



Bloomberg
Philanthropies



DATA FOR
HEALTH INITIATIVE

IMPROVING CAUSE OF DEATH INFORMATION

Reducing challenges to
accurate cause of death
reporting by physicians

CRVS Development Series
August 2017



Target audience

Government policy-makers, in-country CRVS staff, CRVS partners, medical professionals and teaching institutions, health-related ethicists and legal experts, academic institutions.

Description

Concise and easily accessible, the CRVS development series form a lasting archive of synthesised evidence on topics related to CRVS systems and data strengthening. The content of this series is based on a combination of international standards and guidelines, Bloomberg Philanthropies Data for Health Initiative technical knowledge, country (and comparative country) experience, as well as the scientific literature. The series is 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.

Other products available from the Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies Data for Health Initiative:

Resources and tools

Capacity-building resources and tools are designed to assist countries improve their systems and to influence and align CRVS practice with established international or best practice standards. These resources, which are used extensively in Bloomberg Philanthropies Data for Health Initiative training courses, aim to both change practice and ensure countries benefit from such changes, by developing critical CRVS capacity among technical officers and ministries.

CRVS technical outcome series

The series focuses on filling a range of scientific knowledge gaps offering new tools, methods, findings and approaches for CRVS systems and data improvement. The series has a strong empirical focus, reporting on works in progress, particularly for large or complex technical initiatives, or on specific components of projects that may be of more immediate relevance to stakeholders.

CRVS country stories

CRVS country stories describe the capacity building experiences and successes of strengthening CRVS systems in partner countries. The series serves to describe the state of CRVS systems improvement in partner countries, lessons learnt, and provides a baseline for comparison over time and between countries.

CRVS roadmaps for action

Roadmaps for action present a succinct overview of the wide-spectrum of common issues and challenges in CRVS systems and provide a suggested way forward for countries. This series is intended to inform health system dialogue in and between countries and a range of development partners.

Acknowledgements

Hafiz Chowdhury, Sonja Firth, Gulshan Ara Khanom, Rajitha Lakmali Jayasuriya, Avita Streatfield, and Claire Brolan, the University of Melbourne; and Joan Sara Thomas, Vital Strategies.

Published by the Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies Data for Health Initiative

The University of Melbourne
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
mspgh.unimelb.edu.au/dataforhealth

**Made possible through funding
from Bloomberg Philanthropies
www.bloomberg.org**



Abbreviations

BD4H	Bloomberg Philanthropies Data for Health Initiative
COD	cause of death
CRVS	civil registration and vital statistics
MCCOD	medical certification of cause of death
WHO	World Health Organization

Purpose of this paper

Identify and discuss barriers to accurate cause of death reporting by physicians and provide recommendations on potential ways the various actors and institutes can respond - including doctors, national medical associations, medical certification of cause of death 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 – medical certification of cause of death.

Key points

- Accurate medical certification of cause of death (MCCOD) is key for producing reliable mortality data, which is needed in multiple sectors, particularly in health, to underpin and monitor evidence-based policy and planning.
- 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 MCCOD.
- Challenges to accurate COD reporting can arise where
 - the death has been caused by a stigmatised disease or condition
 - the deceased's family pressures the physician to state or avoid a particular COD 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 death is the result of homicide, suicide or other conditions necessitating a coronial enquiry to apportion cause and responsibility
 - complex health system and workplace pressures exist.
- There are several strategies that can be used by various agencies, such as the National CRVS Committee, Office of the Registrar General, medical associations (etc), to protect physicians who certify COD
 - Introduce and enforce legal and policy frameworks that protect physicians from undue pressure when assigning COD
 - Clearly communicate to physicians the legal and policy protections that are available to support accurate COD certification
 - Encourage physician peer support to address challenges associated with MCCOD
 - 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 causes of death 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 to prevent the spread of notifiable diseases¹
- 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.

¹ Centers for Disease Control and Prevention (2015) Standards to Facilitate Data Sharing and Use of Surveillance Data see: [http://www.cdc.gov/nchhstp/programintegration/SC-Standards.htm#DATA-SHARINGfor Public Health Action](http://www.cdc.gov/nchhstp/programintegration/SC-Standards.htm#DATA-SHARINGfor%20Public%20Health%20Action). See also: <http://www.cdc.gov/nchhstp/programintegration/Data-Security-FAQ.htm>

Reducing challenges to accurate cause of death reporting by physicians

Summary of content

Why is accurate medical certification of cause of death (MCCOD) important?

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

What are the constraints to accurate death MCCOD faced by physicians?

What action can be taken to support physicians accurately report the COD?

Summary

Why is accurate medical certification of cause of death (COD) important?

Reliable cause of death (COD) information is crucial for national authorities to generate accurate mortality statistics and understand mortality levels, differentials and trends in their populations.

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.²

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

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

² Phillips DE, AbouZahr C, Lopez AD, Mikkelsen L, de Savigny D, Lozano R, Wilmoth J, Setel PW. Are well functioning civil registration and vital statistics systems associated with better health outcomes? *The Lancet*. 2015;386(10001):1386-1394.

³ Lomas H, Berman J. Diagnosing for administrative purposes: some ethical problems. *Social Science and Medicine*. 1983;17(4):241-244.

It is acknowledged, however, that socio-cultural, community and ethical factors might influence the information a physician enters in the death certificate. These factors are complex and are usually subtle and nuanced.

What are the constraints to accurate death certification by physicians?

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 MCCOD through the *Bloomberg Philanthropies Data for Health Initiative* (BD4H), we have identified various challenges to accurate COD certification by physicians. Roadblocks usually appear to arise where:

- the death is caused by a sensitive or stigmatised disease or condition
- the deceased's family pressures the physician regarding the inclusion of certain causes on the death certificate
- a potential insurance payout could be denied to the deceased's family
- there are doctor-patient confidentiality concerns in releasing the death certificate to family
- the physician fears potential legal consequences
- the death is by homicide, suicide or other cause requiring a coronial enquiry
- complex health systems and workplace pressures.

These seven barriers can be linked to the:

- **mode of death** or underlying COD
- **community responses to the type of death** or underlying cause.

The death is the result of a sensitive or 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 into the death certificate. The main types of stigmatised or "taboo" deaths³ that physicians might be reluctant to explicitly identify on the death certificate are HIV/AIDS and other sexually transmitted diseases, abortion, maternal death in unmarried women, infectious diseases such as Ebola, gender-based violence and domestic violence, and suicide. Unsurprisingly, this contributes to poor quality COD data and under-reporting of deaths resulting from conditions of public health importance.⁴⁻⁸ For example, many reports in the

³ 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(4):610-25.

⁴ Tangcharoensathien V, Faramnuayphol P, Teokul W, Bundhamcharoen K, Wibulpholprasert S. A critical assessment of mortality statistics in Thailand: Potential for improvements. *Bulletin of the World Health Organization*. 2006;84(3):233.

⁵ World Health Organization (WHO). *Preventing suicide: a global health imperative*. 2014. World Health Organization: Geneva.

literature describe inaccuracies in COD certification that targeted misrepresentation of HIV-specific mortality by physicians in the South African context,⁹⁻¹¹ highlighting the complex nature of stigmatisation and HIV/AIDS in that country.¹² However, physician avoidance of stating HIV/AIDS on the death certificate was reported as also occurring in the United Kingdom in the late 1980s.¹³

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 socio-cultural traditions, beliefs and practices.

Physicians might assent to the real or perceived family pressure not to definitively state the cause of (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 as a result of 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,¹⁵ Swaziland,¹⁶ China,¹⁷ Thailand,¹⁸ and the United States.¹⁹ Stigmatisation of

⁶ Pritchard C. Hidden suicide in the developing world. In: Shrivastava A, Kimbrell M, Lester D, editors. *Suicide from a Global Perspective: Psychosocial Approaches*. Nova Science: United States; 2012.

⁷ Chang S, Sterne J, Lu T, Gunnell D. 'Hidden' suicide amongst deaths certified as undetermined intent, accident by pesticide poisoning and accident by suffocation in Taiwan. *Social Psychiatry and Psychiatric Epidemiology*. 2010;45(2):143-152.

⁸ Thapa B, Carlough M. Suicide incidence in the Lalitpur district of Central Nepal. *Tropical Doctor*. 2000;30(4):200-203.

⁹ Burger E, Groenewald P, Bradshaw D, Ward A, Yudkin P, Volmink J. Validation study of cause of death statistics in Cape Town, South Africa, found poor agreement. *Journal of Clinical Epidemiology*. 2012;65(3):309-16.

¹⁰ Burger E, Groenewald A, Rossouw A, Bradshaw D. Medical certification of death in South Africa - moving forward. *South African Medical Journal*. 2015;105(1):27-30.

¹¹ Riffe H, Fouche C. Does anyone die from AIDS in South Africa? *Journal of HIV/AIDS and Social Services*. 2007;6(4):23-36.

¹² Niehaus I. Death before dying: Understanding AIDS stigma in the South African lowveld. *Journal of Southern African Studies*. 2007;33(4):845-60.

¹³ King M. AIDS on the death certificate: the final stigma. *British Medical Journal*. 1989;298:734-736.

¹⁵ 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(8):618-23.

¹⁶ Desmond C, King J, Tomlinson J, Sithungo C, Veenstra N, Whiteside A. Using an undertaker's data to assess changing patterns of mortality and their consequences in Swaziland. *African Journal of AIDS Research*. 2004;3(1):43-50.

¹⁷ 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(3):968-70.

¹⁸ Songwathana P, Manderson L. Stigma and rejection: Living with aids in villages in southern Thailand. *Medical Anthropology*. 2001;20(1):1-23.

¹⁹ Robinson L. Disclosure after a sibling's death from AIDS. *Family and Community Health*. 2002;25(1):22-31.

remaining family connected to a death by suicide in the developed and developing world is further well-documented.^{20,21}

Avoiding potential denial of insurance pay-outs that financially penalise surviving family members

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 pay-out by the family's insurer.²² Fear of the potential of depriving much-needed insurance monies from families, 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 that hold the trust and esteem of local community members.

Fear of confidentiality breach if COD is stated on the death certificate

Unless the patient clearly authorised the release of his/her health information in writing to a third party (such as relatives) before their death (among other medico-legal factors), the physician is usually bound to continue maintaining their deceased patient's confidentiality.²³

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, funeral parlours). Some physicians are particularly anxious in maintaining patient confidentiality where the patient died as a result of a perceived sensitive condition or illness.

Fear of legal consequence if COD is incorrect

Some physicians may become anxious that if they enter an incorrect COD they may be investigated or sued for malpractice. There are a number of 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.

Fear of retribution by correctly stating COD if death was due to homicide

Some physicians fear that if they enter an incorrect COD, or a correct cause associated with

²⁰ Peters K, Cunningham C, Murphy G, Jackson D. '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;25:251-7.

²¹ Harwood D, Hawton K, Hope T, Jacoby R. 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(2):185-94

²² See, for example: Burger E, Groenewald P, Roussow A, Bradshaw D. Medical certification of death in South Africa – moving forward. *South African Medical Journal*. 2015;105(1):27-30.

²³ Kottow M. Medical confidentiality: an intransigent and absolute obligation. *Journal of Medical Ethics*. 1986;12:117-22.

stigma, they are vulnerable to accusations of malpractice and litigation. On the other hand, in extreme circumstances, physicians have anecdotally reported that 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.

Pressure from workplace and health systems to quickly complete the death certificate

Physicians in busy, under-staffed and resource-limited hospital environments have reported pressure from colleagues, nurses, and administrators to attend to the death and quickly complete the death certificate. The pressure to complete the death certificate may be to allow the hospital to speed-up removal of the dead body from the premises, or it may be in response to a family or government demand for urgent release of the body. Junior physicians particularly struggle to accurately enter the COD information in these tense working situations.

What action can be taken to support physicians accurately report the COD?

Below are seven suggestions, multi-pronged in their approach, to guide countries and their partners to address the various barriers to accurate MCCOD, which can be experienced by physicians worldwide.

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 co-ordinated by the National CRVS Committee, or sub-committee.

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

It is important 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 accurately to 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

Where necessary it is recommended that a physician consults 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.

Physician peer-support discussion groups to address the challenges associated with MCCOD

It is suggested that peer/near-peer or eLearning teaching schemes relating to death certification and its implications should be developed, as formal workshops on the subject (although useful) may not be readily accessible to all physicians.²⁴ 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.

Legal and regulatory analysis of insurance company practices and law

It is recommended that analysis of the legal and regulatory frameworks for MCCOD (Recommendation 1) 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 pay-outs, 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 on account of the COD.

Governments should also work with medical associations and professional bodies to clarify the status quo on penalising insurance pay-outs to physicians. The aim should be to alleviate physician's moral and ethical distress on this subject.

Protecting doctor/patient confidentiality in times of death

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 to hand-lodge 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 regards to the deceased's death, it is recommended that this should 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

²⁴ Khan A, Ah-kee E. Death certification: 800 years of practice; time to modernise teaching? *Scottish Medical Journal*. 2016;61(1):32-33.

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 toward de-stigmatising 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 exploring the socio-cultural constructions of stigmatised deaths, how communities can respond, while also building the family and community's knowledge and resilience to counter such stigma, should also be encouraged and invested in.²⁵ 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 awareness raising at the community-level to address stigmatised disease and sensitive health conditions.²⁶

Summary

Physicians can be placed in difficult situations ethically, morally and legally due to barriers that will impact the accuracy of their MCCOD practice. Governments, working in collaboration with their partners (including national medical associations and professional bodies), can address these subtle but very real roadblocks to accurate MCCOD reporting.

²⁵ Gouda HN, Flaxman A, Brolan CE, Joshi R, Riley ID, AbouZahr C, Firth S, Rampatige R, Lopez AD. 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.

²⁶ Van Bortel T, Basnayake A, Wurie F, Jambai M, Sultan Koroma A, Muana AT, Hann K, Eaton J, Martin S, Nellums LB. Psychosocial effects of an Ebola outbreak at individual, community and international levels. *Bulletin of the World Health Organization*. 2016;94:210-214.

The Bloomberg Philanthropies Data for Health Initiative also run courses on MCCOD training for physicians:

For more information please contact: CRVS-info@unimelb.edu.au

Related resources and products from the Bloomberg Philanthropies Data for Health Initiative:

- University of Melbourne. *Physicians need ongoing education and training death certification. CRVS roadmaps for action*. 2017. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.
- University of Melbourne. *Improving the quality of cause of death data in hospitals. CRVS technical outcome series*. 2017. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.
- University of Melbourne. *Handbook for doctors on cause of death certification*. 2017. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.
- University of Melbourne. *Medical certification of cause of death [Summary Flyer]*. 2016. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.
- University of Melbourne. *Medical certification of cause of death. Quick reference guide*. 2016. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.

Recommended further reading:

- Lopez A, AbouZahr C, Shibuya K, Gollogly L. Keeping count: births, deaths, and causes of death. *The Lancet*. 2007;370(9601):1744-1746.
- Link B, Phelan J. Stigma and its public health implications. *The Lancet*. 2006;367(9509):528-529.
- McAllum C, St George I, White G. Death certification and doctors' dilemmas: a qualitative study of GPs' perspectives. *British Journal of General Practice*. 2005;15(9):677-683.

***Disclaimer: No recommendations or advice given in this paper constitute or should be viewed or treated as legal advice by any individual or agency. These are the opinions of the authors alone.**

**Bloomberg
Philanthropies**



**DATA FOR
HEALTH INITIATIVE**



Australian Government
Department of Foreign Affairs and Trade

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:

E: CRVS-info@unimelb.edu.au

W: mspgh.unimelb.edu.au/dataforhealth

CRICOS Provider Code: 00116K

Version: 0817-01

Copyright

© Copyright University of Melbourne July 2017.

The University of Melbourne owns the copyright in this publication, and no part of it may be reproduced without their permission.

Disclaimer

The University of Melbourne has used its best endeavours to ensure that the material contained in this publication was correct at the time of printing. The University gives no warranty and accepts no responsibility for the accuracy or completeness of information and the University reserves the right to make changes without notice at any time in its absolute discretion.

Intellectual property

For further information refer to: www.unimelb.edu.au/governance/statutes