CAUSE OF DEATH FACT SHEET

Improving Cause of Death Information in Countries

Statistics on deaths by age, sex are cause provide the underpinnings for strategies to promote and protect public health and are critical to ongoing monitoring and improvement of population health. In modern societies, cause of death information is produced when deaths are medically certified by a physician in accordance with World Health Organization (WHO) standards.[1] The cause of death information can be used for both legal and statistical purposes.

However, accurate recording of cause of death information is possible in few countries in Africa because only a minority of deaths occur in medical institutions where there is a physician able to issue a medical certificate including cause of death. Therefore, improving the recording and compilation of cause of death information is one of the important elements of the on-going CRVS reform process in Africa. Assessment of the current processes of collection, coding, compilation and use of cause of death information through the APAI-CRVS processes will help identify bottlenecks and develop strategies and action plans to strengthen cause of death collection and analysis. Important to the assessment task team will be understanding where deaths occur and how cause of death information can best be captured.

This note provides a brief overview of the collection process for cause of death information, and guidance on a broad set of strategies that can be adopted as part of improvement strategies.

The Importance of Cause of Death Data

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Key information on cause of death includes the numbers of deaths by age, sex, location, date and cause of death.

Members States of the World Health Organization are required to report cause of death statistics on a regular basis. The information is used for analysis of global mortality levels and patterns, burden of disease analysis, and for the formulation of prevention and mitigation strategies.

At country level, cause of death data are used to evaluate the health of local, regional and national populations, including to:

- Identify emerging diseases and conditions, determine inequities in levels and patterns of mortality, and estimate burden of disease to inform future health planning;
- Monitor and evaluate health system performance and the impact of policies and programmes;
- Guide priorities for intervention programme and allocate and distribute health sector resources;
- Contribute to health research and the generation of evidence.[2]

Collecting Cause of Death Data

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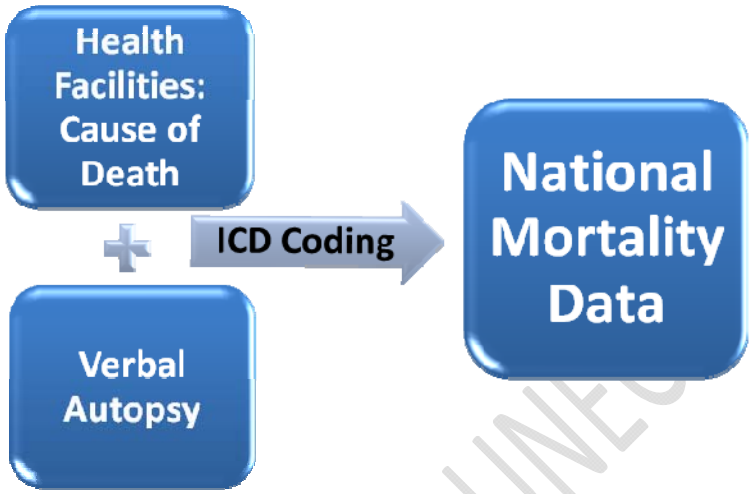
In a functioning CRVS system, causes of death are assigned for all deaths, in accordance with the WHO International Classification for Disease (ICD).



When deaths occur in a medical setting (in a health care facility or where medical supervision is available) the cause of death is assigned by a trained physician who completes the medical certificate of death. In cases where a death occurred as the result of an accident or violence, it is common to have a judicial procedure to determine the precise cause of death.[3] In both cases, the cause of death is subsequently coded to the statistical categories defined by the ICD.

When deaths occur at home and in the absence of a physician able to complete a medical certificate, the probable cause of death can be ascertained using a technique known as verbal autopsy.[4] This involves an interview with relatives or carers of the deceased person. Subsequently the responses are coded – preferably using automated techniques – to categories that are compatible with the ICD. When properly applied, verbal autopsy can yield population-based cause-of-death data of comparable quality to data typically collected in hospitals in developing countries. However, it should be noted that the primary use of cause of death data determined using verbal autopsy is for statistical rather than legal purposes.

Bringing together information on mortality from medical certification and verbal autopsy enables country decision makers to get a picture of levels and trends in mortality across population groups and geographic location.

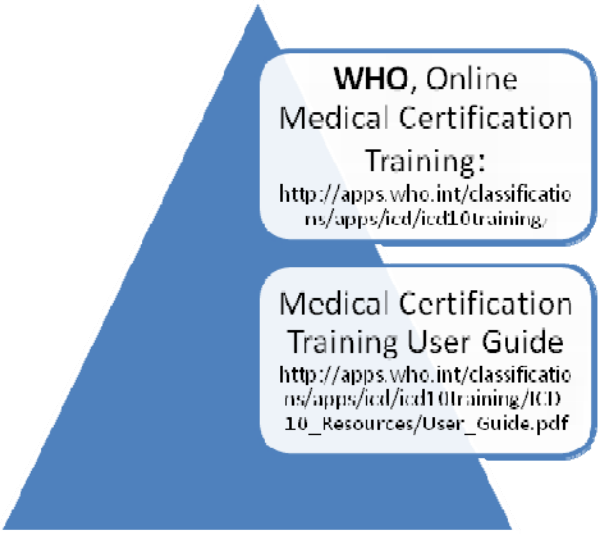
The following sections provide a simple overview of how data can be collected from hospital and non-hosptial sources, and some references. This is intended as a simple schematic guide.

Collecting Cause of Death from Health Facilities

General Sequence

When a death occurs in a health facility or under medical supervision:

- A trained physician should certify the death using the International Form of the Medical Certificate of Cause of Death (IMCCD).[5].
- Once certified, the health facility records system should record and store information about the death (paper-based or electronically), including the details of the IMCCD; and make the IMCCD details available for subsequent coding to the ICD statistical categories.



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Challenges: Collecting Cause of Death Information in Health Facilities

What can hinder the facilities in assigning the cause of death? Some challenges are listed below.

Law

- The law does not make it mandatory for the medical institutions to record causes of death;
- The law does not recognize/make it compulsory for the use of the WHO standards as the conventional standard that the country should follow in assigning causes of death

Standards

- The causes of death are not completed using the International Form of the Medical Certificate of Cause of Death.
- The causes of death recorded in WHO standard form but the quality of causes of death information is poor making it difficult to assign codes according to the ICD.

Processes

information are crucial particularly in case of medico-legal cases; Missing text here?

The key actions required to overcome many of the common problems with death certification, and thus improve the quality of cause-of-death data, are:

- increase awareness among physicians of appropriate death-certification practices and improve their skills;
- introduce the International Form of Medical Certificate of Cause of Death in medical school curricula as well as providing in-service training;
- conduct regular validation of cause-of-death certification in hospitals;
- Increase the proportion of deaths occurring outside hospitals that are medically certified;
- Introduce mechanisms to ensure that cause of death is correctly assigned in cases requiring judicial investigation.

Strategies

Under the APAI-CRVS process, the following are broad strategies that could be adopted for improve causes of death information for deaths occurring in health facilities.

Business Process

Constitute a core team to implement the strategies and plan of action for improvement of causes of death information. This group could design business process that would include identification of the institutions and their responsibilities in the value chain, form flow and monitoring and evaluation mechanisms. Decide on the steps to implement this, which will include development of proposal with implementation time-line. The business process should propose the inclusion of the International Form of the Medical Certificate of Cause of Death.

Law

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Ensure that law provides for compulsory recoding of causes of death in all medical institutions. The law should also specify that the International Form of the Medical Certificate of Cause of Death form should be used by the medical institutions. Finally the law could allocate responsibility to one institution – for example the National Statistics Office – for coding, compilation and dissemination of causes of death statistics on an annual basis.

Road map

Experiences from countries have shown that a number of key steps can be taken to help introduce and sustain improvement strategies. These include the following:

1. Establish an ad hoc committee with senior representation from physicians, medical educators and trainers, public health practitioners, health statisticians, legal and ethical experts and civil-society representatives. The functions of the committee are to:
   - gather information on the current status of cause-of-death certification
   - identify priority actions needed, and prepare a workplan and schedule of activities
   - identify resources needed and sources of technical and financial support
   - report regularly on progress to relevant agencies and institutions.

2. Review existing death certificates and related forms and modify as required to ensure alignment with international standards. Review available guidance materials and manuals and revise and/or improve as necessary – ensuring that these address not only the technical aspects of cause-of-death certification but also its legal and ethical aspects. Ensure that the updated guidance materials are widely distributed and disseminated to all medical professionals.

3. Through discussions with hospital administrators and physicians, draw up an action plan – with timelines – for the ongoing training of physicians in medical certification.

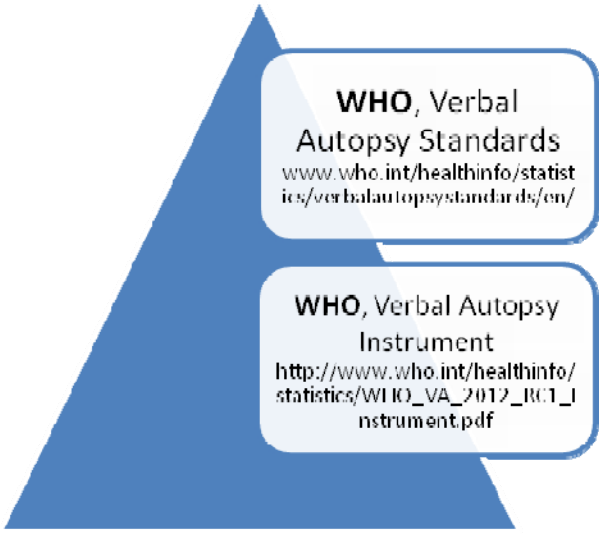
4. Through discussions with universities and medical training establishments, draw up a plan for incorporating information on the purposes and content of the ICD in medical curricula.

Collecting Cause from Deaths Not Occurring in Health Facilities

In cases where a medical practitioner is not available to certify the death – generally for deaths that do not occur in health facilities – then verbal autopsy can be used to provide population-level information on causes of death.

Generally, when a death occurs and a verbal autopsy is required:

- A notification of a death (by age, sex and date) is provided to the local health information centre where the information is recorded;
- After a suitable period of time (bearing in mind local cultural mourning traditions) an interviewer (*not* a medical doctor but preferably a trained lay person)



visits the household where a death has occurred to interview the family or caregivers about the signs and symptoms exhibited by the deceased before death, using a predesigned questionnaire and recording all responses in a standardized manner.

- The pattern of responses is reviewed by a physician (*never* a lay person) to determine the probable cause of death based on the signs and symptoms reported by the family. This process can be aided by reviewing information on the events leading up to death provided by the family in their own words (the "open narrative"), as well as any information reported by the family that resulted from contact with health facilities (for example, being told by a hospital that the deceased had a specific disease).
- An alternative to the expensive and time-consuming option of physician review is the use of computer software to read "patterns" in the responses and to come up with a probable cause of death. [6]
- The information can be collected in a paper format or electronically, and subsequently coded to ICD-aligned cause of death codes. Given the nature of verbal autopsy, it is not possible to determine cause of death with the degree of exactitude of a medically certified death.

Challenges: Collecting Verbal Autopsy Information

What can challenge the collection in of verbal autopsy information? Some challenges are listed below.

Law

- The law does not allow or specify that cause of death information can be collected through verbal autopsy processes.

Standards

- International standards are not used in the verbal autopsy process; potentially meaning data cannot be coded to ICD, or may not be comparable to other cause of death (for example, hospital cause of death data)

Process

- In many countries, there is no systematic process in place for recording and compiling cause of death information for deaths occurring outside the health facilities.
- Although there are some attempts made in a few countries to collect causes of death for non-institutional deaths through verbal autopsy methods, these are largely limited to a few experimental areas. No real attempts have been made to use VA for recoding causes of death data for general population.

Strategies

Under the APAI-CRVS process, the following are broad strategies that could be adopted for improve causes of death information for deaths occurring outside health facilities.

Decide on the steps to implement verbal autopsy, which will include development of proposal with implementation time-line. The business process should propose the inclusion of the WHO verbal autopsy standard and forms.

Verbal autopsy processes may be difficult to implement for **all** deaths occurring outside of health facilities. Countries may consider the introduction of verbal autopsy techniques in sentinel surveillance sites.[7] The newly developed PDA/mobile based verbal autopsy tool developed by WHO could be tried out in scientifically selected representative sample clusters. The pilots should be used to test the whole process from end to end (collection to compilation).

Countries may designate nationally representative sample sites in which verbal autopsy would be conducted on an ongoing basis in order to generate nationally representative data on causes of death.

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- Based on the results of the pilot and tool testing exercise, constitute a core team to should re-design the business process that would include identification of the institutions and their responsibilities in the value chain, form flow and monitoring and evaluation mechanisms. Decide on the steps to implement this, which will include development of proposal with implementation time-line.

Law

- The law could make it compulsory for the assigning of causes of death for non-institutional deaths;
- If not compulsory, then ensure that law allows for recording of causes of death through verbal autopsy.
- The law should also encourage the use of WHO verbal autopsy standard and forms.
- The law should identify the process for national collection, maintenance and reporting of verbal autopsy information.

Training

- Training of lay interviewers in verbal autopsy processes. There should be regular training of persons involved in assigning of causes of death for non-institutional deaths; specifically in applying the WHO VA tools.

Reporting

- WHO and INDEPTH should support these initiatives at the country level in collaboration with the technical working groups of CRVS.

Processes

This group could design business process that would include identification of relevant processes and institutions, which could be used to trigger verbal autopsy processes. The currently available evidence from the use of verbal autopsy in health and demographic surveillance sites and sample registration systems indicators that the health sector is the most feasible entry point for applying verbal autopsy techniques. However, other options could be considered and tested through operational research, for example:

- Verbal autopsy could be triggered by burial processes, where issuing of permits could trigger a verbal autopsy process.
- Other processes for notification of deaths – for example, through local administration or registry processes – could be used to trigger verbal autopsy processes.
- If deaths occur are due to accidents, homicide and suicide, the inquest report by the police would generally provide the causes of death, and could support a verbal autopsy process.

Road map for introducing verbal autopsy

- Constitute a core team to implement the strategies and plan of action for improvement of verbal autopsy / causes of death information.
- Establish a group of stakeholders familiar with the local epidemiological and socioeconomic context to adapt the standard WHO VA questionnaire.
- Work with a social scientist to determine local meanings and terminology for all signs, symptoms, diseases and conditions.
- Translate the agreed questionnaire into the local language(s).
- Recruit and train interviewers (do not use doctors).
- Pilot the questionnaire.
- Validate and revise the questionnaire.
- Develop data-entry screens and a database system.
- Start conducting VAs, preferably using electronic data capture at point of interview.
- Code causes of death, preferably using machine-learning methods. Avoid physician coding.
- Review the quality of cause-of-death results, and prepare annual reports for stakeholders and other users.

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Coding to the International Classification of Disease

Once cause of death has been recorded through medical certification or through verbal autopsy, coding to the International Classification of Disease can be undertaken.

- Coding is a highly specialised task that requires a thorough understanding of the rules for determining underlying cause of death, and assigning the correct ICD code[1]. It is important that this task is undertaken by trained statistical clerks or coders.
- Countries can use centralised coding units to code cause of death data. In some countries, decentralised coding units are used. In decentralised and centralised systems, it is important to ensure quality of coding, and especially the consistency of the coding rules.
- It is important to note that coding technology can allow the quick and standardised coding of many deaths, if the death certification system is of sufficient quality. Coding for certified deaths can be undertaken automatically, through used of automated coders such as IRIS[2] and MMDS[3]. For example, the coding of cause of death in South Africa uses automated coding technology.
- Once classified correctly, the data can be aggregated and used to understand deaths in health facilities, deaths which occur outside of facilities, and national mortality patterns.

Challenges: Coding Causes of Death

Law

- The law does not allow or specify that cause of death information should be coded using the International Classification for Disease.

Standards

- The standards and rules of the International Classification for Disease may not be applied appropriately.

Process

- Coding rules and standards are not applied consistently to all deaths, meaning that data cannot be aggregated.
- Certification information or verbal autopsy information is not received for coding, or is of poor quality meaning that appropriate causes of death codes cannot be applied.
- Coding is indeed a highly specialised function. For the many issues which can specifically affect coding and coding quality, please reference the WHO Resource Kit (www.uq.edu.au/hishub/resource-kit)

Strategies

Under the APAI-CRVS process, the following are broad strategies that could be adopted for improve causes of death information for deaths occurring outside health facilities.

Business Process

[1] WHO 2013 'Strengthening CRVS for births, deaths and causes of death' www.uq.edu.au/hishub/resource-kit.
[2] See http://www.dimdi.de/static/en/klassi/koop/irisinstitute/index.htm
[3] See http://www.cdc.gov/nchs/nvss/mmds.htm

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Constitute a core team to implement the strategies and plan of action for improvement of cause of death information, ensuring coding processes are included in the design business process. Develop a strategy for coding, and develop a proposal with implementation time-line. The business process should propose the use of the rules and standards of the ICD.

Law

Ensure that law provides for coding of causes of death, and the use of the ICD.

Training

Training of coders (available free online) in coding causes of death as per the requirement of ICD. Introduction professional development and support for coders at a national level, and regionally.

Road map for improving coding practices

1. Constitute a small group of mortality-coding stakeholders such as ministry of health and other public health institute officials, national statistics office staff, hospital managers and local WHO representatives.
2. Conduct an assessment of mortality-coding practices in the country by collecting information on who trains coders; the number of trained coders, the type of training they have received, the curricula used for training and organizations using or handling cause-of-death statistics.
3. Identify problems and set priorities. Prepare an action plan that sets out specific activities, responsibilities, resources and expected outcomes.
4. If training is identified as a problem area, conduct a training needs assessment for mortality coding. If necessary, increase training opportunities, and standardize training curricula and education. Identify the components to be taught and be guided by the core curriculum recommended by the WHO-FIC and IFHIMA joint collaboration.
5. If quality or a backlog of coding is identified as problem areas, investigate the feasibility of adopting automated coding or of introducing the manual use of the MMDS ACME decision tables for identifying underlying causes of death. If mortality coding is decentralized to hospitals, investigate any potential efficiency gains in having it performed centrally.
6. Monitor progress by conducting regular coding-quality assessments.

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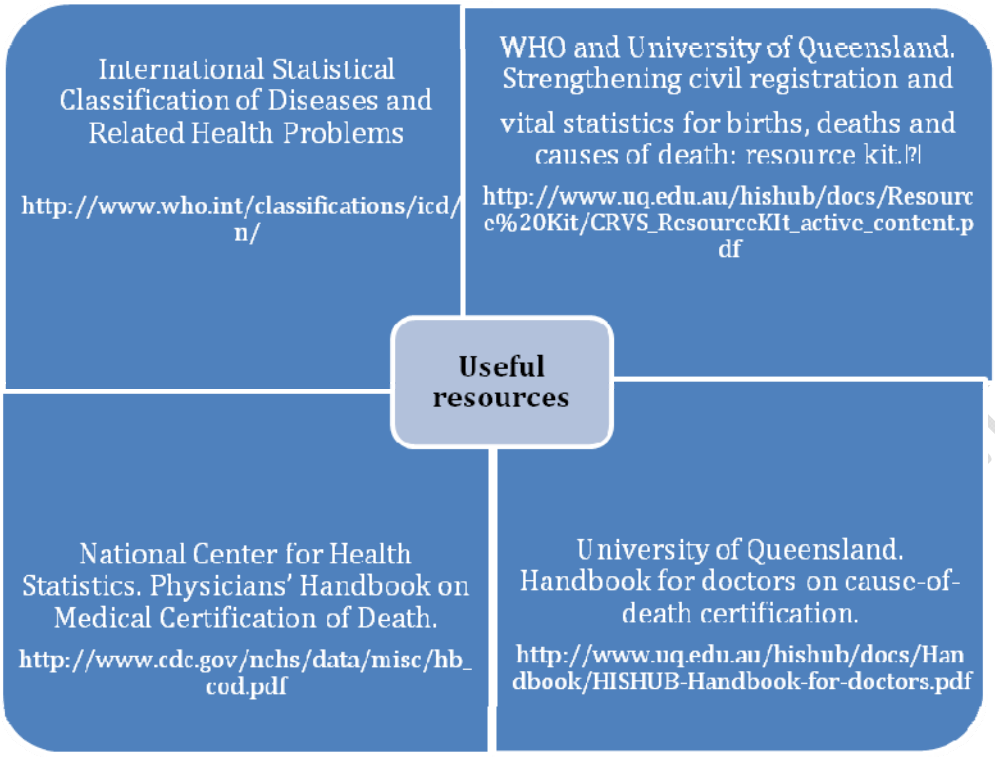

[1] World Health Organization (2010). International Statistical Classification of Diseases and Related Health Problems, 10th Revision. Geneva, World Health Organization. Accessed 22 August 2012 at: http://www.who.int/classifications/icd/en/

[2] World Health Organization and University of Queensland (2013) Strengthening civil registration and vital statistics for births, deaths and causes of death: resource kit. ISBN 978 92 4 150459 1 (NLM classification: WA 900) WHO/HMN/13.1© World Health Organization 2013

[3] WHO 2012 'Fatal injury surveillance in mortuaries and hospitals: a manual for practitioners' sourced at http://www.who.int/violence_injury_prevention/publications/surveillance/fatal_injury_surveillance/en/

[4] World Health Organization (2012). Verbal autopsy standards: Ascertaining and attributing causes of death. The 2012 WHO verbal autopsy instrument. Release Candidate 1. Geneva, World Health Organization. Retrieved 22 August 2012 from: http://www.who.int/healthinfo/statistics/verbalautopsystandards/en/

[5] (see http://www.who.int/classifications/icd/ICD10Volume2_en_2010.pdf)

[6] Lopez AD, et al. (eds.) (2011). Verbal autopsy: innovations, applications, opportunities – Improving cause of death measurement. A thematic series. *Population Health Metrics*, 9. Retrieved 22 August 2012 from: http://www.pophealthmetrics.com/series/verbal_autopsy

[7] http://www.indepth-network.org/index. php?option=com_content&task=view&id=95&Itemid=183