system and a monitoring system, which may establish a difference of attributes. Or even further whether the aimed system is really a monitoring system or a surveillance system.

According to Porta (Porta 2008) the definitions of Monitoring and surveillance are as follow:

Monitoring

- The intermittent performance and analysis of measurements aimed at detecting changes in the health status of populations or in the physical or social environmental. In

principle, it is different from surveillance, which is often a continuous process, although surveillance techniques are used in monitoring. It may also imply intervention in the light of observed measurements and analysis of the effect of the intervention (e.g. on the health status of a population or on an environmental compartment). The process of collecting and analyzing information about the implementation and effects of a public health program.

Surveillance

- Systematic and continuous collection, analysis, and interpretation of data, closely integrated with the timely and coherent dissemination of the results to those who have the right to know so that action can be taken. It is an essential feature of epidemiological and public health practice. The final phase in surveillance chain is the application of information to health promotion and to disease prevention and control. A surveillance system includes a functional capacity for data collection, analysis, and dissemination linked to public health programs. It is often distinguished from monitoring by the notion that surveillance is continuous and ongoing, whereas monitoring tends to be more intermittent or episodic.
- Continuous analysis, interpretation and feedback of systematically collected data, generally using methods distinguished by their practicality than, uniformity, and rapidity than by accuracy or completeness. By observing trends in time, place, and persons, changes can be observed or anticipated and appropriated action, including investigative or control measures, can be taken. Thus they may include mortality and morbidity reports based on death certificates, hospital records, general practice sentinels, or notifications; laboratory diagnoses; outbreak reports; vaccine uptake and side effects; sickness absence records; changes in disease agents, vectors, or reservoirs; serological surveillance through serum banks. The latter can also be seen as an example of biological monitoring.

The presented monitoring definition implies directly an irregular execution of analysis to detect changes in health status, in which the observed results can generate an intervention. This definition goes the length of clarifying that its difference to surveillance is that this later one is a continuous and ongoing process while monitoring tends to be episodic, but that techniques used in both processes are similar.

The surveillance definition clarifies that it is meant to be a regular and continuous process of data collection, analysis, interpretation and timely dissemination of results to promote action, public health action we might add.

So the question to be addressed is still the same, is the intended EuroMOMO project mortality system really a monitoring system or a surveillance system?

If the aim of the project system is to have a systematic and continuous collection of data, analysis to detect unexpected mortality changes and the regular issue of bulletins and flagging of abnormal situations for public health action purposes, it is in fact a surveillance system.

The only argument for the EuroMOMO project aimed system to be a really monitoring system is that it will only irregularly flag unusual mortality events that will require public health action. Otherwise, all arguments seem to be against it. Data collection, analysis and dissemination is regular and ongoing and there is no particular health program being implemented requiring the project monitoring.

In the light of this discussion, independently of what name is used for the system, what is here relevant is that its attributes must be those of a surveillance system.

The attributes of a surveillance system are *simplicity, flexibility, acceptability, sensitivity, predictive value positive, representativeness*, and *timeliness* (1988); advances in health informatics originated the additional attributes of *data quality* and *stability* (German et al. 2001).

The attributes

- **Simplicity** - refers to both its structure and ease of operation. It may be useful to think of the simplicity of a surveillance system from two perspectives: the design of the system and the size of the system. Simplicity is closely related to timeliness and will affect the amount of resources that are required to operate the system.

- **Flexibility** - adaptation to changing information needs or operating conditions with little additional cost in time, personnel, or allocated funds. Flexible systems can accommodate, for example, new diseases and health conditions, changes in case definitions, and variations in reporting sources. Flexibility is probably best judged retrospectively, by observing how a system responded to a new demand. Generally, simpler systems will be more flexible-fewer components will need to be modified when adapting the system for use with another disease.
- **Data quality** - reflects the completeness and validity of the data recorded in the public health surveillance system. Examining the percentage of "unknown" or "blank" responses to items on surveillance forms is a straightforward and easy measure of data quality. However, a full assessment of the completeness and validity of the system's data might require a special study. Data values recorded in the surveillance system can be compared to "true" values through, for example, a review of sampled data, a special record linkage, or patient interview. In addition, the calculation of sensitivity and predictive value positive for the system's data fields might be useful in assessing data quality. Quality of data is influenced by the performance of the screening and diagnostic tests (i.e., the case definition) for the health-related event, the clarity of hardcopy or electronic surveillance forms, the quality of training and supervision of persons who complete these surveillance forms, and the care exercised in data management. A review of these facets of a public health surveillance system provides an indirect measure of data quality.
- **Acceptability** - reflects the willingness of individuals and organizations to participate in the surveillance system. Acceptability is a largely subjective attribute that encompasses the willingness of persons on whom the system depends to provide accurate, consistent, complete, and timely data.
- **Sensitivity** - the ability of a system to detect a health event. The sensitivity of a surveillance system can be considered on two levels. First, at the level of case reporting, the proportion of cases of a disease or health condition detected by the surveillance system can be evaluated. Second, the system can be evaluated for its ability to detect epidemics. A surveillance system that does not have high sensitivity can still be useful in monitoring trends, as long as the sensitivity remains reasonably constant. Questions concerning sensitivity in surveillance systems most commonly arise when changes in disease occurrence are noted.

A search for such surveillance "artifacts" is often an initial step in outbreak investigations.

- **Predictive value positive (PVP)** - is the proportion of persons identified as having cases who actually do have the condition under surveillance. In assessing PVP, primary emphasis is placed on the confirmation of cases reported through the surveillance system. Its effect on the use of public health resources can be considered on two levels. At the level of an individual case, PVP affects the amount of resources used for case investigations. A surveillance system with low PVP-and therefore frequent "false-positive" case reports-would lead to wasted resources. The other level is that of detection of epidemics. A high rate of erroneous case reports may trigger an inappropriate outbreak investigation. Therefore, the proportion of epidemics identified by the surveillance system that are true epidemics is needed to assess this attribute. The PVP for a health event is closely related to the clarity and specificity of the case definition. The PVP reflects the sensitivity and specificity of the case definition and the prevalence of the condition in the population. The PVP increases with increasing specificity and prevalence.
- **Representativeness** - is the capability to accurately describing a) the occurrence of a health event over time and b) its distribution in the population by place and person. Representativeness is assessed by comparing the characteristics of reported events to all such actual events. Although the latter information is generally not known, some judgment of the representativeness of surveillance data is possible. Quality of data is an important part of representativeness. In order to generalize findings from surveillance data to the population at large, the data from a surveillance system should reflect the population characteristics that are important to the goals and objectives of that system. These characteristics generally relate to time, place, and person. An important result of evaluating the representativeness of a surveillance system is the identification of population subgroups that may be systematically excluded from the reporting system. This process allows appropriate modification of data collection and more accurate projection of incidence of the health event in the target population.
- **Timeliness** - reflects the speed or delay between steps in a surveillance system. The interval usually considered first is the amount of time between the onset of an adverse health event and the report of the event to the public health agency responsible for instituting control and prevention measures. Another aspect of

timeliness is the time required for the identification of trends, outbreaks, or the effect of control measures. With acute diseases, the onset of symptoms is usually used. Sometimes the date of exposure is used. With chronic diseases, it may be more useful to look at elapsed time from diagnosis rather than to estimate an onset date. The timeliness of a surveillance system should be evaluated in terms of availability of information for disease control; either for immediate control efforts or for long-term program planning. The need for rapidity of response in a surveillance system depends on the nature of the public health problem under surveillance and the objectives of that system.

- **Stability** - refers to the reliability (i.e., the ability to collect, manage, and provide data properly without failure) and availability (the ability to be operational when it is needed) of the public health surveillance system. A stable performance is crucial to the viability of the surveillance system. Unreliable and unavailable surveillance systems can delay or prevent necessary public health action. A more formal assessment of the system's stability could be made through modeling procedures. However, a more useful approach might involve assessing stability based on the purpose and objectives of the system.

Notes

- The attributes and costs of a surveillance system are interdependent.
- Efforts to increase sensitivity, PVP, timeliness, and representativeness tend to increase the cost of a surveillance system, although savings in efficiency with automation may offset some of these costs.
- As sensitivity and PVP approach 100%, a surveillance system is more likely to be representative of the population being monitored. However, as sensitivity increases, PVP may decrease. Efforts to increase sensitivity and PVP tend to make a surveillance system more complex - potentially decreasing its acceptability, timeliness, and flexibility.
- The acceptability and representativeness of a public health surveillance system are related to data quality. With data of high quality, the system can be accepted by those who participate in it. In addition, the system can accurately represent the health-related event under surveillance.

3.3. Consideration based on existing specific monitoring mortality systems

When searching for scientific literature on mortality monitoring systems a frequently cited reference is the 1998 paper on a sample-based mortality data system developed in the USA (Baron et al. 1988). This mortality system gathered information on all-causes and Pneumonia and Influenza (P&I) mortality from 121 cities and aimed to study its adequacy of mortality surveillance for epidemiological studies. This system receives weekly reports of mortality (from the previous week) due to all causes and to pneumonia and influenza collected from each city mailed to the CDC. Reports include aggregated numbers of deaths by all-causes and P&I and by age group; these include registration of death of people who do not live in the area but died there, and excludes people living in the area but died elsewhere.

The results indicated that the data collected by the system 121 cities, had overall interesting features and some limitations but produced timely data with interest for epidemiological studies. As a great strength it allowed to correctly estimate mortality rates trends. On the limitations side it revealed to be sensitive on elder P&I fluctuating mortality rates, biases generating higher P&I rates and underestimated declining behaviors in mortality rates by age groups.

Characteristics of the surveillance system:

- Sample-Based Mortality System
- Simple
- Aggregated information
- Total mortality, P&I related mortality
- Age group
- Aimed at mortality specific rates

The existence of the North American 121 cities mortality reporting system coordinated by CDC gave way and opportunity to the creation of several timely monitoring systems. One successful of such system was created for the assessment of influenza related mortality (Simonsen et al. 1997a), which was only natural since part of the collected information was on P&I related deaths.

A main point that comes straight forward in this article is that, then, in 1997, excess mortality rates were not timely because national vital statistics would take two to three years to become available (as in most countries). Therefore the use of rapid mortality systems as the mentioned is a solid alternative data source for assessing influenza severity.

Influenza associated excess mortality is defined as traditionally being the number of deaths above a baseline during an influenza epidemic period. In this article mortality baselines were established using cyclical regression models.

The best models and their excesses were compared with results obtained from the national data. The best indicator that resulted was the total of deaths from P&I (best model, greater sensitivity in detection of epidemic weeks).

Information obtained through the system of 122 cities correlated well with national estimates in 90% of the epidemic periods studied.

A European experience on a mortality surveillance system was recently reported the Lancet (Sartorius et al. 2006). The objective of that paper was the description of surveillance system mortality on a weekly basis in Sweden.

Information entered in the system:

- Mortality from all causes present in death certificate
- disaggregated by sex, age groups and municipalities of Sweden
- Aggregation of information per week

The death certificates were transferred electronically to the Institute for Infectious Disease Control Swedish weekly basis with a delay of 2 weeks. The transferred data are: ID, age, and sex, date of death and address (the latter since 2004)

The system was implemented retrospectively to detect outbreaks of deaths by age group and municipality. The aim was to create a system of surveillance (early warning system) that would alert to situations of outbreaks of deaths by age, sex and municipalities.

It was set to be an early warning system for age groups and municipalities.

Detection algorithm based on a threshold. The groups in question are: <1, 1-24, 25-44, 45-64, > = 65 equal to those used by the system of 121 American cities.

Early warning system for municipalities:

Step 1: Calculation of the average mortality rate per week and age group (those above) using the entire population, with data collected since 1992 by the end of 2003.

Step 2: Determination of SMR using annual data from 1998-2004 (see more detail on Page 183)

Due to insufficiency of data at the geographical level the used algorithm adopted the Poisson distribution adjusting for municipalities with higher mortality rates.

The system justification built on the US mortality surveillance maintained by the CDC, described above, stating that the routine surveillance of mortality from civil registration data can provide early insights into trends or other remarkable at diverse population or geographical levels; also stated was the fact that weekly mortality data can be used to complement information linked to morbidity or other sources. This system description didn't include further evaluation of its performance.

An interesting technical approach to establish generic monitoring systems for public health purposes was published in 1999 (Williamson and Weatherby Hudson 1999). The global objective of these systems was a description of a monitoring system to statistically "flag" changes of disease (increase or decrease) to promote measures that will avoid increase disease and mortality events. The system seeks to identify aberrations in data from public health surveillance reports.

In this paper several ideas are interesting though the presented work does not directly relate with mortality event. First it defines as objective the detection of aberrations that are defined as statistically significant departures in the occurrences of a health event from what is expected based on the historical incidence of the event. Second it advocates the importance of using statistical modeling to give insight of disease patterns, citing examples that go back to 1840 and to epidemiology iconic William Farr. And, third, it proposes a two step statistical analysis consisting of 1) Box-Jenkins/ARIMA Modeling to model data and 2) the use of Statistical Process Control Charts to detect departures from expected.

Thought this work focus on weekly aggregated data for several diseases the principle is clearly extensible to mortality data.

The paper accounts for the problem of having a 53rd week, in approximately each 6 years, which was solved averaging data of 52nd and 53rd weeks when these later ones occur.

The US Centre for Disease Control and Prevention (CDC) uses a 7-component national surveillance system for influenza that includes virologic, influenza-like illness, hospitalization, and mortality data.(Thompson, Comanor and Shay 2006) This surveillance system components, which collect and report (on a weekly basis), influenza activity in relation to:

- a) Location and growth of virus activity
- b) Definition of types and strains of virus circulating
- c) Detection of antigenic changes of circulating virus
- d) Monitoring the evolution of ILI (influenza-like syndrome)
- e) Determination of rates of hospitalization associated with influenza in children
- f) Determination of mortality rates associated with influenza

According to the authors of this surveillance system, it needs information disaggregated by age group to implement vaccination programs and medication. Due to increased life expectancy it is also important to keep records of the population, particularly the elderly, as the evolution of mortality should be based on the rate indicator not only of total deaths It is necessary to define baselines or other method for determination of excess, this definition is so much better the longer the history..

Table 1 has a summary of the various models, requirements and limitations for application of the model and results for the USA (adapted from (Thompson et al. 2006))

Table 1. Summary of the models, respective requirements and limitations for estimating influenza impact in the USA

Year [reference]	Technique	Requirements and limitations	Appropriate application
1963 (Serfling 1963)	Linear regression	<ul style="list-style-type: none"> • Baseline data required; • viral surveillance data not required 	Temperate countries; influenza epidemics; influenza pandemics
1997 (Simonsen et al. 1997b)	Linear regression	<ul style="list-style-type: none"> • 5 years of baseline data required; • viral surveillance data not required 	Temperate countries; influenza epidemics; influenza pandemics
2003 (Thompson et al. 2003)	Poisson regression	<ul style="list-style-type: none"> • viral surveillance data incorporated; • type- and subtype-specific estimates provided; • circulation of RSV controlled for; • cannot be used for pandemics 	Temperate countries; influenza epidemics
2005 (Simonsen et al. 2005)	Linear regression	<ul style="list-style-type: none"> • viral data not required 	Temperate countries; influenza epidemics; influenza pandemics

1980 (Barker and Mullooly 1980)	Influenza period rate; winter season baseline rate	<ul style="list-style-type: none"> viral data not required; defining seasons as “influenza free” required; difficulty in identifying seasons with no influenza activity 	Any country; influenza epidemics; influenza pandemics
2000 (Izurieta et al. 2000)	Influenza period rate; peri-season baseline rate	<ul style="list-style-type: none"> peri-season baseline rate when influenza is not circulating defined and required 	Any country; influenza pandemics
2000 (Izurieta et al. 2000)	Influenza period rate; summer season baseline rate	<ul style="list-style-type: none"> summer season baseline rate when influenza is not circulating defined and required 	Any country; Influenza pandemics

On the 2008-9 influenza seasonal epidemic period a fairly high activity was registered in Europe (Goddard et al. 2009). Early activity was registered in Portugal that lasted for several weeks, increase in mortality was observed in the Portuguese Daily Monitoring system (VDM – *Vigilância Diária da Mortalidade*) that allowed to obtain rapid estimated this event excess mortality. In fact an estimate of 1,961 excess deaths was obtained, with approximately 82% of these occurring in the age group of 75 years and older (Nogueira et al. 2009). This estimates were obtained using slightly over of two years of data and cyclical regression models (a subset of trigonometric regression models (Galbraith 2005)) excluding known periods of heat periods and influenza increased activity.

This showed the importance of having a rapid mortality monitoring system on one hand. On the other hand, it generated some confusing information on the social communication and health channels, which were not used to have such information on such a timely manner, perceiving this as a very unusual event or a threat. But this corresponded just to an average influenza related mortality event in Portugal.

Several specific disease oriented surveillance system exist some with high complexity that aim several ambitious objectives. A generic frame work of such systems is given in a 2005 paper on cancer surveillance (Wingo et al. 2005).The objective of this paper was to set a framework for monitoring system cancers in the USA.

The proposed system includes surveillance from the healthy population by the end of life: primary prevention (healthy population), secondary (new diagnoses of cancer), and tertiary prevention (treatment, living with and end of life due to cancer).

For this, is necessary information on: a description of "heavy" burden of disease at national, regional, in the states and communities. Further action is race, ethnicity, socioeconomic status and cultural costs, individual factors, social and biological.

The collection of data routinely has limitations and confidentiality issues, limitations of infrastructure, human resources and expensive statistical precision (especially in geographic areas and small population subgroups).

- In this paper, are summarized the systems that provide data on risk factors and healthy population (primary prevention) systems, data for incidence of cancer (secondary prevention) and treatment, living with and end of life due to cancer (prevention tertiary). Also, the current sources for each of these systems and their limitations and challenges are identified.
- The authors described the actions necessary for cancer surveillance, temporal spectrum of its application and level of difficulty of the operation. According to them, considerable effort should be made on data collection, statistical analysis, human resources and cancer patient care and survivorship areas. Concerning data collection, the main difficulties are expected on “integrating information technology into current systems to improve the completeness, timeliness and quality of reporting and to facilitate the transition from paper to electronic medical records; developing innovative approaches for collecting information about socioeconomic status and measuring disparities in health outcomes and collecting and making available data for cities and local communities, including persons from special populations and medically underserved populations”.

Given the complexity of the systems described, it being a specific disease system, and knowing that these systems have relevant limitations (Izquierdo and Schoenbach 2000) it does not seem relevant for a global monitoring system of all cause mortality. However in the long term, if these disease specific surveillance systems produce relevant information on incidence and incidence trends they might generate relevant data, information and knowledge to model or to improve modeling for mortality baselines.

3.4. *Towards measurement of monitoring system cost effectiveness*

In the scientific literature a very scarce number of articles was found focusing mortality monitoring system directly and none was collected considering such systems' quality and cost effectiveness.

An interesting example of evaluation of a disease specific monitoring, in particular heart disease monitoring, which attempts to measure its costs and benefits (Perry et

al. 2000). In this case an option appraisal design was used to meet the proposed objective. The evaluation procedure considered a review of existing datasets and relevant reports, specification of option, definition and weighting of benefit criteria by key stakeholders, assessment of options by experts, and costs of options. Assessments were performed by 33 stakeholders and 13 experts

Benefits criteria used in weighting and scores considered four dimensions: service utilization, Epidemiology, measuring effectiveness and outcomes and system quality. For the purpose of evaluating an overall mortality monitoring system most of these dimensions do not seem to make sense. The only dimension that made complete sense was “system quality”. This later criteria dimension considered three items: **Compatibility for international comparisons** – stated as ability to adhere to recognized specifications of surveys, diagnoses, or data interpretation that can allow comparison with similar statistics collected elsewhere; **Breadth of coverage** – Ability to gather information that takes into account geographical and demographic differences between communities; **Frequency** – Capability to conduct trend analysis from regular data collection and regularity with which surveys and analysis are performed or disseminated.

3.5. A conceptual framework for evaluating cause-of-death statistics: an example

Departing from the importance of cause-of-death to public health planning and the statement that Civil Registration systems are the main source of such information when in conjunction with medical certification and that quality of all these components must be guaranteed (AbouZahr et al. 2007), an interesting definition of a conceptual approach and respective application was done for the Chinese case (Rao et al. 2005).

This later article states that “although many countries invest considerable resources in the establishment and maintenance of systems to monitor the levels, patterns and causes of mortality” there was no “accepted framework to assess” such information, so it goes the length of proposing one.

This framework recommends that the following criteria should be considered.

- Generalizability (representativeness of statistics with respect to the respective population):

- Coverage (what sectors of the population are included or excluded, particularly relevant for sample-based systems);
 - Completeness.
- Reliability (how consistent is the data with respect to epidemiological expectations):
 - Consistency of cause patterns with general levels of mortality;
 - Consistency of cause-specific mortality rates over time (e.g. over 5 years).
- Validity (evaluate data quality):
 - Content validity;
 - Use of ill-defined categories and codes;
 - Incorrect or improbable age or sex dependency.
- Policy relevance:
 - Timeliness;
 - Geographical disaggregation.

Obviously, although justification for development includes needs for monitoring of levels and patterns of mortality, this framework is focused in cause-of-death statistic evaluation (which is clear up-front). Therefore some within criteria items need to be rephrased for a more generic framework.

For example, Validity criterion was completely put on cause-of-death codification terms, but generic principles apply and can be reformulated.

Policy relevance is a worth considering criterion because it actually is a basic reason for these monitoring systems existence. This criterion includes the Item Timeliness which is obviously completely relevant, it is however noteworthy to look at the definition used in this article: “data on causes of death that are more than, say 2 years out of date rapidly lose their relevance for policy programmes purposes”. This means that there might be some situations in which a timeframe of two year may be of relevance

but obviously within current objectives of mortality monitoring systems such is not the case.

4. Early EuroMOMO Project Contribution

EuroMOMO project initial activities included plenary sessions where, project associated partners, and invited institutions or experts could present their experiences on mortality monitoring or specific disease monitoring systems that related to mortality.

4.1. *Initial Information*

The several presentations held under the EuroMOMO meeting generated information on eleven existing or developing mortality monitoring systems across Europe (originated from nine European countries).

Table 2 and Table 3 below are a summary on the information gathered on those mortality monitoring systems.

The available information was:

- 6 systems collected data daily; 1 system collected data monthly; and remaining systems collected data on a weekly basis;
- 4 systems collected data on the date of death; one of these being the English system that also cited the date of registration making it unclear whether it was a mixed system or not;
- No system reported to treat the special issue of the existence of a 53rd week of the year; this was not an issue for the daily systems;
- Only two system (FR and PT) had daily analysis of mortality data; Only Switzerland system reported to do the weekly analysis on a fixed day – Wednesday;
- Only 5 systems referred an estimation of delay on data collection with these presenting very different ranges;
- Only two Systems (BE and PT) referred to aim at 100% of the country mortality; five other systems (of three countries) referred to be based on sampled mortality information; for the remaining systems and countries this information was not available;

- 5 systems disclosed how information was submitted, these included e-mail, fax and web-portal; for the remaining system this information was unclear;
- In what concerned variables included with the mortality monitoring system:
 - 9 referred to collect some information on age;
 - 8 referred to information about gender;
 - About 5 systems referred to collect information on residence and place of death; Portugal reported to guarantee only information on region of death registration;
 - Only one system (one from Italy) reported to obtain information on the local (home, hospital, etc.) of death;
 - Only one system (one from Italy) reported to collected information on weather (temperature) and Influenza activity; the Portuguese system didn't report this kind of data but was linked to it through existing specific disease/event related surveillance system *ICARO* (for Heatwaves) and *Rede Médicos-Sentinela* [GP Sentinel Network] (for influenza activity).
 - 4 systems referred specific statistical methodologies ranging from CUSUM charts, Regression models, ARIMA models, Poisson loglinear models, etc.; Apart from Belgium system, those referring specific methodologies were more "in development" systems that implemented and stable mortality monitoring systems.
- As sources of data these systems altogether referred:
 - National mortality registration system/ Ministry of Justice;
 - Meteorology Institutes/ Offices;
 - General practitioners networks;
 - Environment departments;
 - Emergency departments;
 - City halls;
 - National Statistics offices.

Table 2. Summary of available information on existing or in development mortality systems in Europe

Country	Belgium	France	France2 (WP5)	England
Time				
Date of registration or date of death	R	D	D	R and D
Regularity of the collect	Weekly	Daily	Daily	Weekly
Definition of week, Monday to Sunday	Not known	Not known	Y	Y
Weekly analysis - fixed weekday or rolling window	Not known	Not known	every morning	Not known
Including week 53	Not known	Not known		Not known
Delay known	85% after 2 weeks and 95% after 4 weeks	50% by 3 d; 90% by 7d; 95% by 10 d	50% by 3 d; 90% by 7d; 95% by 10 d	Not known
All country or a sample?	all population	1042 cities	1042 cities	Not known
Does the system collect information on the cause of death?		Y	Y	Y
How are the data submitted to the surveillance system?		e-death certificate: next step	webportal (2%)	
Variables part of routine monitoring				
Age	Y	Y	Y	Not known
Gender	Y	Y	Y	Not known
Temperature	N	N	N	Not known
Influenza	N	N	N	Not known
Underlying population	N	N	N	Not known
Date of death	Y	Y	N	Not known
Date of death registration	N	Y	N	Not known
Nationality	Y	Y	N	Not known
Place of residence	Y	Y	Y	Not known
Place of death (city, region, country, ...)	Y	N	Y	Not known
Site of death (home, hospital...)	N	N	N	
Model				
CUSUM	N	Not known		N
Regression model	Y	Not known		N
Seasonal Auto-Regressive Moving Average model	Y	Not known		N
Poisson log-linear regression model	N	Not known		Y
Intra-class Correlation coefficient	N	Not known		Y
Log transform				
Sources				
	National Mortality Registration System	Emergency departments		Office for National Statistics
	Meteorology Institute	GP's emergency association		Met Office
	General Practitioners Network	Civil status (city hall)		
	Environment Department			

Table 3. Summary of available information on existing or in development mortality systems in Europe (continuation)

Country	Denmark	Portugal	Spain	Sweden	Italy	Italy 2	Switzerland
Time							
Date of registration or date of death		D	R				
Regularity of the collect	Weekly	Daily	Daily	Daily	Daily	Monthly	Weekly
Definition of week, Monday to Sunday		NA	Y				
Weekly analysis - fixed weekday or rolling window		Daily	Not Known				Wednesday
Including week 53		NA	Not Known				
Delay known		1-2 days	Not Known		100% by 3 d		
All country or a sample?		100%	62% of all population in 2008		Regional capital cities	16%	
Does the system collect information on the cause of death?		N	N	Y	N	N	
How are the data submitted to the surveillance system?		email			email, fax	e-mail	
Variables part of routine monitoring							
Age		Y	Y	Y	Y	Y	Y
Gender		Y	Y	Y	Y	Y	
Temperature		N (other system)		N	Y	N	
Influenza		N (other system)		N	N	N	
Underlying population		N		N	N	N	
Date of death		Y		Y	Y	Y	
Date of death registration		Y		N	Y	N	
Nationality		N		N	N	N	
Place of residence		N		N	Y	Y	
Place of death (city, region, country, ...)		N (of D Registr)		Y	Y	Y	
Site of death (home, hospital...)		N		N	Y	N	
Model							
CUSUM	Y	N	Y				Swiss Office for Public Health
Regression model	Y	N	Y				Statistical Office
Seasonal Auto-Regressive Moving Average model	N	N					
Poisson log-linear regression model	N	N					Y
Intra-class Correlation coefficient	N	N					
Log transform	Y	N	Y				
Sources							
		Ministry of justice	National Institute of Statistics				
			Ministry of justice				
			National Institute of Meteorology				

5. EuroMOMO WP4 - Inventory of the Existing Mortality Monitoring Systems in Europe

EuroMOMO Project WP4 was interested in the availability on existing systems for the timely monitoring of excess mortality which was considered important for the project (Conti et al. 2009). Two main reasons were pointed out

- Methodologies used by different existing systems could give hints and knowledge on what model could be developed on a European level;
- Knowledge of existing systems' mortality data collection could help determining of resources needed in countries without mortality monitoring systems.

Therefore, the objectives of the WP4 were

- The mapping of existing and planned system for collecting mortality data for rapid public-health surveillance, and
- The identification and description of mortality data routine collection procedures.
- Methodology used consisted of two questionnaires surveys.

Results

Existing systems for timely monitoring of excess mortality

32 countries were surveyed; complete information for 28 countries was obtained on existing and planned systems for timely monitoring of excess mortality. From these seven countries (Belgium, France, Germany, Italy, Portugal, Spain, and Switzerland) reported having at least one mortality system, with France and Italy reporting having two of such systems. Altogether nine mortality surveillance systems were enrolled.

Additionally, 9 countries reported having developed or having plans to develop mortality surveillance systems. All these identified systems are managed by national health institutes. Six systems were in pilot phase (Danmark, Germany (Berlin),

Hungary, Ireland, Netherlands, and Scotland), and three in planning phase (Greece, Sweden and United Kingdom).

General characteristics of the systems

The existing systems objectives agreed with EuroMOMO project main objective. Some of the existing system objectives mentioned the specific keywords “real-time”, “rapid”, “early” or “timely”.

All existing systems were all recent ranging their operationalization from 2003 to 2006. Some systems included fairly long series of historical data.

Data collection

Geographical coverage varied widely across countries. But more the half of the countries reported full country coverage, some countries reported NUTS 2 coverage capabilities, with Spain pointing out the capability of monitoring mortality by NUTS3, “certain towns/cities” and “climate zones”, and the Italian cites reporting only for capital cities of the country 21 regions.

System coverage of data (completeness) was reported as complete for three of the nine systems and ranging from 1% to 57% on the remaining systems, with the special case of Germany that is a regional system accounting for 7% of the whole country mortality.

Cause of death

Only two systems, from France, report cause of death using ICD-10th revision. These systems were designed to this end.

Data level

All systems collect data on the individual level. The respective information included indication of age at the time of death (age, age group or date of birth), gender and some indication on localization of death. Only three systems include information on the site of death, like at home or hospital.

Timeliness

The surveyed systems were considered rapid; that were reported as having a median time of 3 days to include mortality information in the system with a range varying from 4 hours to 10 days.

Other variables

Inclusion of variables related with climate and influenza activity were surveyed. Most rapid mortality surveillance systems reported to collect data on climate (7 out of 9) and (4 out of 9) reported to collect data on influenza. The Portuguese system that is not included in either of both categories, since it does not collect that data on its own, but it is linked to existing surveillance system for influenza and for extreme climate events.

Data Analysis

Most systems perform data quality control (6 out of 9).

Analysis if performed by gender (6 out of 9).

Most system produce absolute values (5 out of 9), Belgium produces crude rates and France crude rated adjust by age.

Time series models were reported by 4 systems, some including additional mathematical modeling of several different kinds.

Data dissemination

Dissemination ranged from daily to yearly. And it was mainly done by e-mail or website. France and Switzerland reported dissemination by hard copy reports.

Privacy

Five systems collect personal data but are not authorized to use it.

Main conclusions

- WP4 results revealed that **only 9 completely functional systems** for the timely monitoring of mortality are currently operational in Europe, representing only 7 countries of the 32 surveyed, with all the existing systems located in Western Europe.

- All operational systems but one are **managed by either a health institute or a statistics institute**
- **Two fundamental characteristics** of a rapid mortality monitoring system are **timeliness** with which data are collected and **coverage**.
- **Timeliness range from 4 hours to 10 days with a median time of 3 days**, but the most timely system only covered 1% of its country population
- **Only 3 systems reported 100% of country mortality coverage**, and next highest coverage was 57%

Other relevant points raised by WP4 Report

- EuroMOMO project **must discuss improving and maintain high coverage** balancing both coverage and timeliness
- **Concerns** were stated related with the fact of only about half of the existing **systems collecting data on influenza and climatic data**
- **Privacy** of individuals' mortality **must be enforced** at the European level

6. End-Users Experts' focus group on minimum requirements for a European Mortality Monitoring System

6.1. Methodology

When wanting to have the perspective of potential end-users of a mortality monitoring system, it was necessary to use a qualitative methodology, by forming a focus group. This technique of data collection, used mainly in the social sciences and humanities, is the use of group interaction as a means of generating data exploration and identification of different positions on a given subject, object or product / service (Flick 2002).

If the qualitative methods have the advantage of getting an intensive analysis, "both in breadth and in depth" in order to "get a broad understanding of the phenomenon in its entirety," also has the disadvantage of the inability to generalize, or "Standardization is not conducive to excessive dependence on the capacity and the personal equation of the investigator" (Lima 1987).

Aware of these drawbacks, we resorted to other complementary source that enabled us to get some regularities in the context of quality, by applying an individual questionnaire administered at the beginning of the session.

The use of focus group had a varied group of experts from multiple Portuguese institutions, which joined both people with experience of a national surveillance system of mortality, as individuals who have never had any contact with this type of system, but that may benefit from this type of system. Thus, were invited to the workshop representatives of Health Authorities (national and regional), Civil Protection Authorities (also national and district) and representatives of the National Institute of Health and the Institute of Meteorology. For the workshop were invited experts from 12 institutions, having appeared 14 individuals representing eight of them.

Taking into account the first phase of the workshop groups, and to allow better management, two groups were organized. The distribution of experts in each of the groups was made aiming at achieving maximum diversity with regard to the institution of origin, professional area, and previous knowledge of a mortality surveillance system.

Table 4. Focus groups constitution

Institution	Group 1	Group 2	Number of people with knowledge or involvement in a mortality monitoring system
General Directorate of Health (DGS)	1	1	1
3 Regional Health Administrations (North, Centre, Lisbon)	3	3	2
National health Institute – Epidemiology department (DEP/INSA)	2	-	1
National Civil Protection Authority (ANPC)	1	1	1
Meteorology Institute (IM)	1	1	1
Municipal Civil Protection (Lisbon)	-	1	0

The workshop took place on April 22, 2010 at INSA (Lisbon), between 10.00 and 17.30.

The session resulted from preparatory organization work where participants were *a priori* distributed in two groups in order to obtain the heterogeneity of member profiles. Furthermore, the workshop was grounded on a set of analysis grids, which allowed collecting the data necessary to identify the key features and characteristics of a rapid mortality monitoring system. These analysis axis constituted guidelines for the moderation of subgroups at the end and allowed the systematization of the results obtained for each subgroup.

Each subgroup had an element which acted as moderator (also chosen beforehand). Its role was to facilitate the subgroup work and guiding the discussions, according to the analysis grids previously built.

After individual presentation of each participant and explanation of the purpose of the study group, two elements were asked to voluntarily play specific roles in the session. One element to take notes of main conclusions of the subgroup discussion (filling grids prepared beforehand), and a second element with the role of rapporteur at the end of the session (plenary discussion).

Before the subgroups session, each participant was asked to fill in an individual questionnaire, which aimed to define the minimum and desirable in a mortality surveillance system, through which it sought to identify eight areas:

1. Nature of data collected by the surveillance system of mortality;
2. The relationship between the monitoring system and data from death certificate;
3. The communication process of notification of death to the monitoring system to be developed;
4. Regularity in reporting of deaths to the surveillance system;
5. Sampling mode to set (census or sample basis);
6. System of procedures to be established for ensuring the quality of system data;
7. Recommendations proposed for the analysis of climate data and
8. Recommendations for the analysis of data on influenza activity.

It was understood by *minimum requirements* features or services that are necessary condition for the existence of the mortality monitoring system (without which there is no system) and as a *desirable requirements* characteristics or necessary conditions for achieving an ideal surveillance system.

Group discussion

The discussion of the working group aimed to identify and rank the features and characteristics of a rapid mortality monitoring system, with a range of health professionals or civil protection agents and potential partners and / or users. Its contribution was an asset in identifying a set of analytic categories defined a priori:

1. Attributes and functions.

It was understood by system attributes, the set of items that are characterize it and as functions the small set of ideas that guide the objectives and services provided by the system. For example:

- The attributes of a surveillance system are simplicity, flexibility, acceptability, sensitivity, positive predictive value, representativeness, and timeliness, advances in information technology in health led to the additional attributes of data quality and stability.
- Public health is recognized as being established around three basic functions and 10 essential services. These functions are c1) evaluation, c2) security [assurance] and c3) policy development.

2. Capabilities

It was understood by the system's capabilities, all essential services that it should be able to provide its users.

3. Advantages and Disadvantages

Tried to simply scan which set of advantages and disadvantages that prospective users foresaw the existence of a surveillance system for mortality in both national and European context.

4. Investment / plausible cost

We sought to evaluate the potential costs of implementing a surveillance system and have an understanding to what extent their different possible end users perceived as credible in the investment (s) system (s).

5. Strengths / applications

We looked up for any set of potential services based on the mortality monitoring system(s) created beyond those that define their essential functions that could be envisaged by the end-users the existence.

6. Importance

We sought to evaluate the importance that potential end users attributed to the existence of systems for monitoring mortality.

7. Risk assessment

Sought to know how the potential end users of surveillance systems advocate of mortality that should be made to risk assessment and communication.

Being this work session part of EuroMOMO project which aims to establish a system of rapid monitoring of mortality at European level, and that such construction is intended to foster and integrate systems of different member states of the European community, it seemed natural inquire an expert panel on their needs, ideas and desires for this type of systems at national and European levels. On the other hand there is the reality that the various European member states are at different stages in rapidly monitoring mortality, therefore it wouldn't be adequate to only seek ideas and wishes for an ideal system that would eventually as that would relegate some

countries to a secondary plane, so we tried to establish a manageable/feasible level scenario.

After subgroups discussions the rapporteurs of the two groups presented their results. In the end the work session coordinator, conducted the synthesis of the main conclusions putting them in framework of the EuroMOMO project.

At the end of the session participants were asked to fill out an evaluation form in order to obtain the level of participant satisfaction regarding the organization and methodology used in the workshop.

6.2. Results

6.2.1. Individual questionnaire

The questionnaire analysis concluded that, for most participants, the mortality monitoring system is inseparable from the system of death certification. As a key element in this inseparable relationship highlights the need for the existence of a minimum identification number (without implying knowledge of the name and marital status), and ideally to know the co-morbidity associated with death and the causes contributing to death. For most respondents the communication process of notification of death to the surveillance system should be exclusively electronically.

Notifications, according to participants, should ideally be made on the day of occurrence and any weekday (including weekend). When ideal conditions are not available two regularities were been identified as minimum requirements: one week (once per week or per three-in-three days) and weekday.

The distinction between the minimum and desirable requirements varied when participants were confronted with the system's sampling method. Ideally, the mortality monitoring system should have a census basis, encompassing all the deaths occurring in the country. However, the use of a sample of mortality by region was considered a minimum requirement for the system.

To ensure system's data quality two conditions are required: (1) procedures and audit mechanisms, which allow having data confirmation and verification, and (2) issue regular reports on the quality of data. These reports should, desirably, have regional indicators, the distribution of notifications delays, questions of double reporting and incorrect classifications.

For the analysis of climate data have been made some recommendations that considered the inclusion of maximum and minimum daily temperatures, as a minimum requirement. And as desirable requirements, the inclusion of a standard definition of heat wave and of warm period in a health context, which should be adjusted to regional realities; and the inclusion of levels of minimum temperatures observed. Other climatic indicators were considered relevant, such as rates of ozone and humidity, cold, heat, radiation, and thermal comfort bioclimatic indexes.

Most participants also considered that there should be a recommendation on the inclusion of a component of influenza activity in the mortality monitoring system, based on an epidemiologic definition, considering incidence rates (daily, weekly, or others) or at least scores. The counting system of influenza activity should consider data collection from several sources: data from emergency room visit, hospital admissions codes, codes of family physicians consults and notifications of Family Physicians. Ideally, the standard definition of influenza activity, would build a medical diagnosis, and subsequently validated by laboratory testing.

6.2.2. Focus group

At the workshop held was apparent that independently of the level of knowledge or involvement in a rapid mortality monitoring system, the group of potential end-users had a very clear conception of the minimum and desirable requirements that a system for monitoring mortality should contain. Thus, a mortality monitoring system should be characterized by the following attributes:

- Perform a function of observation and a function of decision support;
- It must be, above all, simple;
- Must have the ability to early detect the occurrence of events with an impact on mortality;
- Requires investment on human and financial resources specifically dedicated.

As assigned functions for mortality surveillances system there was a consistent positioning between groups. Groups did not perceive or indicated dichotomies between an ideal and a feasible system, nor between National and European. The system functions were consensually set as: observation, decision support, issuing alerts between countries and between different information systems, and emission rates of risk.

After fulfilling the essential functions, one of the potential applications identified for the mortality surveillance system would be joining a mitigation plan for heat waves to allow the action in response to heat events.

As further discussed themes, stood out the support to policy development (European level), monitoring cross-border mortality (European level), the matching of several existing information systems (within and between countries) and a means to enable research development of (nationally).

The simplicity, as main attribute of the surveillance system was considered the main characteristic that united the positioning between groups. Another attribute that emerged from the discourse of the participants was the need for a national shared, back-fed and participated by all stakeholders, using a global information model of management that must be transparent, automatic, easy to reach and of unfettered access (e.g. without passwords). Some constraints were identified as applicable to the European level for issues of confidentiality between countries (political and administrative). However, the simplicity of the system is not compatible with the complexity of data in excess, hence the importance of defining the key requirements.

In this sense, were outlined requirements with clear demarcation between what is considered as priority / feasible versus ideal, and national versus European. As feasible requirements were defined: to have the number of deaths, to have a baseline or a model for its calculation, and to have the capability of breakdown the information by region [NUTS or district], and the inclusion of age and sex. As ideal requirements were considered: to have clinical characterization data of the deceased, for example the deceased profession; to have history of disease and knowledge of the causes of death (referred primarily for research purposes); to have environmental characterization data (meteorological data); geographic area [the county appointed as ideal but not absolute agreement on the overall group].

At European level, having the number of deaths, having a baseline or a model, the ability of weekly report and the inclusion of regional level of information (NUTS II) were defined as the feasible requirements. What separated the feasibility at national and European levels were questions of timing and of geography level of reporting. It was felt that a national monitoring system to fulfill the tasks it is essential that mortality data is collected daily. However for the European level, the weekly reporting was considered sufficient. In what concerned the geographical aspect, it was felt that breakdown at the country level was sufficient without the need of being as fine as was considered for the national level. However, one of the participants listed a number of arguments supporting the need to be extensible to daily level, likewise, at European

level, in specific situations, such as alert issuing (e.g. a threat in a border having several countries or a risk of excess mortality).

The group was in agreement about the capabilities that the mortality monitoring system must have: early detection of events and identification of the excess mortality. Another capability that the group discussed referred to the identification of changes in temporal trends in mortality by region (NUTS II - European NUTS II level / district-level National). In an ideal national system, these capabilities enable a geographical breakdown (by districts / NUTS II), by age group and sex, while the European ideal system would also allow information breakdown by cause of death.

Inherent to its capabilities come the advantages, of surveillance, of health risks early detection, planning and implementation of control strategies and prevention and added value to be a current and organized source of information. These advantages are transposed to a European system, and some have been added that allow the monitoring of cross-border events. In contrast, the economic and political interests underlying the implementation of the system, and the very applicability of current information or costs associated with their ignorance were identified as some of the main disadvantages.

From the participants' standpoint, investment in the system would be to create a nationwide management entity, which could even be the National Health Authority, who would be responsible for overall system management, human resources and technology themselves, supported by a shared system of information accessible and represented by entities that feed the system.

Taking advantage of recent example of SICO¹ system aiming at the dematerialization of deaths certification, it did not predict costs for automatic conversion to allow auto-tagging and identification of causes of death, or the integration of other sources of information system. The absence of some essential parameters for a system of surveillance of mortality reveals the embryonic stage at which the system is.

The risk assessment should be the responsibility of an evaluating group, composed of elements from various institutions in different policy areas. That once identified a possible risk, using some tool for risk identification (index calculation), information should be reported to the National Health Authority (in some instances was considered

¹ Sistema de Informação de Certificados de Óbito – Portuguese Information System of Death Certification currently being implemented and that is expect to terminate paper death certification from January 2011 on.

the use of videoconference communication). This whole system of risk assessment (from discovery to report) would involve a rapid interconnection between institutions, via computer automations, and on a daily schedule.

"Having information in real time" is an assumption inherent in any system of monitoring mortality, by definition, is intended to be particularly fast and is able to intervene in relation to health risks.

6.3. Conclusions

This work session was evaluated according to a panel of experts' (also potential end-users from the sectors of health, civil protection and meteorology) opinions on which should be the characteristics of a fast system for monitoring mortality. The panel participants included both individuals with and without prior contact with a national mortality system. In the workshop information was gathered through an individual survey and from information resulting from groups' discussion and then in plenary debate.

In the individual survey experts tended to focus on the ideal aspects of a rapid mortality system. It was denoted that they considered, above all, that mortality monitoring is inseparable from the death certification; ideally requiring the existence of an epidemiological link and a regular exchange of daily information. The system should ideally be a census, but a sample basis was considered as a minimal condition for the existence of a system. When questioned about system data experts considered the existence of procedures and mechanisms for verification and quality assurance necessary. The panel also stated it was necessary to combine components of climate and influenza surveillance with the mortality monitoring system, involving the systematic collection of pertinent data, as well as the adoption of specific epidemiological settings, and possibly in the case of influenza activity, the inclusion of data from laboratory confirmation.

Groups' discussion session was beforehand structured to cover a relatively large set of characteristics that could be relevant for the rapid construction of systems for monitoring mortality either at a national and the European levels. In particular were considered for within and later between groups the following points: Attributes and functions; capabilities; advantages and disadvantages; Investments; potential / applications; importance and risk assessment.

After discussion between the groups they agreed that the essential functions of a rapid mortality system are **observation, decision support**, and alerts issuing between countries; it should have the eminent **attribute of being simple** and the **ability to early detect the occurrence of events** with impact on mortality.

In terms of **requirements for a rapid mortality system groups distinctly demarcated two frameworks: ideal versus feasible, and national versus European**. These seemed to emerge from the most salient features seen on individual questionnaires.

The **feasible requirements** were set as: **to have the number of deaths**, the **existence of a baseline or model** that would calculate it and the **capability to breakdown all this information by gender and age**. In terms of **ideal requirements** it was again set out the need for the existence of an **epidemiological link**, the need to have **information about the causes of death and about clinical history** of the deceased.

The distinction between national and European level has focused almost exclusively on issues of timing and the geographical level to be used. The groups felt that at the European level the time intervals for reports need not be daily, with weekly timing being acceptable. For the geographical level, it was not necessary to be as demanding for the European system as for national systems; the former should only consider country level information.

Groups identified the need of investment for the existence of fast monitoring mortality systems. It was recommended that at national level should be created **management entities**, with link to the entity responsible for public action on the field, but having their own nature.

In its turn was considered by groups that national **risk assessment** should be **conducted by a evaluator group**, preferably composed of elements that operate daily using automatic communication and interconnection between institutions, that would be responsible for communicate risk to the national health authority. The groups did not on the European level focused in particular, but the understanding was that the model would be similar to that level.

In the groups discussion there was some reference to system integration of mortality monitoring systems with heat waves surveillance systems. The integration with influenza surveillance was only spuriously referred and seemed to be relegated to a further secondary plan.

Analysis of the two studied components, individual and group, denoted the presence of some overlapping but proved to be essentially quite complementary. There was

overlapping on what should be the capabilities of the fast mortality monitoring system and on the definition and distinction of what is ideal and what is feasible in such systems. And there was complement in the extent that groups established specific issues, those that must be the system features, its functions, its requirements, its necessity for investments and how should risk assessment be implemented that could not arise from individual questionnaires.

7. International EuroMOMO Experts' Panel Discussion on Minimum requirements for a European Mortality Monitoring System

On March 2009 parallel EuroMOMO Project Workshops finishing with a plenary session were held in Rome, Italy.

A workshop within the framework of Work Package 5 was done with the duration of 1 ½ days that include about ten/eleven experts.

The agenda for this session was:

- Discussion and definition of mortality monitoring objectives
- Discussion and definition of minimum requirements for a mortality monitoring system

The initial part of the session included a brief presentation on points for discussion based on previously discussed and available project presentations. Also preliminary results on Work package 4 were presented.

After a fairly long discussion the expert panel reached the following consensus:

7.1. Objective

The main objective of the mortality monitoring system was defines as - to use a common method to monitor all-cause mortality in age stratified population in order to determine and report the European geographical pattern of mortality. This included the specificity of being able to timely detect excess mortality and relate it to public health events and of allowing the measurement of impacts on mortality such as the pandemic influenza and other public health events.

Comment: this definition concentrates on all-causes mortality (does not demand having causes of death on a timely manner), age, and region data, aims at timeliness,

to relate excess mortality to public health events and puts particular interest on measuring impacts on mortality.

7.2. Suggest Methods

The experts' panel was quick to reach agreement that focus should be on setting a simple and common univariate model as an initial approach.

This simple model approach should consider as Input weekly all-cause mortality, both all age groups and by age group, for each participating country. The output of the model should generically generate all-cause excess mortality, i.e. estimates of differences between observed and expected mortality.

It was further pointed out that regular model/univariate approach output would be integrated into National and European risk assessment framework that must be established at some given moment.

There was an intense discussion on whether the model input should be stated with a weekly timeframe or if it could be put in more generic terms. Southern countries sensibilities tended to want to keep the ability to switch, when necessary, from weekly to daily. This was mainly due to existent public health problems related with heat waves, and knowledge that the weekly framework is in most cases inadequate for this problem. But this necessity was not consensual or fully understood, and most existing mortality systems do not have the capability to switch to a daily monitoring basis, so it was not foreseen as a minimum to be set.

7.3. Requirements for EuroMOMO

The discussion was meant to set the minimum requirements for the mortality system, but since an earlier stage it became clear that the group felt the need to discuss the requirements issue beyond the minimum set. The minimum requirements seemed to be synonymous to feasibility for a wide group of countries in the immediate future. The group agreed that this level didn't have to be very low trying to accommodate all countries but it should be, nevertheless, simple enough to be attractive for non-participating countries.

Therefore, two levels for requirements were considered for the discussion. These were set as: Minimum requirements and additional requirements. Where additional

requirements where informally set as a slightly more ambitious minimum requirements.

7.3.1. Minimum requirements – Input

For **national inputs** the group considered that each country should:

- have the necessary IT (information technology) capability to manage mortality data and developed system to be built, be able to allocate the necessary human resources, and have the political will/drive to be part of the system;
- have available timely all-causes mortality data by age group;
- have a minimum of 5 years of all-causes mortality historical (same disaggregation levels) data – This was not taken as completely an absolute requirement, the tended to be open to less historical data as long as it allowed to have robust mortality baselines;
- Have risk assessment capability – Here also the group tended to accept this as a requirement but it non fulfillment was not seen as complete exclusion criterion;
- Having underlying demographic structures – also not taken as an absolute criterion. In principle all countries should have fairly good information available from national statistics offices.

At the **European Input** level the minimum was considered to be the existence of the national outputs and, eventually, the use of a standardization method to be later on decided.

7.3.2. Minimum requirements – Outputs

At the **national level** it was established that the minimum output should consider the observed and expected numbers of mortality by age group and by week. Some discussion was held on whether number or rates should be the best outputs but no further decision was obtained in this matter.

At the European Levels (EuroMOMO level) the overall consensus was that weekly excess mortality indicators, either for all-causes and all-causes age specific mortality, would be the main objective. A EuroMOMO risk assessment should be established – at this time no further discussing on this was held, it was agreed that this should be established at a later stage. Another minimum requirement at this level was that EuroMOMO should promote the dissemination of results.

7.3.3. Additional requirements – Input

Further requirements about inputs followed a slightly different scheme of discussion; it seemed to concentrate at the national Input level and two complementary perspectives: Improvement model wise and improvement for risk assessment.

Requirements for model improvement would be:

- The inclusion of regional stratified all-causes mortality
 - main discussion centered on having NUTS2 information but several possible approaches to this issue were recognized as feasible: the use of place of residence; place of death or region of death registration, further decision required additional information;
- The inclusion of daily all-causes mortality;
- The inclusion of gender stratified all-causes mortality;
- Include adjustment for mortality data delay;
- The inclusion of date of registration
 - this was not as completely consensual in some cases this could be more easily accessible than date of death, and furthermore having both date (registration and death) they would allow some modeling on the delay of mortality information;
- The use of underlying demographic structure was also discussed at this level – This again aimed at having mortality rates estimated rather than absolute figures - No definite position was established on this.

Additional requirements for national risk assessment discussed were:

- The inclusion of information from indicator-based surveillance such as influenza incidence estimates, climate indicators like temperatures, humidity, and pollution indicators, and so on.
- The inclusion of information from event-based surveillance gathered from media reports, rumors, etc.

7.3.4. Additional requirements – Output

The desirable additional output derived naturally from the additional requirement in Inputs. Again outputs obviously have the national and the European perspectives.

On the national levels the later additional ambitions would allow:

- to have the minimum requirement outputs (observed and expected numbers, thresholds and excesses by regions, by gender and per day);
- to have adjustment for data delay;
- to have advanced risk assessment procedures;

On the European level:

- additional weekly excess mortality indicators by region and by gender would be available;
- daily excess mortality would also be possible;
- and, overall advanced risks assessment procedures would also be possible.

Definitions

From an earlier stage of the discussion perception existed that it was needed to the EuroMOMO project to establish a list of definitions that were often recurrent but to which could not be seen with a unique meaning

The group decided to do an initial set of terms to be later defined.

The list was:

- timeliness
- all-causes mortality
- age groups
- expected mortality
- Threshold
- Excess mortality
- Standardized excess mortality
- Impact
- NUTS2
- ISO Weeks

7.4. Group conclusions

After the long discussion held the group was convinced that a European mortality monitoring system using a simple and robust consensus model was feasible. The group felt that some global definitions within the project should be addressed and clarified. Though the group was particularly comfortable with minimum requirements consensus reached, in what concerned the additional requirements a need to clarify the ambition levels of the project.

The panel recommended that the needs of using more complex methodologies such as multivariate models should be based on the experience from the pilot system to be done under WP8. It was also recommended that using the experience of the pilot the project should facilitate implementation of the monitoring system using the consensus simple model to other countries (not in the pilot).

8. Discussion and Conclusions

This *work package 5* (WP 5) of the EuroMOMO Project sought to have a conceptual perspective of what should be the characteristics of a rapid European Mortality Monitoring system. From the very beginning there was interest in reaching this objective knowing and understanding the existing framework, both at country and European levels, and of having and including the perspectives of implementing institutions and of the potential end-user community.

The chosen methodology to fulfill the WP objective was to gather information on existing mortality systems from review of overall scientific literature and from the field experience existing in Europe, and information on end-users and implementers opinions obtained using qualitative methodologies. End-Users opinions were obtained performing a focus group session and implementers' opinions were obtained in a 1 and a half day's international workshop designed specifically for that purpose.

Existing framework

EuroMOMO project was set with objectives that haven't been previously met in any way internationally. It aims at establishing a mortality monitoring system at the European level when only a few systems exist worldwide at country level and very limited scientific literature is available on this subject, relying mainly on very disease specific contexts. In fact it is shown in this report evidence of the existence of 11 European mortality monitoring systems, existing in different stages, from which only nine were picked up in EuroMOMO WP 4 inventory. Also, scientific literature revealed that there isn't yet a sound established framework for mortality monitoring systems at any level which makes the objective of this work relevant.

European Mortality Monitoring System definition/Objective

The implementers group discussed and reached agreement on a definition for the European mortality monitoring system, that was set as: "the use a common method to monitor all-cause mortality in age stratified population in order to determine and report the European geographical pattern of mortality". This included the specificity of being able to timely detect excess mortality and relate it to public health events and of

allowing the measurement of impacts on mortality such as the pandemic influenza and other public health events.

Though the end-users focus group did not address directly a formal system definition the characteristics that they described did not contradict in any way this definition. In fact, their perception showed to be in close synchronization with this as they agree that “a mortality monitoring system should be characterized by the following attributes: Perform a function of observation and a function of decision support; [...] Must have the ability to early detect the occurrence of events with an impact on mortality”.

Functions

The end-users agreed that the system functions should be: observation, decision support, issuing alerts between countries and between different information systems, and emission risk information. Major functions being the performance of observation and of decision support. Implementers’ international group did not thoroughly and specifically discuss what should be the system’s functions, but stated that the promotion of system results dissemination was necessary.

Attributes

Simplicity was the absolute attribute consensus for the mortality monitoring system. Independently of how sophisticated the system may evolve, general perception is that it must remain simple for the end-users and for the decision makers.

There was some discussion on the necessity of the Monitoring Mortality Information being as open as possible, allowing all involved partners to use all its information interchangeably but constraints were identified at state members level.

Implementers’ group also felt an overall necessity to keep the system as simple as possible. For example they were firm in setting “a simple and common univariate model” as the method to establish mortality baselines.

On the individual level, outside of groups’ dynamics, when questioned, end-users were highly concerned with the system’s data quality and its guarantee. They actually stated that mortality monitoring system cannot be dissociated from death certification and that ideally there should always be an epidemiological link.

Capabilities

The end-users agreed that the mortality monitoring system capabilities should be: early detection of events and identification of the excess mortality. Another capability should be the identification of changes in mortality temporal trends by region (NUTS II - European NUTS II level / district-level National). In an ideal national system, these capabilities should enable breakdown by geographical area (by districts / NUTS II), by age group and sex, while the European ideal system would also allow information breakdown by cause of death. Implementers were, independently, in agreement with this since they expected as minimum that the system should “generate all-causes excess mortality”.

Requirements

This work package results tended to centre on what should be the mortality monitoring system minimum requirements. All studied groups took minimum requirements to be synonymous to feasibility requirements. The implementers group agreed that this level didn't have to be very low trying to accommodate all countries but it should be, nevertheless, simple enough to be attractive for non-participating countries. For focus group's experts the minimum requirements were those that would allow the system existence with some public health relevance.

For the implementers' group, main focus was all in the system's requirements. These were actually divided in minimum and additional requirements, meaning those that are absolutely necessary and those that would improve the system. As the system implementation was a very objective task these requirements were defined as inputs and outputs. There were additionally two levels: the country/member state level and the European level. Therefore national/state member output was foreseen as European level input for the system.

Feasible versus ideal

End-Users defined the minimum or feasible requirements as: to have the number of deaths, to have a baseline or a model for its calculation, and to have the capability of breakdown the information by region [NUTS or district], and the inclusion of age and

sex. As the report regularity this group agreed that weekly was the minimum requirement for the European Level.

Implementers set these minimum requirements at the national level as: to have some Information technology and some human resources; timely all-causes data; and a historical set of mortality data. Report regularity was also defined as weekly. For this group breakdown of information by sex and region was not set as minimum requirements they were referred as additional inputs or requirements for improvements.

The number of deaths can be obtained from a sampling framework as minimum requirement. There was complete agreement on these in all groups and this was supported by the available scientific literature. Obviously, it was also consensual that census mortality data should be used when available.

As ideal requirements end-users considered: to have clinical characterization data of the deceased, for example the deceased profession; to have history of disease and knowledge of the causes of death (referred primarily for research purposes); to have environmental characterization data (meteorological data); to be able to define information by geographic area [the county appointed as ideal but not absolute agreement on the overall group].

Implementers group considered a set of additional requirements that should contribute to system improvement very similar to what the end-user pointed out, but because they were less demanding initially it overlapped also with end-users' minimum requirements. Nevertheless, implementers group additional requirements included: regional stratification of mortality, daily all-causes mortality, adjustment for mortality data delay, use of date of death registration, use of country demographic structure data, use of influenza activity data, and use of event-based surveillance from media reports and rumors.

National versus European

At European level, having the number of deaths, having a baseline or a model, the ability of weekly report and the inclusion of regional level of information (NUTS II) were defined as the feasible requirements. What separated the feasibility at national and European levels were questions of timing and of geography level of reporting. It was felt that a national monitoring system to fulfill the tasks it is essential that mortality data is collected daily. However for the European level, the weekly reporting

was considered sufficient. In what concerned the geographical aspect, it was felt that breakdown at the country level was sufficient without the need of being as fine as was considered for the national level. However, one of the participants listed a number of arguments supporting the need to be extensible to daily level, likewise, at European level, in specific situations, such as alert issuing (e.g. a threat in a border having several countries or a risk of excess mortality).

Investment

The end-users group considered that the construction of mortality monitoring systems required quite substantial investments. However institutions apart from those representing the national health authority would not invest in the system. Investment would include nationwide management entities, owning human resources and technology, which would be responsible for overall system management supported by a shared system of information accessible and represented by entities that feed the system.

Risk assessment

Implementers groups put some emphasis on risk assessment on their minimum and additional requirements discussion. They actually stated that it should be a minimum requirement at country level and advanced risk assessment procedures at the European level were required to improve the system.

End-users looked at risk-assessment as an avoidably associated feature of the system. In their thoughts risk assessment should be the responsibility of an evaluating group, composed of elements from various institutions in different policy areas. That once identified a possible risk, using some tool for risk identification (index calculation), information should be reported to the National Health Authority (in some instances was considered the use of videoconference communication). This whole system of risk assessment (from discovery to report) would involve a rapid interconnection between institutions, via computer automations, and on a daily schedule. They also did not discuss it in European level specific terms, but it is reasonable to think that their approach may also be extensible to the European level

Integration/inclusion with other information systems

Focus group and implementers considered integration with (or inclusion of) other information systems important and discussed it in some length but did not establish it as priority or as essential. Frequently referred were heat waves surveillance systems and influenza activity monitoring. Implementers group discussed this as an additional requirement for risk assessment. End-user tended to give this great importance individually, but in group discussion it was not particularly raised as of great importance.

Advantages and disadvantages

End-users identified mainly advantages in having a mortality monitoring system. Those advantages rose from having health monitoring, possibility of health risks early detection, of planning and implementing strategies of control and prevention, and of having added value of being a current and organized source of information. These advantages are transposed to a European system, and some experts have added that it allows cross-border events monitoring. In contrast, the economic and political interests underlying the implementation of the system, and the applicability of current information or costs associated with some information ignorance were identified as some of the main disadvantages.

It is interesting that both groups, of end-users and implementers, coming from very distinct backgrounds (and even from relevant different geographical areas) gave an overall common idea of what a European rapid mortality monitoring system should be, how it should function, what it should be capable of, and what its requirements should be at country/state member and global level.

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