

IMPROVING THE MORTALITY INFORMATION SYSTEM IN PORTUGAL

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Summary: The inability to invest in and develop mortality information systems has been considered the single most critical failure in health information systems. Health information systems are an integral part of health systems. This includes strengthening not only the information content but also the information systems themselves, health information platforms and infrastructure. In this article, particular focus has been placed on the regional and inter-sectoral approach to implementation adopted in Portugal. The article shows how legal and operational barriers have been overcome and focuses on the potential of the new system to improve the quality and timeliness of mortality statistics.

Keywords: *Electronic Death Certificate, Mortality Information System, Mortality Statistics, Mortality Surveillance, Portugal*

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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] Even where complete coverage has been achieved, the quality of mortality statistics and cause-of-death information remains suboptimal.^[2] Although there have been major developments in information technology with the potential to improve public health information systems,^[3] mortality data collection has remained

largely unchanged in most countries, mainly due to legal and operational barriers. Transition to electronic mortality information systems often requires changing laws and regulations (e.g., electronic signatures, data protection and confidentiality). In addition, for the optimal application of these systems there is a need to invest in ensuring that these systems are made user-friendly for health professionals and the range of professionals outside the health care sector who will provide information to the system.

Electronic registration of death certificates can improve the quality and timeliness of mortality statistics.^[4] There are two approaches to developing electronic

mortality information systems: 1) death certificates are registered electronically using information from paper records (e-death registration) or, 2) all institutions involved in the death certification process enter information directly into an electronic system without relying at all on paper records (e-death certification). The latter – e-death certification – is a more efficient means of synchronizing data from various institutions and ensuring a more complete and accurate record.

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Death Registration and Certification in Portugal

Mandatory civil registration of deaths in Portugal was instituted in 1911, along with the closing of church registries.^[1] Until now, The Mortality Information System in Portugal has been based primarily on paper-based death certification with cause-of-death information registered in accordance with World Health Organization recommended guidelines.^[2] In Portugal, cause-of-death certification was, and still is, performed by a qualified medical doctor and is mandatory for all deaths including foetal deaths (of more than 22 weeks of gestational age).

A national mortality database 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). This system did not allow for timely epidemiological surveillance and depended on paper death certificates being collected centrally, a process that usually took several months, followed by time needed to retrieve and code cause of death. Another challenge was the accuracy and completeness of the information obtained from paper death certificates because of difficulties with reading handwriting,

Table 1: E-death certification implementation period in Portugal, by region of the country

Region	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

Source: Authors' own.

Note: E-death certification implementation period for NHS institutions in each Portuguese region. The private health sector was included on 1 January 2014, except in the autonomous region of Azores (on 4 November 2014).

improper cause-of-death certification, poor descriptions 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 register multiple causes of death. This resulted in a high proportion of ill-defined causes of death, or so-called “garbage codes” (>20%).^[3]

To improve timeliness, accuracy and overall quality of information the Portuguese DGS implemented electronic death certification as the basis of the mortality information system.^[4]

Development of the electronic mortality information system

Between 2007 and 2013, DGS coordinated a joint working group involving the Portuguese Ministries of 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. Their aim was to review the legal framework and operational procedures for death certification in Portugal and to develop a new legal framework to guide e-death certification and web-based software to support the electronic mortality information system.

The development of the legal framework to guide the digitisation of death certificates was concluded in 2012 with publication of a law and four decrees in the Portuguese Official Journal^{[5][6][7][8]} and the approval of the Portuguese Data Protection Authority. The new legal framework requires certification of all deaths in Portugal through an electronic registry and the electronic transmission of death certificates for civil registration purposes. Additionally, it requires that an integrated electronic system is set up to synchronize and link electronic clinical and circumstantial information forms, electronic forensic autopsy reports, and electronic clinical autopsies.

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 system described above (available through <https://servicos.min-saude.pt/sico>). 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 the Ministries of Internal Affairs and Justice.

Upon completion, death certificates registered by medical doctors are forwarded 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 first processed by the Public Prosecution Service and the Institute of Legal Medicine and Forensic Sciences in order to allow for a legally required forensic autopsy before they are forwarded to the central database.

Portuguese legislation requires that a clinical and circumstantial information form be completed by the certifying doctor for deaths of unknown cause and suspected violent death. Once this form is registered in SICO it can be made available to the Public Prosecution Service for investigation.

Causes of death reported on death certificates and registered in SICO are available to the 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 web service 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 but nonetheless important function of SICO is to update the National Health Service (NHS) Users Registry to remove decedents from the health insurance coverage plan. The NHS Users Registry is the national registry of people insured by the NHS, which is used as the basis for planning and evaluation of several disease prevention programs and provision of health services.

Implementation

A strategic multi-step and multi-sectoral approach, across the country, was taken to implement 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 achieving a coherent force for change, and a multi-organizational transition to the electronic system. The regional approach allowed for institutions across the country to be prepared simultaneously for change but also allowed for closer monitoring and support.

The pilot phase started in Coimbra University Hospital Centers in November 2012. During the one month trial phase the software was tested and adjusted to correct system errors and to respond to the end-users' feedback. Adjustments mainly included resolving difficulties in using the software, application errors, operational needs not identified in preliminary testing and web service data flow.

The national stepwise roll-out 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. Each region started using the system on a specific date agreed upon by the Regional Health and Justice Administrations and approved by the Ministry of Health. **Table 1** shows when each region initiated and finalized the transition to the new mortality information system.

Implementation across the country was completed in December 2013 and 100% e-death certification was achieved at the beginning of January 2014.

Improved 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 data collected. From an operational point of view, e-death certification allows for more efficient communication as participants interact electronically and can minimize confidentiality breaches with the elimination of paper records of personal information. This improves the legal and administrative process of death certification. It also ensures that doctors do not have to disclose more sensitive

health or personal data information that can stigmatize the deceased or their family as was reported to occur with paper-based death certification.

From an epidemiologic perspective, e-death certificates have substantially improved the timeliness of access to mortality data. While previously this information was only available after six months it is now available as soon as the death is registered. Electronic certification has also improved the completeness and quality of data through the use of automatic form-filling of demographic data drawn from the civil registry and based on a national identification number, automatic error checking and the use of mandatory field features. Corrections and amendments can be made directly in the database. The need to decipher handwritten entries is avoided and the use of mandatory fields can be used to ensure information that is frequently neglected is complete (e.g., pregnancy at time of death, date of labour and data regarding previous pregnancies and demographic information of the mother for foetal and neonatal deaths).

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A preliminary analysis of improvements in data quality has shown that previously unavailable data has been made available in death certificates (e.g., whether the autopsy was performed; access to the autopsy report before coding). Also, a substantial amount of duplication of information from different sources has been minimized. Previous data collection methods required that different entities of the state register the same information. Now, for example, doctors do not need to write in the death certificate that a forensic

autopsy was performed as that information is already directly available from public prosecution services.

As a result of electronic interoperability between health software and civil registry software (e.g., between the institutions involved in death certification), additional information has been linked with the death certificate and can serve to validate, specify or rectify cause-of-death coding. In a sample of 40,039 e-death certificates registered in 2013, 16.4% had additional relevant information available on cause of death. National emergency forms were available in 6.9% of all deaths, autopsy reports and clinical and circumstantial information forms in 9.9% of all deaths (50% of suspected violent deaths and deaths of unknown cause in the sample used). Clinical and circumstantial information 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.

A more complete evaluation on the impact of this new mortality system on quality of cause-of-death coding will be conducted once a complete year of coded e-death certificates data (2014) is made available.

Conclusions and next steps

Transition to electronic, real-time mortality information systems in Portugal involved strong core leadership and inter-jurisdictional cooperation in both development and implementation from the DGS and the inter-jurisdictional group. The experience has also shown that a regional approach to implementation is an effective way of transitioning to electronic death certification. The transition in Portugal was completed in one year and 100% coverage was achieved in two years. These achievements were also 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 intersectoral stepwise approach allowed for input from a range of sectors (health institutions, public prosecution services, police authorities and civil registry services) that proved to be crucial for supporting the transition period in each region.

Implementation of e-death certification is the first step to improving mortality information in Portugal. Next steps will include: improving electronic error checking and alert functions for medical certifiers and coding staff; improving the registry of clinical and forensic autopsies; developing a process for epidemiological investigation of ill-defined deaths and deaths of unknown cause with local health authorities; developing an integrated automatic coding functionality; and electronic integration with other relevant health information systems.

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