# Mortality Information System in Portugal: transition to e-death certification

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## Abstract

Inability to invest in and develop mortality information systems has been considered the single most critical failure in health information systems and there is a recognized urgent need to improve mortality statistics and cause of death information. Although there have been major developments in information technology with the potential to improve public health information systems, mortality data collection has largely remained unchanged in most countries, mainly due to legal and operational barriers. Electronic registration and certification of death certificates has the potential to improve the quality and timeliness of mortality statistics. The Mortality Information System in Portugal has, since 1950, been a paper-form death certification model. The Portuguese Directorate-General of Health recently implemented electronic death certification as the basis of a new mortality information system. A strategic multistep approach, defined by geographic areas of the country, was planned for implementation of the system. National implementation was completed in December of 2013 and 100% e-death certification was achieved beginning January 2014. This article reports the implementation process and describes the newly established mortality information system.

## Keywords

electronic death certificate; mortality information system; mortality statistics; mortality surveillance

## Introduction

Mortality information is a critical cornerstone of public health surveillance and is at the core of health policy decision making. Inability to invest in and develop mortality information systems has been considered the single most critical failure in health information systems and there is a recognized urgent need to improve mortality statistics and cause of death information (1, 2). Even for countries where complete coverage has been achieved, the quality of mortality statistics and cause of death information remains suboptimal (3). Although there have been major developments in information technology with the potential to improve public health information systems (4), mortality data collection has largely remained unchanged in most countries, mainly due to legal and operational barriers.

Transition to electronic mortality information systems from paper-based systems often requires changing laws and regulations (e.g., electronic signatures, data protection and confidentiality). In addition there is a reluctance to adopt and use new systems by data providers (physicians and other medical or legal professionals outside the healthcare sector).

Electronic registration of death certificates has the potential to improve the quality and timeliness of mortality statistics (5). Electronic mortality information systems can be based on two different approaches: 1) death certificates can be registered electronically using information entered from paper records (e-death registration) or, 2) through a web-based technology, where records are created and sent electronically to all institutions involved in the death certification process (e-death certification). With e-death certification, institutions involved in the death certification process interact solely electronically. As a result, an advantage of e-death certification is the potential to collect other relevant information that complements the death certificate for cause of death coding and data validation purposes.

## Death Registration and Certification in Portugal

Mandatory civil registry of death in Portugal was instituted in 1911, along with closing of church registries (6). The Mortality Information System in Portugal has, since 1955, been a paper-form death certification model with cause of death information in accordance with World Health Organization recommended guidelines (3). Cause-of-death certification was, and still is, performed by a qualified medical doctor and is mandatory for all deaths that occur in Portugal and fetal deaths with more than 22 weeks of gestational age. A national mortality data base was created by combining civil registry information with cause of death coding performed manually at the Directorate-general of Health (DGS) in accordance with the International Statistical Classification of Diseases and Related Health Problems (ICD). The previous system in Portugal had timeliness unsuitable for epidemiological surveillance, as paper death certificates needed to be collected centrally, a process that usually took several months, followed by additional time needed for retrieving and coding of cause of death information. A major challenge, however, was the accuracy and completeness of the information obtained from paper death certificates because of difficulties due to problems with handwriting, improper cause-of-death certification and poor description of cause of death, an inability to collect and use cause of death information from autopsy reports available after death certification, and an inability to do multiple coding of causes of death.

This resulted in a high proportion of ill-defined causes of death and so-called "garbage codes" (>20%) (5).

To improve timeliness, accuracy and overall quality of information the Portuguese Directorate-general of Health implemented electronic death certification as the basis of the mortality information system (7). This article reports the implementation process and describes the established mortality information system since 2014. The success of the transition to an electronic mortality information system in Portugal can be viewed as a model for other countries.

## Development of the Electronic System

Between 2007 and 2013 the Directorate-General of Health coordinated a joint working group involving the Portuguese Ministries Health, Justice and Internal Administration (including the Shared Services of Ministry of Health, the Institute of Civil Registries, Public Prosecution Services, Police Authorities, National Institute of Legal Medicine and Forensic sciences, National Institute of Medical Emergency and the National Institute of Statistics) and the National Medical Board with the aim of reviewing the legal framework and operational procedures for death certification in Portugal and the development of a new legal framework based on e-death certification and a web based software to support the electronic mortality information system. The development of the legal framework for dematerialization of death certificate was concluded in 2012 with publication of a law and four decree-laws in the Portuguese Official Journal (8, 9, 10, 11, 12) and the approval of the Portuguese Data Protection Authority. The new legal framework requires electronic certification of all of deaths occurring in Portugal through an electronic registry of death certificates and electronic transmission of death certificates for civil registration purposes. Additionally, it requires the electronic registry of Clinical/Circumstantial Information Forms and forensic autopsy reports, electronic registry of clinical autopsies and the electronic connection of agencies involved in the process of death certification.

A web-based software SICO (Sistema de Informação dos Certificados de Óbito) was developed by the Shared Services of the Ministry of Health to support the framework described above (available through https://servicos.min-saude.pt/sico). Figure 1 presents an overview of the systems' architecture.. This software is accessed by all doctors in Portugal through a high security password validated by the Portuguese Medical Association. It is also accessed by the Public Prosecution Service and Police Authorities through a high security password provided by Ministries of Internal Affairs and Justice.

Death certificates registered by medical doctors are sent through web service technology to a central database maintained by the Institute of Civil Registries and made available to local civil registry offices. Death certificates for suspected violent deaths and deaths of uncertain cause are deferred until the Public Prosecution Service and the Institute of Legal Medicine and Forensic Sciences can provide preliminary information about the cause of death, as a forensic autopsy is mandated in these circumstances. The final autopsy report is also registered in SICO and used for coding cause of death.

Portuguese legislation requires a Clinical and Circumstantial Information Form to be completed by the certifying doctor for suspected violent deaths and deaths of unknown cause. This form is registered in SICO and made available via web service to the Public Prosecution Service for investigation. Causes of death reported on death certificates and registered in SICO are available to the Directorate-General of Health (DGS) (Ministry of Health) in real time for mortality surveillance and cause-of-death coding. Once information is received and coded, it is sent through a webservice to the National Institute of Statistics. SICO also allows for queries to the National Medical Emergency Institute database in all situations where emergency care was provided directly prior to the death of an individual. This information is then made available to the certifying doctor and also for cause of death coding performed at DGS.

A secondary, although important, function of SICO is to update the National Health Service (NHS) Users Registry to remove decedents from the health insurance coverage plan, which is also done through a web service. The NHS users Registry is the national registry of people insured by the National Health Service, which is used as the basis for planning and evaluation of several disease prevention programs and provision of health services.

## Implementation

A strategic multistep approach, defined by geographic areas of the country, was planned for implementation of the system. It included a pilot phase; training in software use for public and private doctors, forensic medical pathologists, the Public Prosecution Services and Police Authorities; and a national stepwise rollout. A regional framework for the implementation was crucial to achieve a coherent force for change, and a solid basis for a multi-organizational transition from a paper-based to an electronic system. The regional approach allowed for institutions in defined regions to be prepared simultaneously for change and also allowed a closer monitoring and support of field work.

The pilot phase started in Coimbra University Hospital Centers in November 2012. During the trial phase of one month the software was tested and adjustments were made to correct system errors and to respond to the end-users' feedback. These adjustments arose mainly from difficulties in using the software, application errors, operational needs not identified in preliminary testing and from information technology adjustments to webservice dataflow.

The national stepwise rollout started in December 2012. During this period a national training plan was implemented by a core team based at DGS and by regional teams (Regional Health Administrations) responsible for training in their specific geographical areas. Each geographic area started using the system at a specific date defined by consensus of the Regional Health and Justice Administrations and approved by the Ministry of Health. A detailed table showing when each region of the country implemented the system and the implementation period is presented in table 1. National implementation was completed in December of 2013 and 100% e-death certification was achieved beginning January 2014.

# Relevant Changes and Improvements

## Data quality and cause of death coding

The transition to e-death certification in Portugal has resulted in both operational and epidemiological improvements in mortality surveillance, as well as improvements in the quality of collected data. From an operational point of view e-death certification allows for more efficient communication as participants interact electronically and ensures increased security and confidentiality of personal information (death certificate is not printed). This improves the process of death certification from a social perspective and also the reliability of the data collected because doctors can be more confident that health and personal data will not be of public knowledge (unlike paper-based death certification).

From an epidemiologic perspective, e-death certificates have substantially improved the timeliness of access to mortality data from approximately 6 months to real time, i.e., as soon as the death is registered. Electronic certification has also improved the completeness and quality of data through automatic filling of demographic data (drawn from the civil registry and based on a national identification number), automatic error checking and mandatory fields. Corrections and amendments can be made to the original record and corrected simultaneously in the database. Cause-of-death coding is also improved by avoiding the need to decipher handwritten entries and mandatory completion of relevant fields for cause of death coding (for example, pregnancy at time of death and specific fields for fetal and neonatal deaths).

A preliminary analysis of improvements in data quality shows that we are able to collect data on fields of the death certificate that were not previously available in the database before (e.g., "additional information" field often has important information on cause of death, and the autopsy field, that allows coders to know if an autopsy was performed and to access the autopsy report before coding). Also, a substantial amount of duplicate information was gathered directly from doctors for fields that were already available from the Civil Registry. Paper death certificates also had several fields left unfilled, even though this information was collected at the civil registry.

As result of electronic communication between institutions involved in death certification, other relevant information is associated with the death certificate and can be used to validate, specify or rectify cause of death coding. In a sample of 40039 e-death certificates registered in 2013, 16,4 % had information available on cause of death in addition to that reported on the death certificate. National emergency forms were available in 6,9 % of all deaths, autopsy reports and clinical/circumstantial forms in 9,9 % of all deaths (50% of suspected violent deaths and deaths of unknown cause in the sample used). Clinical and Circumstantial Forms and autopsy reports are especially important for non-natural deaths as these often provide detail on the circumstances of death and nature of injury that can substantially improve the specificity of cause of death coding. Similarly, these may be used to identify the cause of deaths that are initially certified as unknown. Formal and complete evaluation on the actual impact of these factors in quality of cause of death coding will be done once a complete year of coded e-death certificates data (2014) is available.

### Mortality surveillance

A real-time, online mortality surveillance module for SICO (e-VM: *Vigilância de Mortalidade Electronica*/Electronic Mortality Surveillance) was also developed and made available online at https://servicos.min-saude.pt/sico/faces/estatisticas.jsp?cpp=1. This surveillance system allows for real-time monitoring (it refreshes every 10 min) of the number of deaths occurring in Portugal and provides comparison with data from previous time periods. It also allows surveillance of natural deaths and non-natural deaths in real time making this data more sensitive for public health purposes, such as heat wave surveillance and flu epidemic surveillance.

## Conclusions and Next Steps

Transition to electronic, real-time mortality information systems requires strong core leadership and inter-jurisdictional cooperation in both development and implementation. The experience in Portugal shows that a regional approach to implementation is an effective way to transition to electronic death certification. The transition in Portugal was completed in one year and 100% coverage was achieved in two years. These achievements were, in large part, due to an adequate legislative framework that defined a horizontal approach to the functions of the State in the vital registration system, good collaboration between all Ministries involved and shared responsibility for implementation of the system between central, regional and local levels of the Ministry of Health. The regional stepwise implementation allowed for close proximity of Health institutions, public prosecution services, police authorities and civil registry services to the core implementation team that was crucial for support during the transition period in each region of the country. Implementation of e-death certification is the first step to improve mortality information in Portugal. Next steps include improving electronic error checking and alert functions for medical certifiers and coding staff, improve the registry of clinical and forensic autopsies, development of a process for epidemiologic investigation of ill-defined deaths and deaths of unknown cause with local health authorities, development of integrated automatic coding functionality, and electronic integration with other relevant health information systems.

## Acknowledgments

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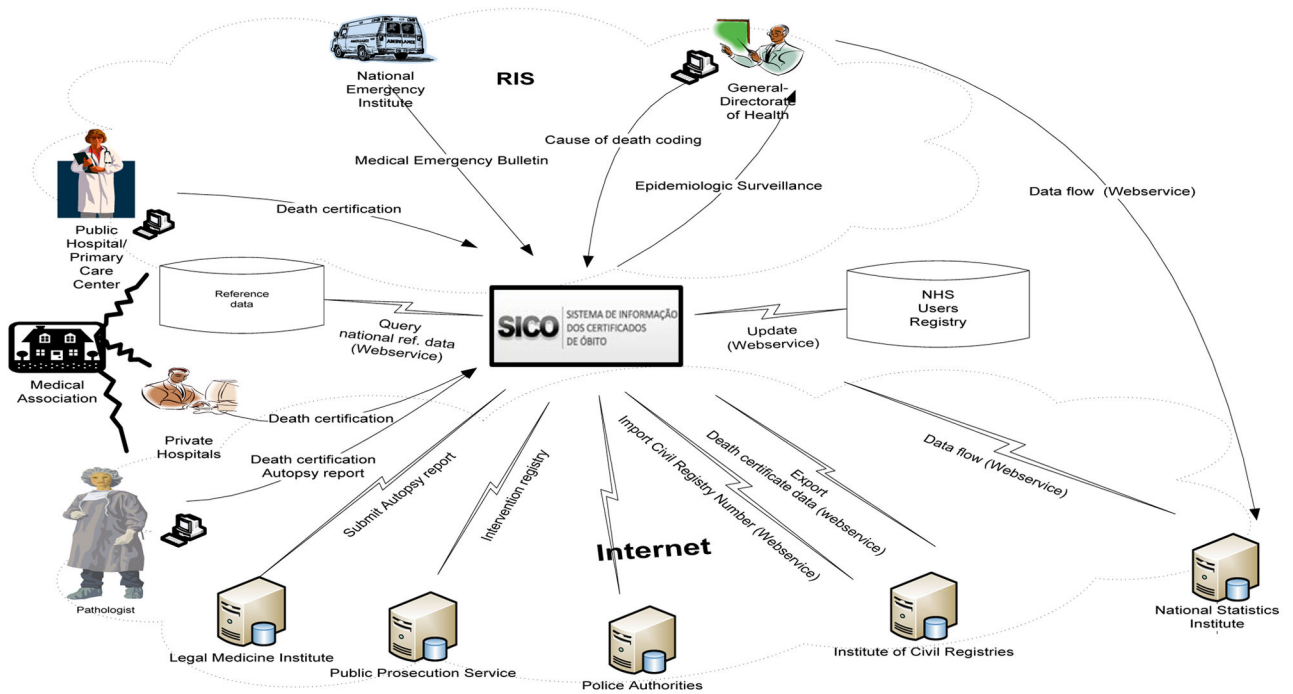
**Figure 1.**
Portuguese Electronic Mortality Information System Architecture Overview. *Notes*: SICO:
Sistema de Informação dos Certificados de Óbito (Death Certificates Information System);
NHS: National Health Service; RIS: Internal Health Network

**Table 1**

E-death certification implementation period in Portugal, by region of the country

| Region of Portugal | E-death certification implementation period | |
|---|---|---|
| | Start date | End Date |
| **Center** | 15 November 2012 | 15 June 2013 |
| **Madeira** | 18 February 2013 | 15 October 2013 |
| **North** | 1 March 2013 | 1 September 2013 |
| **Algarve** | 5 June 2013 | 1 July 2013 |
| **Lisbon and Tagus Valley** | 5 June 2013 | 15 November 2013 |
| **Alentejo** | 10 June 2013 | 5 September 2013 |
| **Azores** | 1 July 2013 | 4 November 2013 |

*
E-death certification implementation period for National Health Service institutions in each Portuguese region. Private health sector was included in 1st January 2014, except in the autonomous region of Azores (4th November 2014).