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HEALTH INITIATIVE

CRVS DEVELOPMENT SERIES

# Reducing barriers to the accurate medical certification of cause of death

May 2018



*Improving death certification and mortality coding*

## Resources available from the University of Melbourne, Bloomberg Philanthropies Data for Health Initiative

### *CRVS development series*

The CRVS development series, generated through the Initiative, form a lasting archive of concise and easily accessible evidence and knowledge on strengthening CRVS systems. The content is based on a combination of technical knowledge and country experiences, as well as the scientific literature. The series are intended to stimulate debate and ideas for in-country CRVS policy, planning and capacity building, and promote the adoption of best practice to strengthen CRVS systems world-wide.

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### *CRVS action guides and summaries*

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Melbourne School of Population and Global Health  
Building 379  
207 Bouverie Street  
Carlton  
VIC 3053, Australia

+61 3 9035 6560

CRVS-info@unimelb.edu.au

[www.mspgh.unimelb.edu.au/dataforhealth](http://www.mspgh.unimelb.edu.au/dataforhealth)

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## Abbreviations

AIDS	acquired immune deficiency syndrome
D4H	Bloomberg Philanthropies Data for Health
COD	cause of death
CRVS	civil registration and vital statistics
HIV	human immunodeficiency virus
ICD	International Statistical Classification of Diseases
MCCOD	medical certification of cause of death
UN	United Nations
WHO	World Health Organization

## Key terms

<b>Cause of death:</b>	Refers to 'all those diseases, morbid conditions or injuries which either resulted in or contributed to death and the circumstance of the accident or violence which produced any such injuries' (Twentieth World Health Assembly, 1967)
<b>Underlying cause of death:</b>	Is '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' (World Health Organization, 1994).

## Key points

- Accurate medical certification of cause of death is critical for producing reliable mortality data, which are needed in multiple sectors, particularly in health, to underpin and monitor evidence-based policy and planning.
- Cause of death (COD) certification is complex and can be affected by social norms and cultural mores.
- Physicians can be placed in difficult situations ethically, morally and legally due to constraints that adversely affect the accuracy of their medical certification of cause of death.
- Challenges to accurate COD reporting can arise where:
  - the death has been caused by a stigmatised disease or condition
  - pressure is placed on the physician by the deceased's family not to disclose a stigmatised death on the death certificate
  - insurance payments to the deceased's family are at risk if the death was due to a cause not covered in the policy
  - the physician is concerned the deceased patient's confidentiality could be breached
  - the physician fears potential legal consequences
  - the death is the result of homicide, suicide or other conditions necessitating a coronial enquiry to apportion cause and responsibility.
- There are several strategies that can be used by various agencies, such as the equivalents of the national civil registration and vital statistics committee, office of the registrar general and medical associations, to protect physicians who certify COD. They can:
  - introduce and enforce legal and policy frameworks that protect physicians from undue pressure when assigning the cause of death
  - clearly communicate to physicians the legal and policy protections that are available to support accurate medical certification
  - encourage physician peer support to address challenges associated with the medical certification of COD
  - encourage physicians to seek guidance from a hospital or medical ethicist, ethics committee, or legal advocate when responding to very challenging individual circumstances around certification of COD
  - ensure that detailed information on individual COD is shared with national statistical agencies for aggregation and analysis when individual identities have been removed
  - enable the sharing of individual COD information with health authorities only in cases of overriding public health imperative, such as to prevent the spread of notifiable diseases
  - raise public awareness through community education and advocacy campaigns to around causes of death that are stigmatised or sensitive and the reasons why it is imperative to report these correctly.

## Reducing barriers to the accurate medical certification of cause of death

This *CRVS development series* paper identifies and discusses common barriers to the accurate medical certification of cause of death by physicians, and provides recommendations on ways the various actors and institutes can respond – including physicians, national medical associations, medical educators, healthcare facilities and government. This paper acknowledges the complexity of death certification due to underlying social and cultural ideas around death, as well as the need for physicians to receive full support to accurately perform a routine duty – the medical certification of cause of death.

- 
- **Why is medical certification of cause of death important?**
  - **What is the 'gold standard' for producing good quality-mortality statistics?**
  - **What are common barriers to the accurate medical certification of cause of death?**
    - **Stigmatised diseases and conditions**
    - **Family pressure**
    - **Insurance policies and payments**
    - **Doctor-patient confidentiality**
    - **Legal consequences**
    - **External causes of death**
  - **What action can be taken to support medical certification of cause of death?**
    - **Legal and regulatory review**
    - **Peer support and training**
    - **Community awareness**
  - **Summary**
- 

Without an understanding of what people are dying from, health planners are unable to develop effective and equitable policies and programs.

### Why is medical certification of cause of death important?

Reliable and timely statistics on mortality and cause of death (COD) are essential for the development of national health and population policies, and underpin the ability of countries to respond to emerging health threats and epidemics (Figure 1). Information on COD allows health authorities to:

- Develop evidence-based health policy and planning initiatives, using interventions that target identified priority diseases, conditions, and risk factors.
- Identify which people are dying, what they are dying from and where they are dying to address health inequities.
- Strategically allocate limited resources for population health.<sup>1</sup>

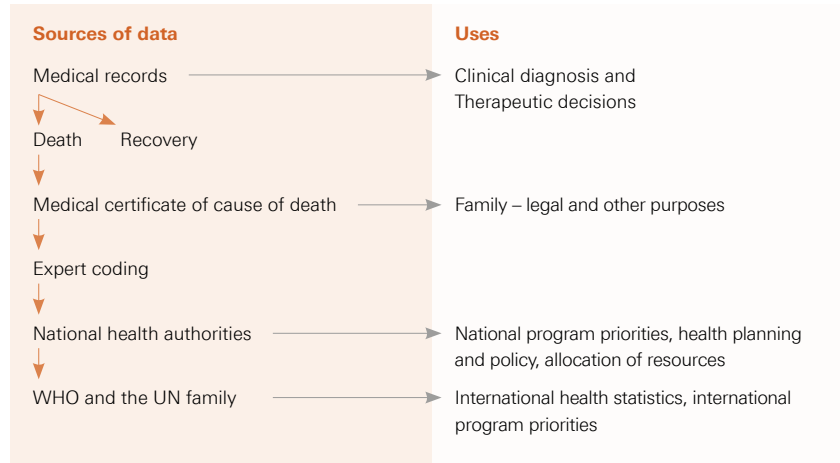
The United Nations (UN) and World Health Organization (WHO) standards for mortality statistics require the recording in the civil registry of all deaths, by age, sex, date and place of occurrence, along with medical certification of the COD by trained physicians according to the International Classification of Diseases (ICD). The information should be regularly compiled into vital statistics through national civil registration and vital statistics (CRVS) systems.

<sup>1</sup> Phillips DE, AbouZahr C, Lopez AD, et al. Are well functioning civil registration and vital statistics systems associated with better health outcomes? *The Lancet* 2015; 386:1386-1394.



Many countries have stepped up their efforts to register all deaths by age and sex. This is a crucial first step that generates invaluable information on levels and distribution of mortality. However, improving the availability and quality of cause of death statistics is particularly challenging.

**Figure 1 Sources and uses of cause of death data**



UN = United Nations; WHO = World Health Organization

The medical certificate of cause of death describes the sequence of events and causes leading to death. It is used to determine the underlying cause of death.

**What is the ‘gold standard’ for producing good-quality mortality statistics?**

The best way to obtain good-quality mortality statistics is to have the cause of death medically certified by a physician in accordance with international standards developed by the World Health Organization.<sup>2</sup> Physicians have a legal duty and ethical responsibility to complete the medical certificate of cause of death (also referred to as the ‘death certificate’) that describes the sequence of events and causes associated with the death, and to identify the underlying COD that initiated the fatal sequence. They should complete the medical certificate of cause of death to the best of their professional knowledge and clinical experience.<sup>3</sup>

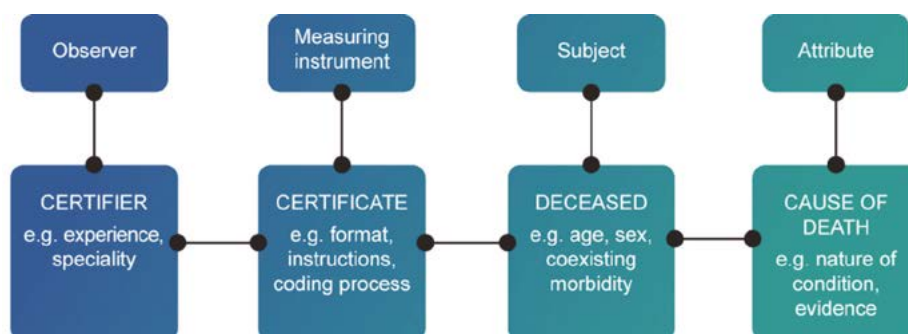
2 For more information on medical certification, see Topic 4: Cause of death in CRVS systems. Available at <https://crvsgateway.info/learningcentre/cause-of-death-in-crvs>  
 3 Lomas H & Berman J. Diagnosing for administrative purposes: some ethical problems. *Social Science and Medicine* 1983; 17:241-244.

## What are common barriers to accurate death certification?

It is acknowledged, however, that sociocultural, community and ethical factors might influence the information a physician enters on the medical certificate. These factors are complex and are usually subtle and nuanced. As shown in Figure 2, four broad factors affect the quality of death certification and cause of death data:

1. The **certifier** – knowledge and skills of the certifying physician.
2. The **certificate** – form used for certification of the cause of death.
3. The **decedent** – characteristics of the deceased person.
4. The **COD** – attributes of the death event itself.

**Figure 2 Four factors affecting death certification**



Sourced from: Maudsley G, Williams L. Death certification – a sad state of affairs. *Journal of Public Health Medicine* 1994; 16(3):370–371

This paper focuses on barriers to certification associated with the actual cause of death itself.

For the purpose of this paper, the fourth factor (attributes of the cause of death) will be further discussed. From reviewing the scientific literature on death certification and stigma, sensitive deaths and medical ethics, as well as experience from in-country capacity-building activities for medical certification of cause of death (MCCOD) through the Bloomberg Philanthropies Data for Health (BD4H) Initiative, six common barriers to certification have been identified:

1. The death has been caused by a stigmatised disease or condition.
2. Pressure is placed on the physician by the deceased's family not to disclose a stigmatised death on the death certificate.
3. Insurance payments to the deceased's family are at risk if the death was due to a cause not covered in the policy.
4. There are doctor–patient confidentiality concerns in releasing the death certificate to the family.
5. The physician fears potential legal consequences.
6. The death is by homicide, suicide or other cause requiring a coronial enquiry.

### The death has been caused by a stigmatised disease or condition

In certain country or community contexts where the deceased has died due to a perceived stigmatised condition or illness, the certifying physician may be reluctant to accurately enter the COD onto the death certificate. The main types of stigmatised or 'taboo' deaths<sup>4</sup> that physicians might be reluctant to explicitly identify on the death certificate are HIV/AIDS and other sexually transmitted infections, abortion, maternal death in unmarried women, infectious diseases such as Ebola, gender-based violence and domestic violence, and suicide.

<sup>4</sup> Chapple A, Ziebland S, Hawton K. Taboo and the different death? Perceptions of those bereaved by suicide or other traumatic death. *Sociology of Health and Illness* 2015; 37:610-625.



When certain kinds of causes of death are systematically unreported, the resulting mortality statistics are biased

Unsurprisingly, this contributes to poor-quality COD data and under-reporting of deaths resulting from conditions of public health importance. For example, many reports in the literature describe inaccuracies in COD certification that involved misrepresentation of HIV-specific mortality by physicians in the South African context,<sup>5,6</sup> highlighting the complex nature of stigmatisation and HIV/AIDS in that country. However, physician avoidance of stating HIV/AIDS on the death certificate was reported as also occurring in the United Kingdom in the late 1980s.<sup>7</sup>

### **Pressure is placed on the physician by the deceased's family not to disclose a stigmatised death on the death certificate**

While family pressure from the deceased's relatives to alter the COD may not be obvious, a physician may feel pressured to not disclose a stigmatised death due to local sociocultural traditions, beliefs and practices.

Physicians might agree to the real or perceived family pressure not to definitively state the cause of (a stigmatised) death on the death certificate because they feel a duty to 'protect' the deceased patient's memory or legacy, and/or 'protect' the deceased patient's family who may be further stigmatised by their relative's COD. Latent HIV/AIDS-related stigmatisation of the deceased and their relatives is documented in a raft of countries, such as South Africa, Swaziland, China, Thailand and the United States. Stigmatisation of remaining family connected to a death by suicide in the developed and developing world is also well-documented.<sup>8,9</sup>

### **Insurance payments to the deceased's family are at risk if the death was due to a cause not covered in the policy**

Physicians may not explicitly state the COD if it is connected to a stigmatised illness or condition, as a way of 'protecting' the family of the deceased from financial penalty. Physicians may fear that stating the COD will negatively impact the life insurance or funeral policy payout by the family's insurer.<sup>10</sup> Depriving families of much-needed insurance monies, especially poor families in poor communities, is not appealing for any physician. This is even more so for those who might be the sole physician living and working in impoverished environments and who hold the trust and esteem of local community members.

- 5 Burger E, Groenewald P, Bradshaw D, et al. Validation study of cause of death statistics in Cape Town, South Africa, found poor agreement. *Journal of Clinical Epidemiology* 2012; 65:309-316.
- 6 Riffe H, Fouche C. Does anyone die from AIDS in South Africa? *Journal of HIV/AIDS and Social Services* 2007; 6:23-36.
- 7 King M. AIDS on the death certificate: the final stigma. *British Medical Journal* 1989; 298:734-736.
- 8 Peters K, Cunningham C, Murphy G, et al. 'People look down on you when you tell them how he died': Qualitative insights into stigma as experienced by suicide survivors. *International Journal of Mental Health Nursing* 2016; 25:251-257.
- 9 Harwood D, Hawton K, Hope T, et al. The grief experiences and needs of bereaved relatives and friends of older people dying through suicide: a descriptive and case-control study. *Journal of Affective Disorders* 2002; 72:185-194.
- 10 Burger E, Groenewald P, Rousouw A, et al. Medical certification of death in South Africa – moving forward. *South African Medical Journal* 2015; 105:27-30.

There should be clear policies and procedures around the sharing of individual cause of death data.

### **There are doctor–patient confidentiality concerns in releasing the death certificate to the family**

Unless the patient clearly authorised in writing the release of his/her health information to a third party (such as relatives) before their death, the physician is usually bound to continue maintaining their deceased patient’s confidentiality. Some physicians, however, fear they will be in breach of doctor/patient confidentiality if the cause of death is placed on the death certificate and this is then given to family members or others (such as insurance agencies and funeral parlours). Some physicians are particularly anxious to maintain patient confidentiality where the patient died as a result of a perceived sensitive condition or illness.

It should also be noted that physicians are required to share individual cause of death information with health authorities in cases of public health importance, such as to prevent the spread of notifiable diseases.<sup>11</sup>

### **The physician fears potential legal consequences**

Some physicians may become anxious that if they enter an incorrect COD they may be investigated or sued for malpractice. There are several reasons why physicians fear they may enter an incorrect COD: they did not have enough time to investigate the underlying COD; they were not present when the deceased died; they do not have the capacity or equipment to properly investigate.

### **The death is by homicide, suicide or other cause requiring a coronial enquiry**

Physicians have anecdotally reported that in extreme circumstances they fear personal or family retribution where homicide or extrajudicial killing might be inferred by the content they have entered on the death certificate. This is especially the case in conflict and low-intensity conflict zones, closed communities and areas that are geographically isolated, where the physician might be one of a handful of trained health personnel living and working among the community.

<sup>11</sup> Centers for Disease Control and Prevention. Standards to facilitate data sharing and use of surveillance data; see [cdc.gov/nchhstp/programintegration/SC-Standards.htm#DATA-SHARINGfor Public Health Action](https://www.cdc.gov/nchhstp/programintegration/SC-Standards.htm#DATA-SHARINGfor%20Public%20Health%20Action) and [cdc.gov/nchhstp/programintegration/Data-Security-FAQ.htm](https://www.cdc.gov/nchhstp/programintegration/Data-Security-FAQ.htm)

## What action can be taken to support the accurate medical certification of cause of death?

Below are seven suggestions to guide countries and their partners to address the various barriers to accurate medical certification of cause of death which can be experienced by physicians worldwide.

The BD4H Initiative has supported 16 countries to create CRVS process maps.

### Legal and regulatory analysis of MCCOD legislation

It is important countries ensure that physicians have the legal safeguards to feel confident and comfortable to medically certify the causes of all deaths. An analysis of country-specific MCCOD legislative and policy frameworks should be undertaken. This could be coordinated by the national civil registration and vital statistics committee, or subcommittee.<sup>12</sup>

### Ensure physicians are aware of the legal safeguards in place to protect them

It is important that countries work with medical associations and professional bodies to clearly communicate to physicians the legal and policy safeguards that are in place to support them to accurately and routinely medically certify deaths, as part of their ordinary professional duties. Clear communication will help mitigate physician fear and anxiety around legal exposure. This will also improve the quality of COD data by reducing the proportion of deaths assigned an incorrect COD.

### Encourage physicians to seek advice from a medical ethicist, legal advocate, and/or ethics review committee if they find themselves in a difficult situation

Understanding what legal safeguards are in place, and how to seek assistance, are important elements to cover in certification training with physicians.

Where necessary it is recommended that a physician consult a medical or hospital ethicist, legal advocate, medico-legal department, relevant ethics committee, or the overarching national medical association or professional body for advice and guidance if they find themselves presented with a challenging MCCOD case. Physicians should not feel they are alone in such circumstances, and they need to be able to comfortably liaise with legal authorities/police for deaths under suspicious circumstances. It is recommended that all advice given to the physician is in writing. It is also recommended that any advice given acknowledges the broader cultural background and political, economic, social and community contexts within which the physician functions.

### Legal and regulatory analysis of insurance company practices and law

It is recommended that analysis of the legal and regulatory frameworks for MCCOD (see above) extend to include analysis of key national insurance companies' policies on death payments for potentially stigmatising illnesses and conditions causing death, such as HIV/AIDS and suicide. It is recommended that governments and insurance companies work in partnership to avoid or remove potentially penalising clauses in death insurance payouts, especially those likely to impact poor families and communities. This ensures that disadvantaged families are not penalised when seeking to apply for a death insurance payout because of the COD.

<sup>12</sup> Vital Strategies and the Global Health Advocacy Incubator, as part of BD4H, have developed a *Civil Registration and Vital Statistics Legal and Regulatory Review: Tool and Methodology*. Available at [https://www.vitalstrategies.org/wp-content/uploads/2018/01/CRVS-Legal-Toolkit\\_11\\_29\\_17.pdf](https://www.vitalstrategies.org/wp-content/uploads/2018/01/CRVS-Legal-Toolkit_11_29_17.pdf)

Governments should also work with medical associations and professional bodies to clarify current rules on penalising insurance payouts to physicians. The aim should be to alleviate physicians' moral and ethical distress on this subject.

### Physician peer support and ongoing training

It is suggested that peer/near-peer or eLearning teaching schemes relating to death certification and its implications should be developed, because formal workshops on the subject, although useful, may not be readily accessible to all physicians.<sup>13</sup> It is also recommended that compulsory MCCOD education and training be incorporated into the learning and professional development programs of medical students, junior physicians and interns, and more experienced practicing physicians.

### Protecting doctor/patient confidentiality in times of death

Implementing standard policies and guidelines around the safe storage, retrieval and transmission of medical death certificates is a critical task.

In the first instance, it is recommended that countries avoid or repeal death registration practices, prescribed by law, which instruct that the family or next of kin are responsible for hand-lodging a hardcopy of the medical certificate of COD with a civil registry office. If any document needs to be given to the family by the physician in regard to the deceased's death, this could be a death certificate that confirms *proof* of death, not *type* or *cause* of death. Certifying physicians can also be given a medical certification identification number or code to place on the death certificate, in lieu of their own name. Nonetheless, it is still the duty of the physician to share information on the causes of death with the health authorities and also, with protection of individual identity, with the statistical authorities.

### Community awareness-raising and education to de-stigmatise sensitive deaths

To work towards destigmatising sensitive deaths, the nature of which will depend on the country or community-specific context, it is recommended that governments work with their public health and community partners to develop appropriate educational and awareness-raising strategies and campaigns. Community-based participatory research should be encouraged and invested in.<sup>14</sup> It can explore the sociocultural constructions of stigmatised deaths and how communities can respond, while also increasing the ability of families and communities to counter such stigma. The documented psychosocial effects of the recent Ebola crisis in west Africa, which included the stigmatisation of survivors and family members of those who died from Ebola, reaffirms the need for education and raising awareness at the community level to address stigmatised disease and sensitive health conditions.<sup>15</sup>

<sup>13</sup> Khan A, Ah-kee E. Death certification: 800 years of practice; time to modernise teaching? *Scottish Medical Journal* 2016; 61:32-33.

<sup>14</sup> Gouda HN, Flaxman A, Brolan CE, et al. New challenges for verbal autopsy: Considering the ethical and social implications of verbal autopsy methods in routine health information systems. *Social Science and Medicine* 2017; 184:65-74.

<sup>15</sup> Van Bortel T, Basnayake A, Wurie F, et al. Psychosocial effects of an Ebola outbreak at individual, community and international levels. *Bulletin of the World Health Organization* 2016; 94:210-214.



## Summary

This paper has discussed common barriers to the accurate certification of cause of death in regards to attributes of the death event itself. It has not attempted to discuss the complex range of barriers that arise when for example, non-standard death certificates are used, or the myriad of complex health system and workplace issues related to certification.

Physicians can be placed in difficult situations ethically, morally and legally due to barriers that will impact the accuracy of their medical certification practice. Governments, working in collaboration with their partners (including national medical associations and professional bodies), can address these subtle but very real barriers to accurate medical certification by introducing and enforcing supportive legal and policy frameworks, providing peer-support and ongoing training opportunities to physicians, and by raising public awareness around the importance of accurate mortality data, including those associated with stigmatised or sensitive causes of death.



## Related resources and products

### **University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Library** <https://crvsgateway.info/library>

*Assessing the quality of death certification: Guidance for the rapid tool.* CRVS resources and tools.

*Handbook for physicians on cause of death certification.* CRVS resources and tools.

*Strategies for improving the quality of cause of death data in hospitals.* CRVS development series.

*Intervention: Medical certification of cause of death.* CRVS summaries.

*Medical certification of cause of death: Quick reference guide.* CRVS summaries.

*Training and education on medical certification of cause of death: Effective strategies and approaches.* CRVS development series.

### **University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Learning Centre** <https://crvsgateway.info/learningcentre>

Topic 4: Cause of death in CRVS systems.

### **University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Courses** <https://crvsgateway.info/courses>

Medical certification of cause of death.

## Further reading

Bradshaw D, Schneider M, Dorrington R, Bourne D, Laubscher R. South African cause of death profile in transition – 1996 and future trends. *South African Medical Journal* 2002; 92:618-623.

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Yu N, Chow A, Chan C, Zhang J, Stewart S. Stigma never dies: mourning a spouse who died of AIDS in China. *Psychiatry Research* 2015; 230:968-970.

The program partners on this initiative include: The University of Melbourne, Australia; CDC Foundation, USA; Vital Strategies, USA; Johns Hopkins Bloomberg School of Public Health, USA; World Health Organization, Switzerland.

Civil Registration and Vital Statistics partners:



## For more information contact:

CRVS-info@unimelb.edu.au  
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