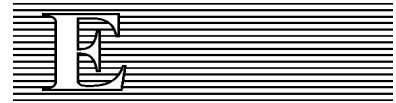




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## **Generating reliable cause-of-death information within a civil registration and vital statistics system**

**An overview of concepts, standards  
and implementation**

**World Health Organization**

July 2012



African Union Commission



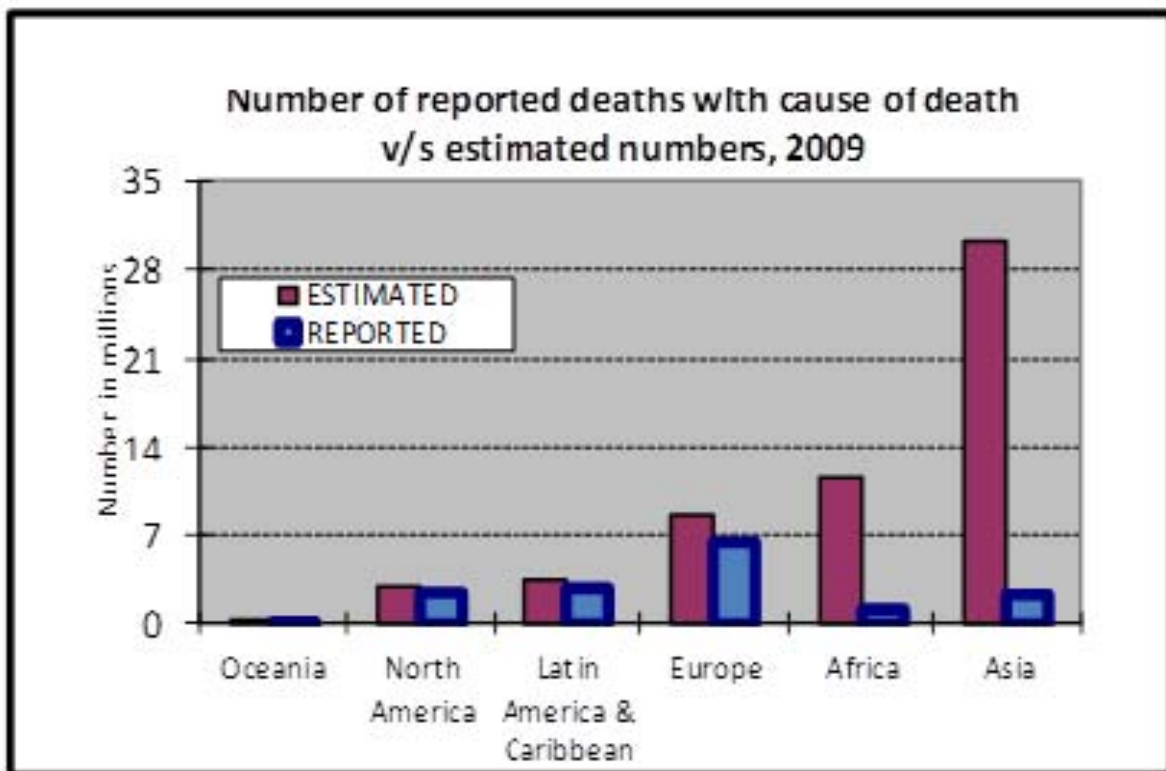
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## I. Introduction

1. Reliable knowledge on the mortality and causes of death of a population is critical for policy making. Civil registration and vital statistics systems (CRVS), when functioning properly, are the most reliable source of continuous data on fertility, mortality and causes of death. Cause-specific mortality statistics by age, sex and geographic location, derived from such systems are instrumental in guiding national, regional and global policies and priorities for health and development.
2. This paper describes the current situation in Africa, including the obstacles that need to be overcome to obtain good cause-of-death statistics, the requirements of a good system, the international standards for cause of death registration, and suggests priorities for improvement of current practices.

## II. Counting the dead and what they died from – the current situation

3. One of the most challenging products of the CRVS is cause-of-death information. The level of registration of deaths in some countries could be high but the information on the cause of death is either absent or of low quality. Overall only around one-third of all the deaths in the world are recorded in civil registries with the cause-of-death information<sup>i</sup>. There is a huge disparity in generating cause-of-death information across continents. In Asia and Africa with the largest number of deaths, capturing cause-of-death information remains a big challenge (see Figure). In Africa, South Africa, Egypt, Mauritius and Seychelles are the only countries where all to nearly all the dead are counted with their respective cause of death information<sup>ii</sup>. On the same continent, the remaining countries have such data only for very limited areas or part of their population.



### **III. Generating cause-of-death information**

4. In settings where most deaths take place in health facilities, the health sector plays a key role in notifying and registering such events. In Egypt and some other countries the Ministry of Health is responsible for registering all births and deaths, including those that occur outside health-care facilities. The Ministry of Health is also responsible for compiling vital statistics. In health facilities, the presence of doctors enables the medical certification of the cause of death. When the medical certificate of cause of death has been completed by the doctor, the family of the deceased would take it to the local civil registrar to register the death. The registrar would complete the death registration form with the usual administrative information on the deceased and would also include the cause of death obtained from the medical certificate. The registrar would then issue a death certificate which is the legal document that allows the family of the deceased to proceed with the burial and perhaps claim for social benefits or inheritance.

5. On the government side, the chain of procedures still continues. The information on the cause of death is then coded according to the International Statistical Classification of Diseases and Related Health Problems (ICD)<sup>iii</sup>. Depending on the country, the coding could either be done by the Ministry of Health or another designated body. Every record of the deceased is then compiled including the ICD codes. The chain of procedures involves several ministries and agencies such as the civil registration authorities, the Ministry of Health, the Ministry of Justice, the Ministry of the Interior and the National Statistical Office.

### **IV. Applying standards in cause-of-death data collection**

#### **Definition of the causes of death to be recorded**

6. The World Health Assembly adopted rules and guidelines for the certification and coding of cause of death. In 1967, it defined the causes of death to be entered on the medical certificate of cause of death as “all those diseases, morbid conditions or injuries which either resulted in or contributed to death and the circumstances of the accident or violence which produced any such injuries”. The purpose is to ensure that all relevant information is recorded and the certifier does not select some conditions for entry and omits other information.

#### **Definition of the underlying cause of death**

The underlying cause of death should be used for primary tabulation.

7. Underlying cause of death is defined as “the disease or injury which initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury” in accordance with the rules of the International Classification of Diseases.

8. From the public health perspective, it is necessary to specify the chain of events, distinguishing the precipitating or underlying cause from consequences of the condition. For example someone who suffered from gangrene, vision loss and diabetes and died subsequently, the underlying cause of death is diabetes.

## The International Form of the Medical Certificate of the Cause of death

9. The above principles should be applied uniformly by using the International Form of Medical Certificate of Cause of Death, as shown below, which is designed to facilitate the selection of the underlying cause of death when two or more causes are recorded. Part I of the form is for diseases related to the train of events leading directly to death, and Part II is for unrelated but contributory conditions.

10. However in practice, there could be some variations in the medical certificate of the cause of death as used by countries. Nevertheless the concept of the underlying cause of death is still applied.

11. In all settings, the medical practitioners or other qualified certifiers should use their clinical judgement in completing the medical certificate of cause of death.

INTERNATIONAL FORM OF MEDICAL CERTIFICATE OF CAUSE OF DEATH		Approximate interval between onset and death
<b>Cause of death</b>		
<b>I</b> Disease or condition directly leading to death*	(a) .....	.....
	due to (or as a consequence of)	
<b>Antecedent causes</b> Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last	(b) .....	.....
	due to (or as a consequence of)	
	(c) .....	.....
	due to (or as a consequence of)	
	(d) .....	.....
<b>II</b> Other significant conditions contributing to the death, but not related to the disease or condition causing it	.....	.....
	.....	.....
*This does not mean the mode of dying, e.g. heart failure, respiratory failure. It means the disease, injury, or complication that caused death.		

## The International Classification of Diseases (ICD)

12. The ICD is a classification system developed by WHO that provides codes to classify diseases and a wide range of signs and symptoms, abnormal findings and external causes of injury or disease. It is the standard diagnostic tool for epidemiology, health management and clinical purposes. It contains over 14,000 different codes and is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and reasons for primary, secondary and tertiary health care encounters.

13. The ICD is revised periodically and is currently in its tenth edition. The ICD is widely used for morbidity and mortality statistics. Most countries which are implementing the ICD are using the 10<sup>th</sup> revision. The 11<sup>th</sup> revision is currently being developed. The use of the ICD allows comparability across countries statistics and contributes to a better understanding of the health of nations over time.

14. Coding of the causes of death is essentially assigning an ICD code to each cause written on the death certificate. The coders select the underlying cause of death by following the ICD selection and modification rules and guidelines.

## **V. Setting the right framework**

### **Legal framework**

15. A CRVS system operations are driven by laws and regulations which enforce the registration of vital events including deaths. For causes of death, the laws or regulations generally specify those officials who are authorised to certify the causes of death. The laws should also set the conditions necessary before issuance of the death certificate to the survivors of the deceased particularly in the case of unnatural deaths.

### **Administrative framework**

16. The task of registering a death and issuing a death certificate is the responsibility of the authority or ministry responsible for civil registration. Accessibility of the general population to civil registries influences to a large extent the frequency of registered events. In some hospitals in Kenya, nurses act as registration agents making it easier to register an event. Depending on context, each country has its network of civil registration agents or close-to-community agents to strengthen its capacity in reporting and registering vital events. Geographical dispersion of the population also means that it can be necessary to implement out-reach system such as mobile registration offices.

### **Collaborative framework**

17. Obtaining cause-of-death information requires primarily the collaboration of the health sector. Authorised certifiers fall under the aegis of the ministry of health or the ministry of justice in the case of certifying deaths from non-natural causes. For deaths occurring at home, provisions in the legislation and regulations are important to ensure how those deaths would be certified. A clear definition of duties and responsibilities of each authority is essential. Depending on the country the coding and compilation of the cause-of-death information is carried out either by the Ministry of Health, the civil registration authority or the national statistical authority.

## **VI. Encountering problems in identifying the cause of death**

18. Data on causes of death collected by WHO as a part of its mandate to collect information on health and health-related conditions indicate that since 1950 that there has been progress in obtaining such cause-of-death statistics until mid-1980s. The situation has stagnated since and there have been very few new countries that have started to produce reliable cause of death statistics While the high-income countries are capable of producing cause-of-death statistics, several middle-income countries are also showing improvement in this area. Most of the countries which do not report cause-of-death information are low- and lower-middle income countries.

19. In Africa and Asia many countries do not have cause-of-death information that is representative of their country. Some have such information only for hospital deaths while others only have local demographic surveillance sites which generate such information for a specific population. Others rely on household surveys to obtain information on some specific causes. In some countries, population censuses may include a specific module to capture information on specific causes such as causes of maternal deaths for example.

20. Because of the complexity of the framework in which cause-of-death statistics are generated, any dysfunctional elements in the chain of procedures would impact on the output. As cause-of-death information is a product of the public administration, government commitment is crucial should such a product be available on a routine basis. It is clear that a weak or dysfunctional CRVS system would not be conducive to the generation of cause-of-death statistics. There are several areas where the governments need to review, revise, update or strengthen but the main ones are as listed below.

### **Inadequate or outdated legislation**

21. Where the legislation is inadequate or outdated for cause-of-death reporting, enforcement will be difficult. Hence, non-compliance of the public to the laws is not seen as a fault but rather as the consequence of poor public administration.

### **Lack of infrastructure and insufficient budget**

22. In low-income countries the lack of infrastructure is a major reason for the non-registration of vital events. Where the civil registration offices are not close to residential areas, spending several hours and travel costs to reach a civil registration office is deterring to families. Irregular, non-reliable or non-existent public transport systems further complicate the situation.

23. When the government budget does not provide for civil registration offices that are properly staffed and equipped, delays in receiving the public and issuance of certificates discourage the public.

### **Lack of medically-qualified certifiers**

24. For deaths occurring in health-facilities, doctors are present to certify the cause of death. However in low-income countries, it is often very difficult or even impossible to find a medical doctor in remote areas. In such cases, even with a very good legislation in place, it is difficult for the government to implement it and for the public to abide by it.

25. To tackle the absence of medical certifiers, some countries have made provisions in the laws or regulations. In Kenya, the Assistant-Chiefs are authorized to give their best judgment of the cause of death. However, such lay-persons are not medically-qualified to certify the cause of death rendering the exercise totally hazardous. In contrast for deaths from non-natural causes such as road traffic accident or homicide, the police are requested to certify them.

### **Lack of training in certification and coding**

26. Considering that hospitals have qualified personnel, it seems reasonable to believe that cause-of-death information obtained there is of a good standard, meaning that the doctors would have correctly certified the cause of death and the coding of the causes is carried out according to the rules of the ICD. In reality even in some high and middle-income countries, training of the authorised medical certifiers in the completion of the medical certificate of cause of death is inadequate or nonexistent. Badly completed death certificates do not enable the coders to select properly the underlying cause of death.

27. Cause-of-death coding according to ICD rules and guidelines is either done at a central or decentralized level. Lack of ICD manuals and training for coders to fulfill their tasks are commonly seen in many hospitals in low-income countries.

28. Both certification and coding of the cause of death are often considered purely as administrative tasks and thus do not feature as priority areas for development or improvement.

### **Poor or non-existent collaboration among various public authorities**

29. The lack of communication between public authorities hinders information exchange from the health authorities to the body responsible for civil registration and subsequently to the national bureau of statistics generally responsible for the release of official statistics.

## **VII. Envisioning solutions**

### **Mobilising support**

30. For CRVS systems to produce cause-of-death statistics, they would need the ongoing collaboration of several public authorities. Governments have to show commitment by supporting the framework which sets the responsibilities and duties around certification, registration and cause-of-death coding. They can also influence changes in legislation and adopt resolutions to improve cause-of-death reporting following an assessment of the current situation. They can mobilize financial or human resources as needed. At the regional level, more pressure to obtain information on causes of death from individual countries to monitor internationally-set goals would help to raise awareness of the importance of obtaining such information.

### **Using WHO standards**

31. The WHO standards for implementing cause-of-death reporting are the outcomes of a thorough long-time collaboration of a wide network of experts and professionals involved in public health. When countries adopt these standards, they align themselves with the best on-going practices. Standards ensure comparability of information across countries and enable health professionals to learn from other countries epidemiological evolution over time through their cause-of-death statistics. They also foster exchange of expertise between countries.

### **Training certifiers and coders**

32. Training of certifiers in completing correctly the death certificates and coders in selecting and coding the right underlying cause of death needs to be carried out regularly. Universities or teaching hospitals can be engaged to deliver such training as part of their teaching curriculum. Standard training materials as developed by WHO are available for free<sup>iv</sup>. When necessary, training materials may be adapted to local situations with emphasis on the frequent diseases or conditions that are prevalent in a specific population or area.

### **Conducting verbal autopsy**

33. In settings where the majority of deaths still occur at home and where civil registration systems do not function, there is little chance that deaths occurring away from health facilities will be recorded at all, let alone certified as to the cause or causes of death. As a partial solution to this problem, verbal autopsy has become the primary source of information about causes of death in populations lacking vital registration and medical certification. Verbal autopsy is an interview carried out with family

members and/or caregivers of the deceased using a structured questionnaire to elicit signs and symptoms and other pertinent information that can later be used to assign a probable underlying cause of death. Verbal autopsy is an essential public health tool for obtaining a reasonable direct estimation of the cause structure of mortality at a community or population level, although it may not be an accurate method for attributing causes of death at the individual level<sup>v</sup>.

### **Using innovation**

34. Infrastructural barriers impede the registration of vital events. To overcome them, some countries have already integrated the use of mobile and wireless technologies to support the registration of vital events. The growing sophistication of the wireless networks and affordable and more powerful handsets offer the possibility of citizen-focused services<sup>vi</sup>. For example, community agents can use mobile phones to notify events, officially-designated registration agents can follow-up closely to ensure the formal registration of the events and finally the information can be transferred in real time to a central authority. As mobile phones can display questionnaires, they can be used for conducting verbal autopsy to generate causes of death.

### **Using cause-of-death statistics**

35. More focus will be brought to cause-of-death statistics if they are being disseminated and used on a regular basis. There is a general reluctance to use incomplete data or data of poor quality. However even if the data are imperfect, they can allow some insights into a country CRVS system in generating cause-of-death information as well a general overview of the main conditions that afflict the population. Provided that the limitations of the data are clearly indicated, the data should be made public through government web sites or regular publications. This would facilitate access to those statistics for decision-makers and other users such as academic researchers. In the long run it will also build awareness of the need to generate good cause-of-death information within a country's CRVS system.

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<sup>i</sup>World Health Statistics 2012, WHO 2012

<sup>ii</sup> WHO Mortality Data base, <http://www.who.int/whosis/mort/download/en/index.html>

<sup>iii</sup> International Statistical Classification of Diseases and Health Related Problems, Tenth Revision, 2010 Edition, WHO 2010

<sup>iv</sup> The WHO Electronic ICD-10 training tool, <http://apps.who.int/classifications/apps/icd/icd10training/>

<sup>v</sup> Verbal Autopsy Standards: Ascertaining and attributing cause of death, WHO 2007

<sup>vi</sup> mHealth New Horizons for health through mobile technologies, Global Health Observatory for eHealth series – vol. 3, WHO 2011