EU PROJECT – HEALTH INFORMATION SYSTEMS IN EUROPE

COUNTRY REPORT

MORTALITY SURVEILLANCE SYSTEMS IN THE AUTONOMOUS REGIONS OF SPAIN

MORTALITY SURVEILLANCE SYSTEMS IN THE AUTONOMOUS REGIONS OF SPAIN

Page

General background

The systematic recording of deaths has a long-standing tradition in Spain, dating back to the 19th century when the first mortality classification was made in the decade 1861 – 1870.

Death registration according to cause was initially divided under five disease headings and registration in the Civil Register of all data on deaths occurring in towns was made mandatory for Town Councils.

In 1951 the International Classification of Diseases (ICD) was devised together with a series of international rules for selecting the basic cause of death. Spain's mortality registry system has now been decentralised and comprises 17 data coding teams, one per Autonomous Region in the country, who use the medical diagnosis classification according to WHO criteria now included in ICD version 10, which encompasses over 6,000 diseases.

Spanish Law stipulates that all deaths must be registered in the books held at the municipal offices of the Civil Registry. A medical death certificate, issued by the Spanish General Medical Council, is to be duly completed. This document is purely for administrative purposes and is filed at the Civil Registry offices to enable the magistrate to grant permission for burial.

The Statistical Death Bulletin (BED) is a statistical document provided by the Spanish National Statistics Office that compiles data on all deceased persons who have lived for more than 24 hours (age, gender, marital status and address provided by the deceased's relatives) and the cause of death stated by the physician certifying death.

Apart from the above, there is also a form for a statistical questionnaire known as the Statistical Birth Bulletin which compiles details of deaths occurring within the first 24 hours of life.

At the end of each month, the Civil Registry municipal offices remit all information compiled in the BED to the Provincial Branches of the Spanish National Statistics Office (INE) in pursuance to provisions contained in Regulations for the Law on the Civil Registry where the demographic information contained in the bulletins is duly coded. Mortality Statistics according to cause of death are the statistical item reflecting changes in the population's health status. Cause of death is defined as "the disease or injury that triggers the chain of pathological events that led directly to death. When the cause is an accident or injury, the circumstance of the accident or violent act that caused the lethal injury is deemed as the basic cause".
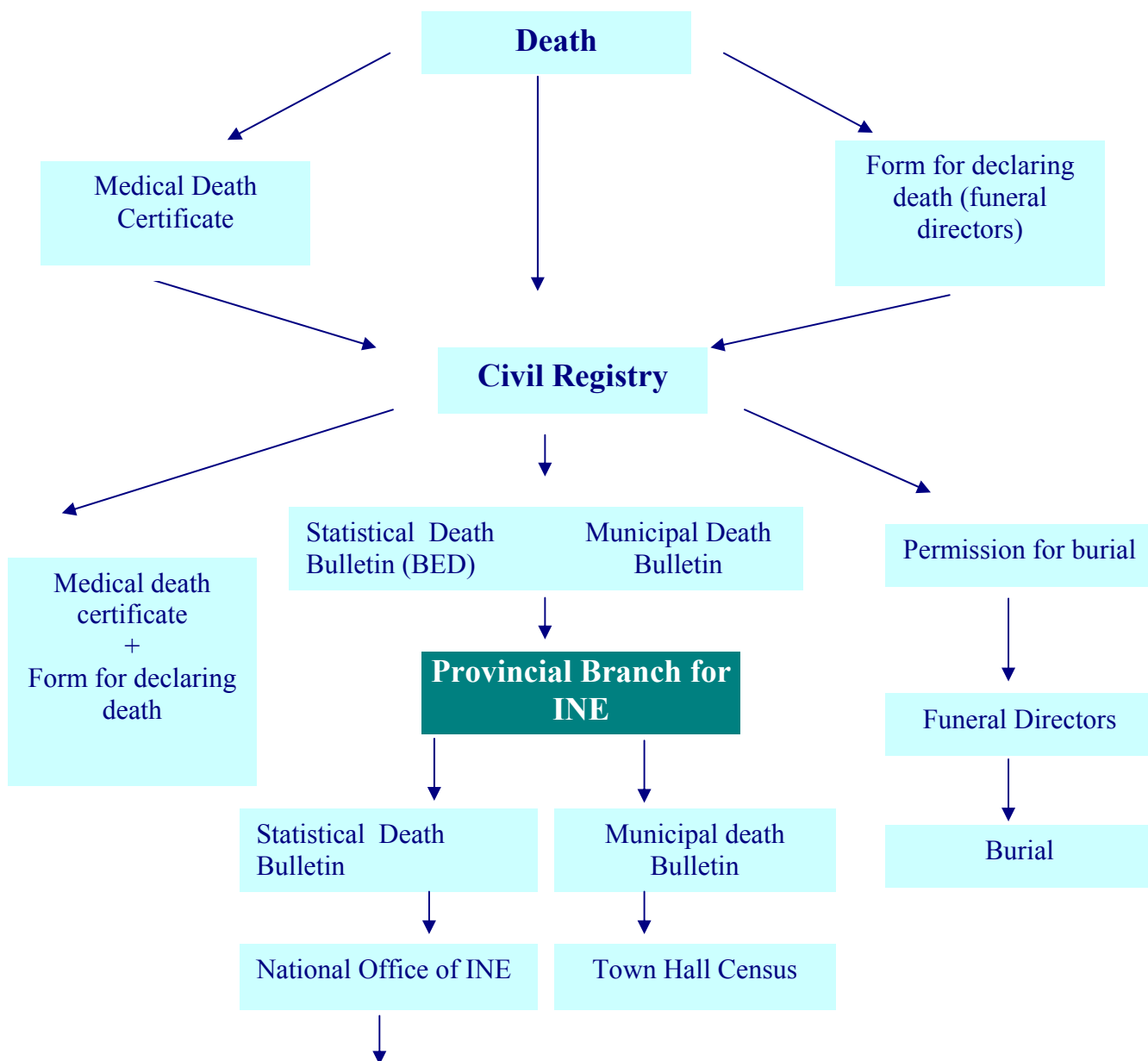
Statistical information provided by INE considers mortality according to the basic cause of death, as well as to the distribution according to gender, age, place of residence and month, and also delivers indicators that enable comparisons to be drawn between

different geographical areas and calculation of premature mortality rates (for example, standardised mortality rates and years of potential life lost).

All personal details compiled by the statistics offices either from reports or through administrative sources as considered in Art. 13.1 of the Law on Public Statistics Service dated 9th May 1989 are subject to statistical secrecy. As a result, all members of staff at statistics offices are bound to comply with this ruling (Art. 17.1 of the Law on Public Statistics Service).

Law 4/1990 also stipulates that provision of data requested for the purposes of drawing up statistics is mandatory. Statistics Offices may also request data in respect of all Spanish nationals and foreign, natural and legal, persons resident in Spain (Art. 10.1 of the Law on Public Statistics Service).

In general terms, the mortality surveillance system in Spain is structured as follows:

```
                            Death

   Medical Death                          Form for declaring
   Certificate                            death (funeral
                                          directors)

                         Civil Registry

 Medical death    Statistical Death   Municipal Death    Permission for burial
 certificate      Bulletin (BED)      Bulletin
    +
 Form for declaring   Provincial Branch for          Funeral Directors
 death                        INE

                  Statistical Death   Municipal death          Burial
                  Bulletin           Bulletin

                  National Office of INE   Town Hall Census
```

Publications

Goals

♦ To identify the key factors in the Mortality Surveillance System in Spain's Autonomous Regions[1].

♦ To identify the positive and negative issues regarding mortality data management in Spain's Autonomous Regions according to the view of technical professionals, experts and managers.

♦ To compile proposals for the improvement of the mortality data management system currently in force in Spain.

1. Methodology

A qualitative design, using a technique of semi-structured interviews, has been chosen to appraise the current status of mortality data management within each of the Autonomous Regions of Spain. Annex 1 provides the check list for the interviews.

The population interviewed were technical professionals, experts and health managers in the autonomous regions consulted.

The scope of the study encompassed five Autonomous Regions, namely Madrid, Valencia, Andalusia, Murcia and the Balearic Islands. Participants were selected according to responsibilities and the experience of the professionals vis à vis mortality data management.

This report contains the opinions expressed by experts, technicians and political authorities linked to healthcare following content analysis, using the NUDIST VIVO programme. The information has been organised according to dimensions and a matrix that takes into account both positive and negative issues and proposals for improvements.

Dimensions of the analysis.

D 1: General opinion on the health status of the population in your region

D 2: General opinion on the health status of the population in your region

D 3: Characteristics of the organisations involved in mortality data management:

- Identification of organisations and duties performed
- Mechanisms for co-ordination between organisations
- Gaps and duplications in mortality data management
- Usefulness of mortality data

D 4: Characteristics of source organisations

- Role in mortality data management
- Aim, mission and duties to be performed
- Procedures for data management (arrangements, analysis units, etc.)
- Availability of and access to mortality data
- Negative issues in the analysis or interpretation of mortality data

D 5 Existence of a Strategic Plan regarding Mortality

D 6: Strategies for Improvements

Dimensions of the analysis.

D 1: General opinion on the health status of the population in your region

What do you think of the health status of the population in your region?

D 2: General Opinion on health /mortality information systems in Spain

In general terms, what do you think of the health information system in your region?

D 3. Characteristics of the organisations involved in mortality data management

Now, I would like to ask you a couple of questions on the organisations that manage the health information system in your area, particularly on the mortality surveillance system.

- Identification of the organisation and duties performed

What are the main public and private organisations available in your region/setting for the management of the mortality monitoring system?

What duties are performed by each organisation?

---

health, education, etc. within the Autonomous Region. Andalusia, for instance, is the southernmost region in Spain with full responsibility for health throughout its eight provinces.

- Mechanisms for co-ordination between organisations

What co-ordination mechanisms are in place to ensure that duties are performed in an organised way?

- Gaps and duplications in mortality data management

Are there any gaps and/or duplication in the collection, coding and transmission of mortality data? If so, why?

- Usefulness of mortality data

Do you use the knowledge available on mortality and health status on a regular basis to set priorities as well as to devise and assess public health strategies and programmes? Can you give two or three examples?

D4. Characteristics of source organisations

- Role in mortality data management

Now I would like to ask you a couple of questions on your organisation. Can you explain in detail what role your organisation plays in the management of mortality data? .

- Goal, mission and duties to be performed

Please explain briefly the goal, mission and main duties of your organisation in general terms.(If necessary, define the goal as the raison d'être of an organisation according to setting; for instance, from outside and top-down; mission as the raison d'être developed from within the organisation bearing in mind the stated goal; this defines the goals and contents more accurately and pinpoints client needs and requirements; duties as a core activity, i.e. services and products delivered) Could we have a document that illustrates this point?

- Procedures for data management (arrangements, analysis units, etc.)

What unit within your organisation manages the analysis and interpretation of mortality data?

Are there any explicit arrangements to analyse and interpret data on mortality as a key dimension of health status? (If necessary, define arrangements as the model or general description used to analyse a phenomenon. Used normally, health status arrangements will include disease burden and quality of life in health) Are these available? (Could you provide us with a copy of a document that describes these procedures?)

Over the past few months, how often have you been in contact (calls, personal conversations, email exchanges) with other organisations that monitor mortality?

- Availability and access to mortality data

Are the details you require available in time?

- Negative aspects in the analysis or interpretation of mortality data

Are there any problems within your organisation as regards analysis and interpretation of mortality data?

D 5: Existence of a Strategic Plan regarding mortality

Has a strategic plan for monitoring mortality been set up in your region? Could you supply a copy of the relevant document?

D 6: Strategies for Improvement

What suggestions can you make to improve the standing of health status and mortality data analysis?

Would you like to add anything else?

3. - Results

Opinion on the health status of the population in the region

In general terms, there is a perception of overall improvement in health status, as supported by available information; certain opinions reflect that the situation may vary according to region, regional authority and provinces; inequalities in health status among certain groups (i.e. immigrants), geographical considerations (i.e. industrial areas) or differences in setting health promotion policies are identified as predisposing factors.

"Three quarters of the population perceive that their health status has been good, very good or excellent over the past twelve months ..."

"Taking into account available data, I think that the health status of the Andalusian population has improved substantially over the past 20 years ..."

"Inter-provincial inequalities still persist and should be addressed ......"

General opinion on Health/Mortality Information Systems in Spain

Findings from the interviews reveal differences in the mortality surveillance system in Spain according to region. In general terms, the system works appropriately. Some interviewees even perceive the system locally to be above the Spanish national average, quoting the ready availability of data or leadership in research projects linked to topics of coding and data publication to support their view.

"There is a high degree of development ..."

"It has improved greatly over the past few years, but there are still deficiencies ..."

There is general agreement that there are multiple information systems within each autonomous region. Poor communication between organisations linked to these systems is pinpointed, however, with differences only in exceptional cases. In spite of this, interviewees insist that improvements have been made in quality and thoroughness, which means that more and better information is currently available.

"Each component in the system, right down to each individual centre and unit, has developed its own information system and there is no communication between them, they are closed systems, proprietary in many cases, and do not even place importance on communication ..."

Complete information on areas relevant for public health is still missing, scant epidemiological analysis is made of available data, little use is made of this information by managers responsible for planning at all levels, data bases are difficult to access or poorly completed.

"You can't make good health information systems unless you analyse information and there won't be a lot of analysis if the results from health information are not being used…"

"Researchers have been able to access the CMBD[2] hospital database for several years now, but there are deficiencies in certain fields..."

Characteristics of the organisations involved in mortality data management

Identification of the main organisations involved and the duties they perform.

---

[2] Translator's Note: Community of Madrid Database

According to the professionals interviewed, the main organisations involved in mortality data management in their respective settings are as follows:

- Spanish National Statistics Office (INE)
- Provincial Branches for the Spanish National Statistics Office
- Mortality Registries – Health Department
- Regional Statistics Centres
- Municipal Civil Registries

Globally, the duties of compilation, coding and transmission are undertaken (with variations according to region, in the opinion of interviewees) by the Spanish National Statistics Office and its provincial branches and by the Mortality Registries or Regional Statistics Centres. As for data interpretation and usage, the different Health Departments[3] are quoted although it should be pointed out that local research institutions also make use of the data.

Analysis and interpretation is performed, according to region, either at Mortality Registries accountable to Health Departments, Public Health Departments in health districts or Healthcare Planning Departments. However, in certain cases, it was also mentioned that analysis units are not always available within the organisations and that only mortality indicators are provided together with publication of regional trends.

"Granada's Cancer Registry, under the responsibility of the Andalusian Public Health School (EASP), is a user of information on mortality rates specifically from cancer within the province of Granada..."

Co-ordination between organizations

In general terms, co-ordination is insufficient; in practice, there is no single organisation that is responsible for this co-ordination or for evaluation and correction of discrepancies on a national scale.

---

[3] Translator's Note: These departments are the regional health ministries with full responsibility for healthcare and public health in the Autonomous Region.

Again differences between regions and regional authorities are perceived, with co-ordination mechanisms arising locally. Mention was also made of agreements with the National Statistics Office, Regional Centres and Health Departments that enable access to original documents (i.e. Statistical Death Bulletins BEDs) or that enable Mortality Registries to be set up. Procedure manuals devised by certain Mortality Registries, the use of INE death nomenclators, monthly and yearly lists of unlikely or erroneous causes of death, besides review of indicators prior to publication were also mentioned.

There are even cases of agreements with Town Councils to make information on a district scale available.

"I believe that there are appropriate relations between the Andalusian Statistics Office and the Health Department, meetings are held regularly."

Understanding of and compliance with the duties that each organisation performs should contribute towards co-ordination of work; it is also pointed out that Civil Registries compile and file the Medical Death Certificates, the Statistical Death Bulletins are filled out and sent to the Provincial Statistics Office where the data is recorded and coded.

The Mortality registry records, purges, retrieves, codes and confirms healthcare information contained on the Statistical Death Bulletins.

Once the data has been confirmed, the National Statistics Office performs analysis for publication and dissemination. Finally, following receipt of the annual data base, the Health Department uses the data on all diseases that are analysed, published and disseminated.

"As it is a structured system, according to areas of responsibility, duplication has been eradicated and there is no doubling up in any of these fields..."

Gaps and/or duplications in mortality data management

Although some professionals do not acknowledge any gaps or duplications within the data management system, a series of items were mentioned as areas for improvement, such as the legal loophole arising from the absence of an agreement between the National Statistics Office and the Statistics Centres in the autonomous regions to code the Statistical Bulletins for stillborns and infants dying within the first 24 hours of life; or that mortality statistics are deemed mainly as demographic and not health data, as well as variability arising from work performed by 17 classification and coding teams besides the lack of mechanisms to facilitate access to individualised data.

"There are 17 coding teams, who logically introduce a degree of variability in the classification of medical diagnoses, even though they all use the criteria stipulated in the International Classification of Disease..."

"At the moment, there is no mechanism in place that enables disaggregated mortality data to be passed on to researchers without violating confidentiality issues on data."

Usefulness of mortality data

The degree of usefulness of information on mortality is valued differently according to the context of each interviewee but allows areas for priority action in Health Schemes and signed Programme Contracts to be pinpointed. This situation is borne out by the existence of specific programmes.

Data on morbidity, however, were said to be of greater use as they enable evaluation and follow-up, amongst other things.

Health Departments receive the annual data base and use the information it contains to prioritise causes of death that may be prevented by implementing health measures through health schemes and programmes, such as epidemiological surveillance for instance. The data can also be used to assess service quality and enable a wide variety of institutions to assess situations and undertake research.

"Researchers at EASP request information from the Cancer and Mortality Registries to conduct a wide range of studies. The results obtained from this information are interpreted and disseminated so as to contribute towards improving health in our area..."

"I work for the Epidemiological Surveillance Department in Andalusia (SVEA). We do not manage data, we only use data to analyse health and surveillance status..."

"Amongst other things, a typical surveillance report for a disease includes mortality rate analysis. The Mortality registry systematically provides the data we need..."

"We use ready tabulated data for surveillance of each disease."

Characteristics of source organisations

The role of the source organisation in mortality data management.

This varies according to the kind of organisation where interviewees responsible for specific mortality data work. The main most salient points mentioned by interviewees are listed below.

- Health Departments: Receipt of mortality databases at year end on a yearly basis that include cause of death, gender, age and geographic distributions of deaths.
- Statistics Office: Delivers data from population census or registers for analysis, use of database to analyse: distribution of mortality rates according to gender and age, cause and healthcare districts and areas.
- Mortality Registries; it was specifically pointed out that in Andalusia the Registry comprises personnel from the Health Department and the National Statistics Office and is organised in three working units:

- **Administrative** unit, responsible for receiving, recording, handling and developing the Statistical Bulletins of Deaths, Births and Marriages.

- **Statistics** unit, responsible for recording all the revised information from the Statistical Death Bulletins in magnetic format so as to detect, purge and correct any errors and to prepare files for quarterly, yearly publications, etc..

- **Coding** unit that uses the International Classification of Disease criteria (ICD 10) to sort diagnoses stated on death certificates (BEDs), evaluating the quality of data and retrieving information by telephone from the civil registries. There is no analysis unit at this level.

Goal, Mission and Duties

According to working context, the main responsibility lies in political representation in the region (in the case of Provincial Delegates for Health), the basic mission of organisations is to protect the population's health, co-ordinate service provision and ensure targets are met by healthcare providing centres.

A number of the interviewees think the goal of the organisation they belong to is to take responsibility for healthcare management, identifying health as a social good that is a very sensitive issue for the population (the general population considers health as a citizen's right), by tackling problems from an intersectorial viewpoint.

Other duties to be performed include: setting needs, once available technical information and data have been made known; delivering political and regulatory guidelines; evaluation and consultancy for the region's mortality data activity; drawing up reports on epidemiological surveillance; publication of analysed statistical outcomes; encourage and promote statistical research activity that will lead to a greater understanding of the social and economic situation in the region, etc.

"The Mortality Registry has the mission of improving the quality of data available on mortality, of generating information on mortality in the Autonomous Region, of catering for the specific needs of the local Administration..."

"To make best use of the information provided by the National Statistics Office in analysing mortality in Andalusia..."

"At the epidemiological surveillance unit, we follow up on mortality rates for diseases subject to surveillance..."

The goal of Health Departments is to monitor public health for the population at large, and to accomplish their mission of ensuring health maintenance and improvement, they undertake duties such as analysing and drawing up reports on health status, epidemiological surveillance, other health programmes, etc.

"Monitor, maintain and improve the health of the Madrid population".

"To protect the health of the Andalusians through ongoing analysis of health so as to pinpoint situations that require immediate, mid-term or long-term public health measures (alerts)..."

This information can be found in documents such as the agreements signed between various autonomous organisations, annual reports published by Health & Consumer Affairs Departments, Regional Health Plans and Laws on healthcare planning.

Existence of arrangements and units devoted to analysis and interpretation of mortality data

Certain arrangements are in place to reproduce annual mortality statistics by cause of death and periodic updates published in the Epidemiological Bulletins in the Autonomous Regions; only some autonomous regions are known to have arrangements, while others have not even devised protocols.

Regional differences are also apparent for dedicated data analysis and interpretation units, in some regions Epidemiological Departments, Public Health Services in Healthcare Areas and Healthcare Planning Departments are mentioned, while in other cases reference is made to the Regional Statistics Centres for the Autonomous Region

and Mortality Registries, as well as to the absence of specific dedicated analysis units in other areas.

"There is no specific Unit for mortality data analysis. Research projects using this kind of information are under the supervision of a certain Co-ordinator who is ultimately responsible for the analysis and interpretation of results..."

"Each project presents a series of aims and appropriate methodology for information analysis and interpretation..."

"Each institution has its own procedures in place that are intended to register thorough, top-quality information..."

Contacts with other organisations involved in mortality data management

The frequency of contact varies and depends on the kind of duties performed by the organisation the interviewee belongs to. In the case of Mortality Registries, there is a high rate of communication with the Regional Statistics Centre and Provincial Branch of the National Statistics Office through some means or other. Contact with other Mortality Registries, however, is more sporadic.

In the case of the Health Department, frequent contact is quoted firstly with Civil Registries and with the Branches of the National Statistics Office.

"Members of our team are in contact with the mortality registry on average once a month..."

Availability and access to mortality data

Interviewees agree that there is a certain time lag between the date of death and the collation of data by the Registers. However, this is not unreasonable and, given that this is a known fact, does not cause undue delays. Some interviewees point to legal restraints hindering the usage of health data as a curb on access to data. For others, however, this does not affect data availability.

"As a general rule, 2 to 6 months after the date of death"

"You usually have to wait some time for the data requested, but it is never too long..."

"These data are confirmed throughout Spain. One and a half years after the year end, which means that, except for particular problems, the data is available in time..."

Some interviewees consider access to be a complex issue, especially when individualised information on mortality is required for research purposes, efforts to obtain information often fail, aggregate data is available only in certain areas (municipalities, districts, census divisions, etc.) given the confidential nature of this information.

"This is a great problem for access to micro data and individualised information"

Individualised data is accessed through the Medical Death Certificate and not through the Statistical Death Bulletin; Civil Registries have not been computerised which renders the search for information more painstaking; currently the Civil Registries do not register cause of death in their books, which makes access to this kind of data more difficult.

"The Law mentioned hinders detailed monitoring and surveillance on certain diseases that have a major impact on public health..."

Negative issues in the analysis and interpretation of mortality data

The following have been identified as the weaknesses in the information systems:

The existence of a Data Protection Law.

In some cases, there are no dedicated analysis units for mortality information in regions such as Andalusia; both the procedures for analysis and interpretation are in place but are not always strictly observed, with differences arising between those who calculate the indicators and those who then interpret them.

Waiting time for access to updated information.

Other issues identified as negative points within the system include the lack of accuracy in the completion of death certificates and the fact that the system collating data falls outside the health system.

The fact that a confirmed register exists is, however, considered as a strong point.

Existence of a Strategic Plan regarding Mortality

In Spain, the National Statistics Plan provides the instrument for the organisation of statistics of nationwide interest; the National Statistics Office contributes to this effort by providing death statistics according to cause of death, including late foetal deaths. However, there are no specific strategic plans for mortality, except for the aims stated in the Autonomous Regions' Health Plans or certain documents which cannot be made public as they are intended for internal use only.

"There is no common strategic plan today for all the bodies that monitor mortality data..."

Escuela Andaluza de Salud Pública
CONSEJERÍA DE SALUD

Strategies for Improvement

For a large number of interviewees, improvements are required in the following areas: in access to updated data, in promoting quality control and harmonisation of the system used in the different regions, in strengthening epidemiological surveillance networks, in providing incentives for conducting health surveys and allocation of resources, in creating analysis departments for health information both on mortality and from other sources that would draw up regular reports on health status in the region and would conduct research aimed at steering healthcare provision; in legislation that acknowledges mortality statistics by cause of death as health data and not merely demographic data; improvements to national and regional co-ordination systems, and access to sources of nominal information on causes on death in Spain for research purposes.

"It would be a great option if they were available on the Health Department Webpage for usage in research and situation analysis..."

"On the other hand, quality control should be set up for the collation of data provided."

"Analysis department for health information both on mortality and from other available sources..."

"Research aimed at providing guidelines for healthcare that should have a high scientific output"

Escuela Andaluza de Salud Pública
CONSEJERÍA DE SALUD

Positive Points	**Negative issues**
• Existence of a confirmed register	• Lengthy waiting time before updated data becomes available
• Agreements signed between INE and Regional Health Departments	• Difficulties in accessing disaggregated data
• Enhanced quality and accuracy of data	• Inadequate communication and co-ordination between organisations
• In some regions, leadership in research with usage of mortality data	• Non-existence of a dedicated unit for data analysis and interpretation in certain regions
	• Insufficient epidemiological analysis of mortality information.
	• Insufficient usage of information on mortality in planning.
	• Differences between regions in mortality data management.

Proposals for improvements

• Improve access to updated data

• Promote quality controls and harmonisation among regions

• Strengthen epidemiological surveillance networks

• Set up dedicated departments for analysis and interpretation of mortality data

• Draw up regular reports on health status in the region

• Pass legislation that acknowledges mortality data by cause of death as health data

• Improve both regional and national co-ordination systems

Annex 1

Questionnaire for Technical Staff and Experts

Data collection, coding and transmission

1. In general terms, what do you think of the health information system in your region?

2. Now I would like to ask you a couple of questions about the organisations responsible for managing health information system in your setting, particularly on the mortality surveillance system.

3. What are the main private and public organisations responsible for managing the mortality monitoring system in your setting?

4. What duties does each organisation perform?

	Org 1	Org 2	Org 3	Org 4	Org 5	Org 6	Org 7	Org 8
Collection								
Coding								
Transmission								
Analysis								
Interpretation								
Usage								

5. What co-ordination mechanisms are in place to guarantee that duties are performed in an organised way?

6.   Are there any gaps and/or duplications in the collection, coding and transmission of mortality data? If so, why?

7. Now I would like to ask you a few things about your organisation.

8. Can you explain in detail what role your organisation plays in mortality data management?

9. Please give a brief description of the general goal, mission and main duties of your organisation (If necessary, define goal as the raison d'être of an organisation according to setting; for instance, from outside and top-down; mission as the raison d'être developed from within the organisation bearing in mind the defined goal; this defines the goals and contents more accurately and pinpoints client needs and requirements; duties as a core activity, i.e. services and products delivered) Could we have a document that illustrates this point?

10. Which unit within your organisation manages the analysis and interpretation of mortality data?

11. Are there any explicit arrangements to analyse and interpret mortality data as a key dimension of health status? (If necessary, define arrangement as the model or general description that can be used to analyse a phenomenon. Used normally, health status arrangements will include disease burden and quality of life in health) Are these available? (Could you provide us with a copy of a document that describes these procedures?)

12. Over the past few months, how often have you been in contact (calls, personal conversations, email exchanges) with other organisations that monitor mortality?

13. Are the details you require available in time?

14. Are there any problems in your organisation with the analysis and interpretation of mortality data?

15. Has a strategic plan been devised for the mortality monitoring system in your region? Could you provide us with a copy of the document?

16. Is there anything you would like to add?

Escuela Andaluza de Salud Pública
CONSEJERÍA DE SALUD
JUNTA DE ANDALUCIA

Questionnaire for Managers

Data collection, coding and transmission

1. First of all, I would like to ask you a few questions about the organisations within the health information system in your region.

2. What is your view on the health status of the population in your region?

3. Please give a brief description of the general goal, mission and main duties of your organisation. (If necessary, define goal as the raison d'être of an organisation according to setting; for instance, from outside and top-down; mission as the raison d'être developed from within the organisation bearing in mind the defined goal; this defines the goals and contents more accurately and pinpoints client needs and requirements; duties as a core activity, i.e. services and products delivered).

4. Could we have a document that illustrates this point?

5. What do you think are the main strong and weak points in the health and mortality information system in your region? For instance, is information on health status and mortality available in a reasonable time span? Is the information provided relevant?

6. Do you use knowledge on mortality and health status on a regular basis to set priorities and to devise and evaluate public health strategies and programmes? Could you provide two or three examples?

7. What suggestions could you make to improve the standing of health status and mortality data analysis?

8. Would you like to add anything else?

Annex 2

Analysis of the Opinion of Professionals responsible for management

General opinion on health status of the population in your region

The professionals interviewed all agreed that there has been a positive improvement in health status of the general population, with differences occurring between regions; the perception of citizens of their own health status is stressed in support of the preceding statement; as a result, many citizens consider their health to be good, very good or excellent; in line with studies conducted, there has also been an increase in preventive practices.

Difficulties are perceived, however, in areas such as a common policy throughout Spain as regards health promotion; all interviewees agree that persistent pockets of inequalities, both between regions and within certain regions, remain one of the current weaknesses of the system.

The epidemiological profile reflects a rise in chronic disease.

"Three quarters of the population perceive that their health status has been good, very good or excellent over the past twelve months ..."

"Taking into account available data, I think that the health status of the Andalusian population has improved substantially over the past 20 years ..."

"Inter-provincial inequalities still persist and should be resolved ......"

"Pockets of inequalities (immigration, social exclusion ....), difficulty in setting health promotion policies as part of government policy, segregation..."

24

General opinion on health/mortality information systems in Spain

The existence of such information systems was stated, but a series of problems is making improved management and usage of the information difficult; specifically as regards mortality data, the fact that mortality data is outside the scope of the health system is seen as a drawback, as this leads to a lack of information on topics relevant to the healthcare sector and poor accessibility to up-to-date data.

"... usage for healthcare analysis does not provide the soundness that mortality data offering information from the health standpoint would…"

"This means that it has all the problems inherent in secondary data."

Characteristics of the organisations involved in mortality data management

Co-ordination between organisations

In this area, implementing duties leading to intersectorial work was considered to be important.

Usefulness of mortality data

The usefulness of mortality data for healthcare management was acknowledged, although several interviewees pointed out that morbidity data is more useful in certain topics; for others mortality information is a tool in the framework of health diagnosis for an Autonomous Region that enables planning for specific programmes.

"Knowledge on mortality and health status to devise specific programmes: in the case of the HIV/AIDS epidemic, outbreaks of legionellosis or food poisoning scares in the 90s..."

"Priorities for areas of study have been set in the Health Plan, based on the understanding of health status and mortality data for the Balearic Island population..."

"From experience he was able to say that health status and morbidity data were more useful than mortality data..."

Characteristics of the source organisations

Goal, Mission and Duties

There was general consensus in pinpointing that the mission achieved through representations in each of the Autonomous Regions is both political and eminently social since they were responsible for achieving the goal of contributing towards improvements in health status among the population, tailoring policies to meet local health needs; interviewees identified the overall community of citizens in a given jurisdiction as the target for measures; one of the aims is intersectorial work to provide a more thorough approach to problems affecting citizens' health, which marks the difference between these organisations and others that are only healthcare providers.

"Aim: Company that places the right to health among its priorities..."

"Social awareness to public health problems in general and health protection in particular..."

"Health protection and promotion in society..."

"Need to deal with health determinants by tackling intersectorial barriers..."

A series of duties were identified, such as taking part in local health diagnosis, planning services and programmes, prioritising actions to match needs, intersectorial co-ordination of actions and evaluation of interventions**.**

"A*nalyse results and determine needs that enhances prioritisation of measures...*"

Availability of and access to mortality data

A series of difficulties in obtaining access to up-to-date data were mentioned, i.e.:
Inaccurate death certificates.
Existence of a Data Protection Law.
Time elapsing before information becomes available.
Interviewees agreed that the fact data is qualified as statistical and not as health information acts as a barrier.

"It must be said that data on the health status among the Andalusian population is not particularly easy to access and, above all, it is not up-to-date"

"Source of analysis: Balearic Statistics Office..."

"Usage for healthcare analysis does not provide the soundness that mortality data offering information from the health standpoint would…"

Strategies for Improvement

Although there was no consensus on all issues for improvement, interviewees pinpointed a series of strategies that could be feasibly implemented, bearing in mind the possibilities available locally; along these lines, the need to harmonise data management on a national and international scale (analysis, coding, quality control mechanisms, etc.) was stressed so as to avoid current variability and to guarantee the transparency of the system.

Finally, improvements in the content of death certificates and the regular updating of data using new technologies is indispensable for further progress to be made in this area.

"Incentives must be given for drawing up Health Surveys, with homogeneous content in different regions and countries".

"Strengthen epidemiological surveillance networks and Information Systems, specifically health indicators..."

"It would be a great option if they were available on the Health Department Webpage for usage in research and situation analysis..."

"On the other hand, quality control should be set up for the collation of data provided."

Positive Points	Negative issues
♦ Existence of an analysed Mortality Registration System that has improved over time ♦ Usefulness of data both for statistical and health management purposes	♦ Mortality data are considered as statistical and not health data ♦ Lack of accessibility for certain updated data ♦ Inaccurate death certificates ♦ Existence of a Data Protection Law ♦ Time elapsing before information becomes available

Proposals for Improvements

♦ Harmonise data management (analysis, coding, quality control mechanisms, etc.)

♦ Unify health surveys and the systems for analysis of data arising from them on a national and international scale

♦ Regular updating of data, using new technologies (i.e. Webpages)

♦ Strengthen epidemiological surveillance networks

♦ Improve the content of death certificates

Annex 3

Analysis of the Opinion of Technical Professionals

General opinion of health/mortality information systems in your region

The opinions given reflect the perception of improvement in health information systems in general terms over the past few years; some even qualified this as a highly developed process.

Despite the above, there are still deficiencies both in access to certain health data and in quality of information in given health databases.

"Researchers have been able to access the CMBD[4], hospital database for several years now, but there are deficiencies in certain fields..."

"...is developed to a high degree..."

Characteristics of the organisations involved in mortality data management

Identification of the organisations involved and the duties each performs.

Basically interviewees pinpointed public institutions involved in mortality data, such as Health Departments, Autonomous Regional Statistics Offices and Mortality Registries.

Within the different regions consulted, however, there are organisations that are linked to the data management system only in that they use the information available in statistical bulletins or Webpages, such as the Cancer Registry in Granada, under the responsibility of the Andalusian School for Public Health.

Some interviewees also identified private hospitals as the body responsible for compiling data.

Co-ordination between organisations

Co-ordination varies according to region and information requirements of the organisations or research groups; meetings are quoted as the means of contact for staff compiling, coding, analysing, interpreting and using mortality data.

"I think the relations between IEA (Andalusian Statistics Office) and Health Department are adequate, with regular meetings..."

"Hospitals and Civil Registries give access to Cancer and Mortality Registers for data collation..."

"Information collected by the Registries can be requested for use by other organisations for research purposes..."

Gaps and/or duplication in mortality data management

While some interviewees see no gaps in current data management, others pointed to the absence of any mechanism enabling access to disaggregated data; it is only possible under exceptional circumstances to obtain personal details of the deceased given the mandatory confidentiality of personal data.

"The steps that must be taken to conduct studies requiring socio-demographic, professional or personal data on the deceased are painstaking and often lead nowhere..."

"I cannot pinpoint any, even supposing they exist..."

---

[4] Translator's Note: Community of Madrid Datbase

Usefulness of mortality data

Usefulness was linked to improvements in health diagnostics in the setting through the interpretation of compiled data. The usage of this information for research purposes was also acknowledged.

"Researchers at EASP request information from the Cancer and Mortality Registers to conduct studies of different kinds..."

Characteristics of source Organisations

Role of the source organisation in mortality data management.

The professionals interviewed stated they have no direct responsibilities as regards the various stages of data collection, but that use is made of information that has already been processed.

"I work for the Epidemiological Surveillance Department in Andalusia (SVEA). We do not manage data, we only use data to analyse health and surveillance status..."

"At the epidemiological surveillance unit, we follow up on mortality rates for diseases subject to surveillance..."

Goal, mission and duties

All professionals interviewed agreed on the general mission pursued by their organisations, namely to protect the health of the population in their particular region; duties, however, vary according to the competences of each Institution, ranging from ongoing analysis in order to identify risk situations that require public health measures, to research in this field that may contribute towards an enhanced understanding of both the health and health determinants of the populations.

"…*to pinpoint situations that require immediate, mid-term or long-term public health measures (alerts)...*"

"*The mission of the Andalusian School is to co-operate in the development of health services by drawing up analyses, recommendations, opinions on services and deepening understanding of health and health determinants among the population, amongst other things...*"

Existence of arrangements and dedicated units for the analysis and interpretation of mortality data

Different situations were quoted both as regards arrangements and dedicated units for the analysis and interpretation of data; the professionals interviewed claimed to be users of processed information, without there being specific analysis units or arrangements for that purpose; only protocols for research were mentioned; the outcomes are used to draw up reports on health status, epidemiological surveillance and research, without any arrangements in place.

"*We use data that is ready tabulated for surveillance of each disease. A typical surveillance report on a given disease includes mortality analysis, amongst other things...*"

"*In this sense, there is no single document that describes these procedures, only specific purpose-made protocols for each research project...*"

"*The Mortality Registry systematically provides the data we need...*"

"*The Health Department Information Division systematically analyses all information...*"

Contacts with other organisations involved in mortality data management

Frequency of contact is linked to the kind of organisation the interviewee belongs to, with more frequent contact with the Mortality Registries in each autonomous area.

""Members of our team are in contact with the Mortality Registry on average once a month..."

Availability and access to mortality data

The professionals interviewed stated that there is a delay in information becoming available, although this does not interfere with work. A conflict was quoted, however, as regards access to disaggregated data, information is only available according to area, either on a town or census district scale etc., due to the Law on Confidentiality.

"You usually have to wait for a while for the data you have requested, but it's never too long..."

"Mortality Register, you can only access aggregate data for certain areas..."

Negative issues in mortality data analysis and interpretation

While some interviewees stated there were no negative issues in the analysis and interpretation of data, others mentioned deficiencies in staffing levels and qualifications for both data analysis and interpretation.

"EASP has the support of researchers and experts for analysing and interpreting mortality data. This is why we don't usually have any problem with this kind of study..."

Existence of a Strategic Plan regarding mortality

The interviewees pointed out the absence of strategic plans to be implemented by the organisations involved in mortality data management; internal procedures have been put in place to guarantee the quality of outcomes at each stage of the system. In some strategic plans, aims linked to mortality data have been included, though not specifically for this topic, such as epidemiological diagnosis targeted at reducing mortality rates from certain causes.

"Each institution has its own procedures in place that are intended to register thorough, top-quality information..."

"Not as such. There are Strategic Plans, guidelines for health policy in the Regional Administration though..."

Positive Points	Negative issues
◆ Improvements to the system over time	◆ Accessibility to certain databases, particularly individualised information
◆ Clear usefulness of the information obtained through the existing mortality data management system	◆ Quality of certain registers
◆ Existence of agreements between Mortality Registries, Health Departments and the Statistics Office	◆ Absence of specific units for the analysis and interpretation of data in some of the autonomous regions consulted
	◆ Lack of qualified human resources for the analysis and interpretation of information on mortality

Annex 4

Analysis of experts' opinions

<div style="background-color:navy; color:white; text-align:center; font-weight:bold;">

General opinion on health/mortality information systems in Spain

</div>

Regional differences are pinpointed, i.e. in Andalusia there is a series of health information systems, and there are some systems with information that cannot easily be accessed even from within the region itself.

Overall, the mortality information system in particular is perceived as a data management system that has improved over the years in most of the stages in the process, both in terms of quality and quantity of information available, as well as transparency.

"The system is thorough, it compiles all deaths of residents and registered persons in the Community of Madrid, even though death may have occurred elsewhere...."

"In the Public Health System in Andalusia, each component in the system, right down to each individual centre and unit, has developed its own information system and there is no communication between them, they are closed systems, proprietary in many cases, and do not even place importance on communication ..."

"More and better information is now available on morbidity and mortality, perceived health status, disabilities, etc..."

Despite the above, several interviewees stated their views on areas where there is room for improvement, such as specific information of certain data such as mortality rates for cancer or insufficient epidemiological analysis which curbs wider usage, amongst other issues.

"You can't make good health information systems unless you analyse information ..."

"I cannot understand why only partial information on cancer incidence is available since this is one of the most serious public health problems ..."

Characteristics of the organisations involved in mortality data management

Identification of the main organisations involved and the duties they perform.

Basically, the experts also quoted the same organisations involved in data management, i.e. compilation is in the hands of Civil Registries at the Town Councils; in the case of Andalusia, however, the Town Council for Seville, has taken on additional duties for coding, transcription, analysis, interpretation and usage of the data.

Interviewees agreed in identifying the National (INE) and Regional Statistics Offices as the bodies responsible for compiling, coding, transcribing and using data. In the Community of Madrid, mention is made of data analysis duties performed at the Community's own Statistics Office, contrary to the situation in Andalusia (I.E.C.M.[5])

The Health Department is responsible for analysing, interpreting and using information from databases.

Co-ordination between organizations

Mention was made of agreements between the National Statistics Office, its regional branches and the Regional Authorities through such institutions as the Mortality Registries and Health Departments in order to guarantee greater expediency and quality in data management.

"Two agreements were signed in Andalusia in 1991. The first was between the INE and the Andalusian Statistics Office (IEA), and the second between the IEA and the Department for Health. The IEA has recently signed a further agreement with the Town Council of the City of Seville..."

The experts interviewed identified a series of bodies and stages that data pass through from compilation to dissemination in the Mortality Bulletins both in each autonomous region and nationwide; there was general agreement on the basic points comprising the data management system, i.e. in general terms, data undergo the following stages:

♦ Civil Registries compile all Medical Death Certificates and file them, draw up the Statistical Death Bulletins (BED) and sends them to the INE.

♦ INE records and codes the personal identification data from these bulletins and sends the recorded and coded files in a database and the bulletin in paper format to the Mortality Registry.

♦ The Mortality Registry records, purges, retrieves (if necessary) codes and confirms health information contained in the BED.

♦ At year end, the INE receives the data base back for confirmation on a national scale and is responsible for publication and dissemination.

Once the annual database is received, the Health Department uses the data for all diseases; these are analysed, published and disseminated; some interviewees pointed out that the Health Department is also responsible for managing improvements in areas such as causes of mortality through contact with the doctors certifying deaths.

"*Amongst other things, the Department for Health is responsible for managing the healthcare sector...*"

In the view of the experts interviewed, contact is made between the institutions involved in processing data. However, despite frequent contact, there are variations in both regularity and the personal responsible for contact.

---

[5] Translator's Note: Community of Madrid Statistics Office

Interviewees mentioned the Mortality Registries as the body assigned to this duty, and report very frequent contact on a regional scale with the National Statistics Office, followed by the Department for Health and only sporadic contact with other autonomous regions.

".. INE, twice or three times a week for ICD-10 codes, on a weekly basis for the Health Department and only sporadically with other Mortality Registries..."

Gaps and/or duplications in mortality data management

The experts interviewed perceived a sound level of organisation within the system, some stated this was the case even prior to setting up Mortality Registries in the Autonomous Regions since the basis of the process, i.e. registration of mortality by cause, had already been put in place; organisations have made improvements, however, in expediency and availability of information within the autonomous regions; the fact that the system has been decentralised, however, i.e. there are now 17 working teams for each of the 17 Autonomous Regions in Spain, poses problems for comparison of outcomes; variation was noted in the classification of medical diagnoses; some felt that there should be a co-ordinating body to correct and evaluate information.

"As it is a structured system, according to areas of responsibility, duplication has been eradicated and there is no doubling up in any of these fields..."

"Perhaps there has been a loss of comparability in information by cause between the various Autonomous Regions..."

"There are 17 coding teams, who logically introduce a degree of variability in the classification of medical diagnoses, even though they all use the criteria stipulated in the various versions of the International Classification of Disease..."

Usefulness of mortality data

Among experts there was a clear opinion on the usefulness of the information obtained through the analysis of mortality data, since analysis of this information can be conducted in terms of distribution by gender, age, large groups of causes; greater accuracy is achieved in situation analysis by health district and area through specific indicators. This enables enhanced planning for preventive programmes or evaluation of service quality, to name but a couple of examples.

Moreover, some interviewees stated a specific usage through dissemination of this information in quarterly BEDs that are issued from the Autonomous Regions and from the INE encompassing the overall situation in Spain.

"These are used in planning for health schemes to set priorities for diseases that may be prevented by taking community-wide measures..."

"The Department for Health uses this information for analysis and interpretation so as to pinpoint health needs and to plan healthcare services..."

"Amongst other usages, mortality is distributed according to age and gender; mortality by causes in line with the large ICD groups; gross mortality rates, main causes of death by age and gender with their rates, mortality according to healthcare districts and areas..."

Characteristics of source organisations

Role of the source organisation on mortality data management.

Roles vary according to both the source organisation the expert belongs to and the Autonomous Region; although certain differences were revealed, a couple of examples from Andalusia can be given: the Mortality Registry performs administrative, statistical

and coding duties assigned to specific units although there is no dedicated unit for information analysis. The Department for Health in the Community of Madrid, on the other hand, receives information for analysis at the end of each year.

"The Mortality Registry in Andalusia comprises staff from the Health Department and the Andalusian Statistics Office, which means there is a dual dependency although the Registry works as a single unit as regards compiling mortality statistics for Andalusia..."

"Administrative unit responsible for receiving, recording, handling and returning Death, Birth and Marriage Statistical Bulletins..."

"It classifies diagnoses contained in the BEDs, besides evaluating data and retrieving information through telephone calls and visits to Civil Registries and so on.

"Statistics unit, responsible for recording all information contained in BEDs in magnetic format, for detecting, purging, correcting errors and preparing files for systematic quarterly and annual publications, etc ."

"*The Statistics Office supplies data from the census or population register that have been duly updated, and disaggregated as required for their analysis...*"

Goal, Mission and Duties

The definitions provided for the goal, mission and duties of the Organisations vary, given that the Institutions forming part of the process have specific duties to be implemented; in general terms, the mission is identified as contributing, from the public health area in the region in question, towards surveillance, maintenance and improvement of health status among the population, either through mortality registers that ensure quality of mortality data or thorough analysis and planning for programmes in line with the outcome reflected by health diagnosis in the region.

"Make full use of all the information provided by INE in mortality analysis in Andalusia..."

"To collate information on mortality in Andalusia quickly that caters to the specific needs of the Andalusian Administration."

Existence of arrangements and dedicated units for mortality data analysis and interpretation

While some interviewees pointed out that arrangements are in place, others stressed that they are not available and there are no dedicated units for data analysis either.

"Yes, you can attach the general mortality report and mortality by cause for the Community of Madrid".

"There is no arrangement or protocol for mortality analysis in Andalusia".

"For several years now, a series of indicators has been calculated, but either no interpretation or analysis at all is made of these indicators or it is poorly implemented ..."

Contacts with other organisations involved in mortality data management

There are differences in the frequency of contact with the various organisations involved in mortality data management although, overall, the most frequent contacts occur with INE, Civil Registry Offices and Health Departments.

"It is usually the person responsible for the Mortality Registry in Andalusia who contacts other Organisations such as: Health Department, number of contacts: weekly".

"INE number of contacts, two or three a week for ICD-10 codes"

Availability of and access to mortality data

Interviewees generally agreed that data is available when required; the lengthy time to dissemination is a known factor that is taken into account when planning its usage; difficulties refer to accessibility to disaggregated data as a result of the Law on confidentiality that protects individualised data.

"Except for on-the-spot instances of immediate surveillance - that the data source is not designed for - data are always available in time".

"It's a problem of access to micro data and individualised data, given the enormous legal restrictions it's practically impossible to use the data for healthcare purposes. "

Negative issues in the analysis and interpretation of mortality data

A number of the experts consulted identified the Secrecy Law for Statistics as a hindrance to access individualised data on mortality that would enable improved interpretation. Other issues mentioned included the geographical analysis in particular communities, together with monitoring and surveillance of diseases of major importance for public health. Further negative aspects quoted include the non-existence of a single dedicated unit for data analysis and interpretation; the need to encourage units for the analysis and interpretation of mortality data as functional units that are sufficiently resourced to strengthen the remaining management units in the Organisation within the autonomous Regions

"The Secrecy Law on Statistics means that disaggregated causes of death cannot be analysed in towns with fewer than 5000 inhabitants..."

"For several years now, a series of indicators has been calculated, but either no interpretation or analysis at all is made of these indicators or it is poorly implemented and there is a rift between the person calculating the indicator and the person interpreting it ..."

Existence of a Strategic Plan regarding Mortality

According to the experts consulted there is no specific strategic plan in place for the mortality surveillance system in Spain; actions aiming to lower mortality rates, however are included in the aims of strategic plans as well as situation analyses that use information compiled from mortality data.

"Not as such. However, there are Strategic Plans, guidelines for health policy of the Regional Administration (Andalusian Health Plan, Integrated Cancer Plan, Andalusian Diabetes Plan …) that state actions that are intended to achieve a reduction in mortality rates according to causes…"

"There are the goals contained in Andalusia's Health Schemes"

Strategies for Improvement

It was felt that setting up a unit that would analyse data bases, both on mortality and from other sources from a healthcare standpoint and that would enable information to be delivered for planning, research and programme evaluation in the various Autonomous Regions would provide a positive thrust to scientific output and would favour detailed understanding of the health status of the various populations.

"Analysis Department for Health Information, both on mortality and from other available sources..."

"Research aimed at steering healthcare provision with a high standard of scientific output"

Positive Points	Negative issues
♦ Improvements to the system over time ♦ Clear usefulness of information obtained through the existing mortality data management system ♦ Existence of agreements between Mortality Registries, Health Departments and Statistics Office	♦ Problems in accessibility to certain databases, particularly for individualised information ♦ Quality of certain registers ♦ Absence of specific units for data analysis and interpretation in some of the regions consulted ♦ Lack of qualified human resources to analyse and interpret mortality information

Proposals for Improvements

- Set up a department that would analyse and pool mortality databases and other health information sources

- Devise regular reports of health status monitoring among the population