Improving the Quality of Cause of Death Information Related to Maternal Mortality

As Required by

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Executive Summary

Senate Bill 17, 85th Legislature, First Called Session, 2017 (S.B. 17), directs the Department of State Health Services (DSHS) to study the process and procedures for collecting cause of death information including any challenges to collecting accurate information relating to maternal mortality.

A report including the findings and recommendations from this review must be submitted to the Governor, Lieutenant Governor, Speaker of the House of Representative, and appropriate standing committees of the legislature by December 1st of each even numbered year.

This report outlines the current process of collecting cause of death information and discusses the findings and recommendations identified from four assessments on the issue. Findings from these assessments include the following.

- Errors often occur in attempting to identify the underlying cause of death.
- Errors in reporting pregnancy status for female decedents may contribute to an inflated maternal mortality rate.
- Some providers do not understand the role of death certificates in public health.
- Lack of training is a barrier to quality reporting on death certificates.
- Logistical inefficiencies within the death registration process lower data quality.
- Some medical certifiers need more resources to support them in their role in the death registration process.

Recommendations made in the report include the following.

- Improve death certificate quality through medical certifier training and support.
- Facilitate communication among stakeholders to reduce role confusion in completing individual death certificates.
- Enhance DSHS capacity and expertise to support continued evaluation and improvement in cause of death reporting.
- Foster stakeholder input to identify opportunities and challenges to improve quality of death registration data.

1. Introduction

Death certificates serve public health, administrative, and legal purposes. Death certificates contain medical information such as cause of death , manner of death, pregnancy status, whether an autopsy was performed, whether tobacco use contributed to death, and injury information for deaths where the manner is not natural. The death certificate is as important to public health as the medical record is to patient care. It is therefore vital to ensure that the information in death certificates is of high enough quality to support state efforts to provide reliable mortality statistics and public health programming.

Senate Bill 17, 85th Legislature, Regular Session, 2017 directs the Department of State Health Services (DSHS) to study the process and procedures of collecting cause of death information including any challenges relating to maternal mortality. DSHS may examine

- issues relating to the quality of death information collected, including the accuracy and completeness of the information;
- the role of medical certifiers in death information collection;
- the perception of individuals collecting death information regarding the information's integrity;
- required training for individuals collecting death information; and
- structural, procedural, and technological issues of collecting the information.

In their study, DSHS is directed to examine national standards and may convene a panel of experts to advise the department, and work with the Maternal Mortality and Morbidity Task Force in developing recommendations.

In the following report, DSHS will

- outline the process of reporting cause of death;
- describe findings on challenges to quality cause of death information including maternal mortality data; and
- provide recommendations on how information quality can be improved.

2. Background

Vital events, including births, deaths, fetal deaths, and marriages, that take place in Texas must be reported to the DSHS. There are approximately 900,000 vital events registered each year. DSHS works with medical facilities, funeral homes, and local government offices to ensure events are reported timely and accurately. Once vital events are reported from statutorily authorized data providers, such as physicians, medical examiners, Justices of the Peace, birth clerks, and midwives, the reports are reviewed and registered as official vital records.

The resulting vital records serve public health, administrative, and legal purposes. The medical information captured on birth, death, and fetal death records underlie public health research and surveillance into areas such as maternal mortality, birth defects, and leading causes of death. DSHS staff must work with data providers to ensure that the information provided accurately reflects medical and health records. Certified copies of birth and death records are issued to qualified applicants for various administrative and legal purposes, such as school enrollment, passport applications, and settling estates. DSHS staff must examine customer applications to minimize identity theft and prevent fraud.

DSHS collects, registers, amends, issues, and preserves vital records for legal and administrative purposes, and uses vital statistics for public health activities to improve the health and well-being of Texans. Public health interventions, based on mortality statistics, seek to prevent deaths by intervening as early as possible in the sequence of events that lead to death. Incomplete, inaccurate, or nonspecific reporting on death certificates can lead to under- or over-counting of causes of deaths, which can affect public health programs, policy, and funding as well as responses to disasters, outbreaks, and emergencies.

However, reporting and collecting high quality data through death certificates can be difficult, and current processes need to be examined in order to understand local context and challenges to quality data reporting.

Between 1903 and 2007, death registration in Texas was a paper-based process. House Bill 1739, 80th Texas Legislature, Regular Session, 2007, was enacted requiring electronic death reporting for funeral homes and medical certifiers. To comply with this requirement, DSHS implemented mandatory electronic death reporting using the Texas Electronic Registrar (TER) system.

The conversion from paper-based reporting to electronic reporting improved the timeliness of death registration, promoted standardized death certificate reporting, and made mortality data more readily available as a surveillance tool for measuring health. Electronic reporting is considered a national standard and best practice in vital statistics, with automated checks and functionality to enhance data quality, timeliness, and security that do not exist in paper-based reporting.

Though DSHS has adopted electronic reporting and registration, there is still a business need for paper records. Electronic storage is not considered an acceptable permanent media storage option in part because disks have a more limited life-span (less than 30 years) compared to the long-term options of specialized paper and microform (50-100 years). The software required to store and retrieve electronic records also changes over time adding additional barriers to long-term storage and retrieval. Currently, DSHS works with the Texas State Library to transfer records to microfilm to maintain the quality and integrity of vital records.

Texas has reviewed the quality and security of the statewide system of vital registration over the last several years. In 2012, DSHS, in conjunction with a birth-record security workgroup established as a provision of the 2012-2013 General Appropriations Act, House Bill 1, 82nd Texas Legislature, Regular Session, 2011 (Article II, Texas Department of State Health Services, Rider 72), developed a set of recommendations that addressed the security and effectiveness of the state's birth record information system. Recommendations to improve the security of vital event data included the replacement of the existing Texas Electronic Registrar (TER) system. The Texas Electronic Vital Events Registrar (TxEVER) Project will result in the implementation of a new system, TxEVER, starting on January 1, 2019.

In this report, DSHS is directed to assess the quality of cause of death information in relation to maternal mortality. In recent years, policymakers, researchers, and the public have focused attention on the number of Texas maternal deaths and severe health outcomes resulting from pregnancy and delivery. In response to reports of higher rates of maternal mortality in the state, the Texas Legislature established the Texas Maternal Mortality and Morbidity Task Force in 2013 to review cases of maternal death, determine whether they were pregnancy-related, and identify recommendations to improve maternal outcomes. DSHS remains committed to improving maternal health, and preventing maternal mortality and morbidity in Texas.

3. Collecting Cause of Death Information

Collecting cause of death information, regarding the circumstances under which an individual died, is required for filing a death certificate for registration.

Death Registration Requirements in Texas

The process of registering a death begins with the funeral director, or person acting as such, filing a Report of Death with the local registrar (for the registration district where the person died) within 24 hours of taking custody of a body. It is the responsibility of the funeral director to complete and file the Certificate of Death within ten days of the date of death (Texas Health and Safety Code, Section 193.002 and 193.003). Completion of the death certificate requires collaboration among the funeral director, the person responsible for medically certifying the death, and others as necessary to complete the certificate.

The Texas death certificate follows the United States standard death certificate set by the National Center for Health Statistics (NCHS) at the United States Centers for Disease Control and Prevention (CDC), and includes items such as name, date of birth, date of death, cause and manner of death, and burial or disposition information.[1] The reporting process is electronic, and the death certificate must be electronically signed by the funeral director and the medical certifier prior to becoming registered by the state as an official vital record.

The medical certifier must be a physician, medical examiner, or Justice of the Peace (JP) with exceptions allowed only as specifically outlined in statute (Texas Health and Safety Code, Section 193.005; Code of Criminal Procedure, Section 49.04 and 49.25). In most circumstances, a physician will be the most appropriate individual to medically certify a death certificate. If the manner of death is anything other than natural and/or the death meets any of the circumstances outlined within statute, the JP or medical examiner should be called immediately for investigation or inquest as to the cause and manner of death and will be the one to medically certify the death certificate. Additionally, in accordance with Code of Criminal Procedure, Section 49.04, the medical examiner or JP should be notified of the

[1] www.cdc.gov/nchs/nvss/revisions-of-the-us-standard-certificates-and-reports.htm

deaths of children under the age of six, upon which an inquest is done to determine whether the death was unexpected or the result of abuse or neglect.

Once the death certificate is completed and signed, it must be filed electronically with the local registrar and DSHS within ten days of the date of death by the funeral director or the person acting as such.[2] Once the death certificate is registered as an official vital record by the state, it may only be updated or corrected through an amendment process.

Reporting the Cause of Death

Texas is one of 57 vital records jurisdictions that is independently responsible for overseeing vital statistics systems in the United States. These jurisdictions send data to CDC NCHS to create national-level vital statistics. CDC NCHS provides written guidance and best practices to ensure high quality death certificate and cause of death data, including handbooks and guides for physicians, medical examiners, and funeral directors on medical certification of death and death registration. These can be found at www.cdc.gov/nchs/nvss/training-and-instructional-materials.htm.

The cause of death section on the death certificate is where the medical certifier reports the final diseases or conditions that resulted in death, according to their best medical judgment. The cause of death section on the Texas death certificate is divided into two parts – Part 1 and Part 2 – and follows the national standard set by the CDC.

Part 1 in the cause of death section on the death certificate contains four lines - a, b, c, and d - to use for recording, in reverse chronological order, the causal sequence of events or conditions leading to death. The medical certifier must complete Part 1(a) with the immediate cause of death, which is the specific condition that directly preceded the death. To complete the sequence leading to death, the medical certifier works backwards from Part 1(a). The intermediate cause(s) are the significant conditions that preceded and gave rise to the immediate cause of death, and these are listed on the lines below Part 1(a) on the death certificate. The last line is used for the underlying cause of death, which is

[2] Fetal deaths, as defined in 25 Texas Administrative Code, Section 181.1 (11), do not have associated birth and death certificates and instead have a Certificate of Fetal Death as the sole vital record to evidence the pregnancy.

the initiating condition that triggered the sequence of events leading to death (see Appendix A). The underlying cause of death reported on the death certificate is what drives mortality statistics on leading causes of death.

In general, the medical certifier should try to provide a specific and clear causal sequence of events that resulted in death. If the medical certifier is unable to determine a sequence or chain of events that ends in death, then the medical examiner or JP may need to be consulted about conducting an investigation.

The medical certifier can use terms like *probable* or *presumed* when reporting the cause of death on the death certificate. Also, if the certifier is unable to determine the cause, they should record the cause as *unknown*, *undetermined*, or *unspecified*.[3]

Part 2 is for reporting all other significant diseases, conditions, or injuries that contributed to death, but which did not result in the underlying cause of death given in Part 1.

An excerpt from the CDC's *Physicians' Handbook on Medical Certification of Death* is reproduced in Appendix B to show the accurate completion of Part I and Part II of the cause of death section of the death certificate.[4]

Reporting Pregnancy Status on the Death Certificate

The US Standard Death Certificate was revised in 2003 to include a pregnancy status question for medical certifiers to identify whether a female decedent was pregnant at time of death or had been pregnant in the last year. Texas adopted this item in 2006. On Texas's death certificate form, medical certifiers are presented with a drop-down menu with the following options:

- *Not pregnant within past year*;
- *Pregnant at time of death*;
- *Not pregnant, but pregnant within 42 days of death;*
- *Not pregnant, but pregnant 43 days to 1 year before death*; or
- *Unknown if pregnant within the past year.*

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[3] Ibid.

[4] https://www.cdc.gov/nchs/data/misc/hb_cod.pdf

Information from the pregnancy status item is a factor used to determine maternal mortality rates.

2017 Death Certificate Data Analysis

Basic descriptive statistics were conducted in order to understand the context in which deaths are registered in Texas.

Using 2017 provisional data, there were 200,863 total deaths registered in Texas, of which 80 percent were certified by physicians, 10 percent by medical examiners, and 10 percent by JPs.

Of the total deaths, 63 percent took place in a medical facility setting (of which 39 percent took place in a hospital), 31 percent at the decedent's home, and 6 percent in an "other" setting.

There were 13,558 physicians who certified death certificates in 2017, with an average of 12 deaths being certified by each physician during the calendar year.

4. Assessments and Findings

The Department of State Health Services (DSHS) has conducted multiple assessments to study the quality of cause of death data on death certificates, the current process of collecting cause of death information, and any challenges relating to the quality of that information.

Assessments

To study the quality of cause of death information on death certificates, DSHS relied on the following assessments.

Literature Review

DSHS began its assessment by reviewing the related academic and professional research to identify challenges to process and quality experienced in other vital records jurisdictions. This included recent DSHS research published in *Obstetrics and Gynecology*, which analyzed methods used to identify cases of maternal death.[5]

Environmental Scan on Maternal Mortality Data

A Maternal Mortality and Morbidity Forum (the Forum) was hosted by the Texas Medical Association (TMA) and DSHS on September 30, 2017. The purpose of the Forum was to convene medical and public health professionals to identify how medicine could reduce maternal morbidity and mortality in Texas. The Forum consisted of three workgroups: Data Collection and Reporting, Public Health, and Systems of Care. The Vital Statistics State Registrar led the Data Collection and Reporting Workgroup, which focused on (1) establishing guidelines and best practices for reporting pregnancy-related deaths to the medical examiner or JP in each Texas county, and (2) correctly completing the death certificate of a person whose death was related to pregnancy.

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[5] Baeva S, Saxton DL, Ruggiero K, Kormondy ML, Hollier LM, Hellerstedt J, Hall M, Archer NP. Identifying Maternal Deaths in Texas Using an Enhanced Method, 2012. *Obstet Gynecol* 2018;131;762-769.

As part of its action plan, the workgroup conducted an environmental scan of how death certificates are completed in Texas, and how maternal and pregnancy-related deaths are identified. The environmental scan entailed surveys, discussions, and conference calls with data providers and stakeholders. TMA and the Texas Health Association supported the environmental scan by sending out surveys to members and hosting discussions with stakeholders. Physicians, medical examiners, Justices of the Peace (JPs), researchers, and hospital executives participated. Guiding questions for the environmental scan can be found in Appendix C.

Maternal Mortality and Morbidity Task Force

Health and Safety Code, Section 34.002 established the Maternal Mortality and Morbidity Task Force. The 17-member multidisciplinary Task Force, administered by DSHS, reviews and studies cases of maternal death and trends in severe maternal morbidity, identifies trends and disparities, reviews best practices, and submits a joint biennial report on recommendations to reduce the incidence of pregnancy-related death and severe maternal morbidity in Texas. In 2017 the 85th Legislature, First Special Session, passed Senate Bill 17 to extend the life of the Task Force to 2023 and expand its membership to 17 multi-disciplinary members.

For this report, DSHS reviewed Task Force reports for findings and recommendations on death certificate accuracy for cases of maternal mortality. DSHS specifically looked at Task Force Joint Biennial Reports for years 2016 and 2018.

On September 14, 2018, DSHS also met with the Task Force for input on the challenges they see when completing death certificates. DSHS asked the Task Force for recommendations to improve the death registration process.

Focus Groups on the Death Certificate Process

In 2017, DSHS began partnering with Texas A&M University School of Public Health, USA Center for Rural Public Health Preparedness to develop online trainings for data providers responsible for completing death certificates. The trainings are scheduled to roll out in 2019. Focus groups were conducted in early 2018, using a facilitation guide, to gather information on current practices. There was one focus group session held with funeral directors, physicians, and Justices of the Peace (JPs), respectively. Focus groups, while not a comprehensive representation of the medical community, provide meaningful insights to inform further steps in

improving death certificate quality in Texas. See Appendix D for the Focus Group Questions.

Panel of Experts

As part of its review of the quality of cause of death data on death certificates, the State Registrar convened a panel of experts in July 2018. The panel participants are listed in Appendix E.

The panel represented broad expertise and experience with vital registration in Texas, other states, and at the national level. The central question posed to the group was *What are the challenges in collecting accurate death data?*

DSHS has used the above assessments to study the process and procedures of collecting cause of death information including any challenges relating to maternal mortality. These include

- issues relating to the quality of death information collected, including the accuracy and completeness of the information;
- the role of medical certifiers in death information collection;
- the perception of individuals collecting death information regarding the information's integrity;
- required training for individuals collecting death information; and
- structural, procedural, and technological issues of collecting the information.

Findings from this study are described below.

Findings

Finding 1

Errors often occur in attempting to identify the underlying cause of death.

Through literature review, DSHS has identified common errors made in the cause of death section of death certificates. The most common error is listing the mechanism of death as the underlying cause of death. In the CDC case history presented in Appendix B, if only "cardiac arrest" was reported, information regarding pneumocystis carinii pneumonia, AIDS, and HIV would have been lost, along with the potential for public health programs and policies to prevent such deaths. Other

common errors in cause of death reporting include listing conditions in the incorrect causal order or listing a nonspecific condition as an underlying cause.

Another common error among physician certifiers is not including the initial event that brought a patient to the hospital. Physicians may focus on the natural disease processes experienced by the patient in the hospital and only include that information on the death certificate. However, there are cases when a non-natural process, such as trauma, brought the patient to the hospital in the first place. If a non-natural event initiated the chain of processes leading to death, the event should be listed as the underlying cause of death. However, if this detail is missing, the physician may not notify the medical examiner or JP whose role it is to certify the non-natural deaths. Also, the true underlying cause of death would not be included in the vital statistics that inform public health funding and programming.

In the 2016 Task Force and DSHS Joint Biennial Report, the Task Force recommended improving the quality of death certificate data. This is because death certificate data is the main source of maternal death information for maternal mortality reporting.[6] In the 2018 Task Force and DSHS Joint Biennial Report, the Task Force reiterated this recommendation.[7] The 2018 report also underscored the importance of supporting state initiatives to improve maternal death data and ensuring continuing education for death certifiers. The Task Force recognized that death data needs to be accurate to effectively inform Task Force recommendations and public health strategies to reduce maternal mortality.

Finding 2

Errors in reporting pregnancy status may contribute to an inflated maternal mortality rate.

Using the standard method of determining maternal mortality rates (MMR), research in 2016 reported a sharp increase in the MMR in Texas between 2010-2012, peaking in 2012 to 38.7 deaths per 100,000 live births.[8]

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[6] dshs.texas.gov/Legislative/Reports-2016.aspx

[7] dshs.texas.gov/Legislative/Reports-2018.aspx.

[8] MacDorman MF, Declercq E, Cabral H, Morton C. Recent increases in the U.S. maternal mortality rate: disentangling trends from measurement issues. *Obstet Gynecol* 2016;128:447-55.

DSHS recently studied Texas maternal deaths for 2012 using an enhanced methodology to assess death certificate accuracy.[5] DSHS used vital records matching and medical records review to determine whether the 2012 Texas maternal deaths identified using the standard method were truly maternal deaths. DSHS then used data matching to identify additional maternal death cases that were missed by the standard method. Using this enhanced process for maternal death identification, DSHS researchers determined that 56 maternal deaths occurred in 2012 (within 42 days of the end of pregnancy), which corresponds to an MMR of 14.6 per 100,000 live births. This new estimate was less than half the number and MMR that was previously reported for Texas (n=147 maternal deaths, MMR=38.4/100,000 live births).

The standard method of identifying maternal deaths relies on the pregnancy status and cause of death listed on the death certificate. DSHS results indicate that mistakes in reporting the pregnancy status was likely a main reason for the higher MMR reported using the standard method and is consistent with over-reporting of positive pregnancy status on death certificates across the United States. In particular, 74 maternal deaths identified using the standard method were found to have no evidence of pregnancy upon investigation (using data matching and medical and other records review), and three-quarters of these (76 percent; 56 deaths) were identified as being pregnant at the time of death on the death certificate.

In the current Texas electronic death registration system, which follows the United States standard death certificate, the pregnancy status item appears as a drop-down list where *pregnant at time of death* is directly below *not pregnant within the past year*. DSHS believes that the layout of the current pregnancy status item may have contributed to medical certifiers unintentionally selecting the incorrect pregnancy status. This observation is also shared by the Task Force who noted, in the 2018 Joint Biennial Report, that inaccurate pregnancy status on the death certificate occurred in a majority of the 89 cases they reviewed.

In 2019, DSHS plans to launch a new electronic system for completing death certificates, called the Texas Electronic Vital Events Registrar or TxEVER. As part of this new system, there will be a validation check to prompt the certifier to confirm pregnancy, which will ensure that erroneous pregnancy status selection on the electronic death certificate is minimized in the future.

Finding 3

Lack of training is a barrier to quality reporting on death certificates.

The lack of training for medical certifiers, particularly physicians, is frequently cited in the literature as a common barrier to quality reporting on death certificates. In Texas, there are three general categories of medical certifiers on death certificates, all of whom have varied education and experience: physicians, medical examiners, and JPs.

Physicians are generally not trained in-depth on how to complete death certificates and determine causes of death in medical school, whereas, becoming a board-certified medical examiner requires this training. Further, certain physician specialties may naturally lead to more interaction with the death certificate process while other specialties may have little to no involvement in the process during a given year. These factors can lead to a significant variance in how experienced and trained doctors are in accurately completing the death certificate process. For those doctors who are less trained or experienced, strict timeframes for completing the death certificate can further stress an already unfamiliar situation.

JPs are elected officials and are medical certifiers where there is no county medical examiner office and the death is considered not natural (e.g. manner of death is suicide or homicide) or a physician is not available to medically certify the death. Medical training is not required for JPs, and they do not always have training on completing the death certificate. Often, they will seek out the decedent's physician to obtain any medical history for completing the cause of death.

The focus groups and the panel confirmed that training and education are likely large contributing factors to data quality. Focus group participants expressed concern about the lack of training opportunities on how to complete the death certificate and why an accurate death certificate is important.

Finding 4

Some providers do not understand the important role of death certificates in public health.

In the focus group of funeral directors, participants reported that their biggest challenge in the death certificate process is that physicians have little understanding of the importance of the death certificate. Funeral homes report

regularly having to contact physicians because a death certificate must be completed and/or cause of death information needs to be corrected. From the family perspective, a more accurate cause of death means that an insurance company could pay a claim sooner. When a cause of death is unclear, processing an insurance claim can take longer. From a public health perspective, cause of death information has significant impact on public health research, surveillance, and intervention planning. The physician's focus group confirmed that there is often little awareness among some physicians as to importance of the death certificate or how to complete the cause of death section.

This challenge may reflect the lack of training that physicians receive on how to complete a death certificate, an issue often cited in the literature.

Finding 5

Logistical inefficiencies within the death registration process lower data quality.

The process to file a death certificate requires coordination among the funeral director, the person responsible for medically certifying the death, and others to obtain all necessary demographic and medical information, identify the appropriate medical certifier, and file the certificate within the required ten-day timeframe.

Feedback across the focus groups indicated that it is usually the funeral home/funeral director who receives the initial notification that a death certificate must be filed, often receiving calls from county clerks, the State, families, and medical examiners. Ultimately, funeral homes drive the entire process of death registration. Funeral home administrative staff support the process to ensure quality procedures. This includes keeping logs of calls to other stakeholders and maintaining timeframes for all cases to ensure timely death registration.

A completed death certificate requires signatures from both an authorized data provider attesting to the demographic and disposition information on a decedent, and an authorized data provider attesting to the cause of death and associated medical information. However, there are challenges in obtaining the necessary information to complete the death certificate.

For instance, the physician's focus group stated that when the patient dies at home without a physician present to understand the circumstances of the death, it is challenging to complete that patient's death certificate accurately. They further

explained that they need to be careful not to upset the grieving family in asking them questions about the patient's history.

A similar situation may occur when there is a maternal death. To identify pregnancy-related and maternal deaths, a pregnancy status item is included on the death certificate. However, medical certifiers explain pregnancy history is difficult to ascertain unless evidence of pregnancy is discovered during an autopsy, and/or the death was related to a comorbid condition with pregnancy. Unless the woman was pregnant at time of death, or the death appears to be related to a recent pregnancy, her pregnancy history is often unknown to the medical certifier. The Task Force suggested that the funeral director, who works directly with the next of kin in completing the death certificate, should have a reliable means of relaying relevant information to the medical certifier so the pregnancy status item can be completed accurately.

At times, the issue is identifying who should certify the cause of death for a specific death. The panel discussed that the appropriate medical certifier for a death certificate is not always immediately evident, and professionals may have varying opinions on their responsibilities.

Focus groups found that the medical certifier who is immediately available may feel they are not the best individual to sign a death certificate. In other situations, such as those identified by some JPs, the challenge may be getting emergency room physicians to sign death certificates for patients who die in the emergency room or are dead on arrival. Many physicians also rotate among hospitals, making it more difficult for those in the death registration process to establish who should certify a specific death.

These logistical inefficiencies impact the timeliness of completing the cause of death information and signing a death certificate. Failure to meet those requirements may lead to disciplinary action for medical certifiers and funeral directors. Health and Safety Code, Sec. 193.0041, prohibits professional licensing agencies from taking disciplinary action if written documentation outlines good faith efforts to timely file the death certificate, and demonstrates that circumstances beyond the person's control hampered timely filing. The factors outlined above may be a barrier to timeliness, but also be difficult to provide written documentation for, leading to potential disciplinary action.

Finding 6

Some medical certifiers need more resources to support them in their role in the death registration process.

Whereas medical examiners and JPs routinely complete death certificates, many physicians do not use the electronic system every day. As per medical examiners and JPs, some physicians do not want to sign death certificates because they do not know how to use the electronic system and do not have support when using it. This often leaves the death certificate to be completed by the medical examiner or JP, who has minimal knowledge of the patient.

Physicians report no administrative support for completing death certificates. Processes and workflows to streamline and standardize collection of information do not always exist in medical facilities, resulting in operational inefficiencies in the death registration process.

All participants agreed that a more user-friendly electronic system used to file death certificates, including prompts and data checks, would be helpful in providing immediate assistance and feedback during the data entry process.

5. Recommendations to Improve Data Quality

The Department of State Health Services (DSHS) has developed, from its assessments, recommendations on potential measures they could implement that would improve the quality of cause of death information on death certificates. Some of the recommended actions are included in the DSHS Legislative Appropriations Request submitted for fiscal years 2019 and 2020. These recommendations are listed below.

Recommendation 1 (for Findings 1, 2, 3, and 4)

Improve death certificate quality through medical certifier training and support.

Findings from all four assessments identified the perceived lack of training for medical certifiers as a barrier to quality cause of death reporting on death certificates. Medical certifiers have varying experience and training with completing death certificates. Some physicians report not receiving such training in medical school and many note they do not recognize the importance of these documents to public health activities. Justices of the Peace (JPs) are not required to receive training on medically certifying deaths, often do not have a medical background, and must rely on others for information to accurately complete the death certificate.

The panel confirmed the relationship between training and quality cause of death reporting. As such, DSHS recommends data providers receive increased training on the death registration process and how to properly complete a death certificate. Such training will give data providers an understanding of the important role of death certificates in public health as well as what their responsibility is in the process. Any training should include information on as best-practice workflows and systems that facilitate efficient death registration. Training should also highlight accurate reporting of pregnancy status for female decedents. Such support would be especially helpful to data providers who have little experience with the death registration process or time to devote to this activity.

DSHS has customer and field services representatives whose responsibilities entail training and outreach to data providers, and data quality is being integrated into trainings. The development of online trainings on cause of death reporting is in

progress, and there are plans to add disaster-related cause of death reporting trainings as well.

The Task Force also recommends the state continue to support initiatives to improve maternal death coding and ensure effective continuing education for death certifiers.

DSHS expects that through these training opportunities, and those through other organizations, medical certifiers will improve their ability and motivation to complete death certificates accurately.

Recommendation 2 (for Findings 4 and 5)

Facilitate communication among stakeholders to reduce role confusion in completing individual death certificates.

High quality death data is essential to public health activities and must be supported by all participants in the death registration system. DSHS has found that communication among data providers can be difficult. Focus group participants described the challenges they have in identifying the appropriate medical certifier for certain deaths and collecting the necessary information to complete the cause of death information.

DSHS recommends promoting opportunities to expand communication and discussion on roles among of members of the death registration process. This may involve working with institutes of higher education, medical schools, medical societies, and professional associations to forge new connections between medical certifiers and to clarify their role in different circumstances.

One mechanism where DSHS has already begun this promotion is with their vital statistics regional and annual conferences. At these conferences, DSHS emphasizes the importance of data quality and encourages those involved in the death registration process to improve working relationships and receive training on medically certifying deaths.

DSHS expects that by facilitating communications and networking in the death registration system, participating members will increase in knowledge, ability, and confidence and the quality of the resulting data will improve.

Recommendation 3 (for Findings 1, 2, 3, and 5)

Enhance DSHS capacity and expertise to support continued evaluation and improvement in cause of death reporting.

Focus group participants, especially physicians, expressed the desire for more support completing death certificate information. Many physicians are unfamiliar with the current electronic death registration system and are as such hesitant to act as medical certifiers. All participants agreed that a more user-friendly system would help them in their work.

DSHS has initiated a process to enhance their ability to focus on data quality in its ongoing work. A DSHS proposed exceptional item will expand the capabilities of the section in identifying potential improvements to systems and processes in order to improve the quality of data being reported.

The launch of Texas Electronic Vital Events Registrar (TxEVER) will update the state's electronic death registration system, and the system will be continuously updated to incorporate stakeholder feedback. For instance, TxEVER will include prompts and data checks, which will help improve accuracy in reporting pregnancy status.

Recommendation 4 (for Finding 5)

Foster stakeholder input to identify opportunities and challenges to improve quality of death registration data.

Stakeholders in the death registration process are a vital resource in identifying issues and solutions to death data quality. DSHS has benefitted from this opportunity to reach out to stakeholders and experts and to learn from their experiences through the assessment process.

Building upon the findings of this report, DSHS will begin formalizing the creation of a stakeholder workgroup. A stakeholder workgroup will give voice to the concerns of those participating in death registration and cultivate ambassadors of cause of death data quality improvement initiatives related to the above recommendations. The stakeholder workgroup will have the ability to work with DSHS and assist in identifying and developing action plans for the most pressing issues affecting the death registration process and reporting quality data.

6. Conclusion

Death certificates serve public health, administrative, and legal purposes. Incomplete, inaccurate, or nonspecific reporting on death certificates can lead to under- or over-counting of causes of deaths, which can incorrectly affect public health programs, policy, and funding as well as responses to disasters, outbreaks, and emergencies. Research shows that this may have been the case in determining the state's maternal mortality rate in 2012.

The Department of State Health Services (DSHS) has reviewed literature, completed an environmental scan, conducted focus groups, and led a panel of experts to assess the current state of death data quality in Texas. Through these assessments, DSHS found there to be a need for training, improved communications, and modern electronic systems.

To achieve improvements in death data quality, DSHS recommends the following activities.

- Improve death certificate quality through medical certifier training and support.
- Facilitate communication among stakeholders to reduce role confusion in completing individual death certificates.
- Enhance DSHS capacity and expertise to support continued evaluation and improvement in cause of death reporting.
- Fostering stakeholder input to identify opportunities and challenges to improve quality of death registration data.

Finding 6, regarding the need for more resources to support medical certifiers in the death registration process, is not addressed in these recommendations. While training on completing a death certificate will improve the knowledge and skills of medical certifiers, providing administrative support falls outside the purview of DSHS.

DSHS will address the above recommendations in current and future activities and asks stakeholders to support improved quality in cause of death reporting through similar endeavors. Through a proposed exceptional item (EI) in the Legislative Appropriations Request (LAR) for fiscal years 2020-2021, DSHS has requested additional funding to support hiring additional staff to focus on evaluation and implementing quality improvement projects. The proposed EI also requests

additional funds to increase the security, quality, and capacity of vital records, and improve customer service.

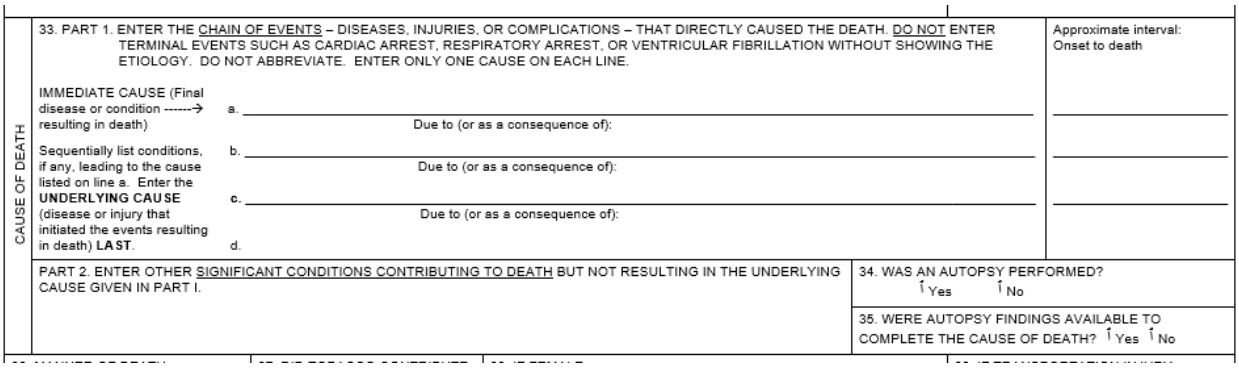
Addressing challenges with the quality of cause of death information necessitates a broad participatory approach focused on improving the death registration process. The activities conducted to fill the requirements of this report are an essential first step in informing next steps, and bringing together the broad group of stakeholders who contribute to the death certificate process. DSHS is committed to increasing the quality of death certificate information to best carry out their mission to improve the health, safety, and well-being of Texans.

List of Acronyms

Acronym	Full Name
CDC	United States Centers for Disease Control and Prevention
DSHS	Department of State Health Services
EDRS	Electronic Death Registration System
JP	Justice of the Peace
NCHS	National Center for Health Statistics
S.B.	Senate Bill
TER	Texas Electronic Registrar
TMA	Texas Medical Association
TxEVER	Texas Electronic Vital Events Registrar

Appendix A. Death Certificate Cause of Death Section

Figure 1. A Texas Death Certificate Form Showing Parts 1 and 2 for Cause of Death



CAUSE OF DEATH

33. PART 1. ENTER THE CHAIN OF EVENTS – DISEASES, INJURIES, OR COMPLICATIONS – THAT DIRECTLY CAUSED THE DEATH. DO NOT ENTER TERMINAL EVENTS SUCH AS CARDIAC ARREST, RESPIRATORY ARREST, OR VENTRICULAR FIBRILLATION WITHOUT SHOWING THE ETIOLOGY. DO NOT ABBREVIATE. ENTER ONLY ONE CAUSE ON EACH LINE.

Approximate interval: Onset to death

IMMEDIATE CAUSE (Final disease or condition ------→ resulting in death)
a. _____
Due to (or as a consequence of):

Sequentially list conditions, if any, leading to the cause listed on line a. Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**.
b. _____
Due to (or as a consequence of):
c. _____
Due to (or as a consequence of):
d.

PART 2. ENTER OTHER SIGNIFICANT CONDITIONS CONTRIBUTING TO DEATH BUT NOT RESULTING IN THE UNDERLYING CAUSE GIVEN IN PART I.

34. WAS AN AUTOPSY PERFORMED? ☐ Yes ☐ No

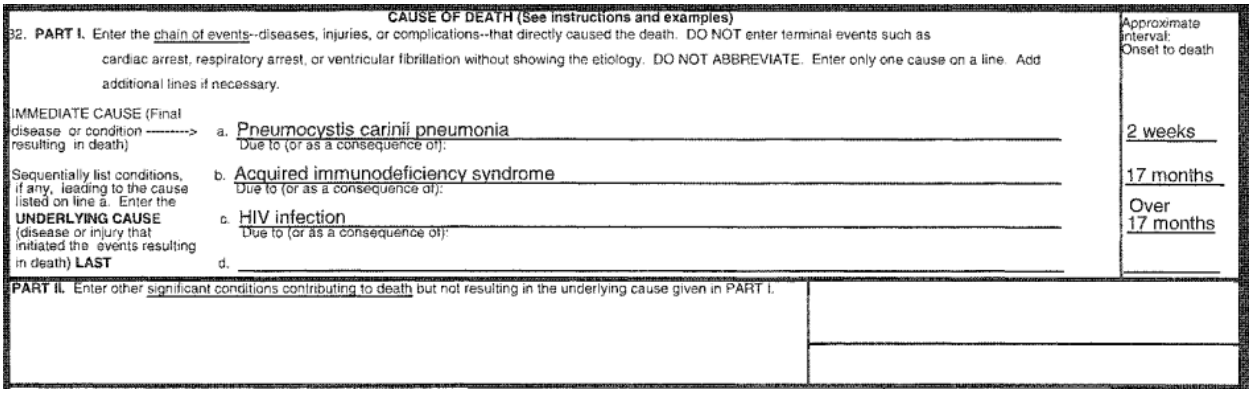
35. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? ☐ Yes ☐ No

Appendix B. CDC Excerpt on Death Certificate Completion

An excerpt from the CDC's *Physicians' Handbook on Medical Certification of Death* is reproduced below to show the accurate completion of Part I and Part II of the cause of death section of the United States standard death certificate.[9]

> *Case History no. 6*
> *A 34-year-old male was admitted to the hospital with severe shortness of breath. He had a 9-month history of unintentional weight loss, night sweats, and diarrhea. The patient had no history of any medical condition that would cause immunodeficiency. An Elisa test and confirmatory Western Blot test for human immunodeficiency virus (HIV) were positive. T-lymphocyte tests indicated a low T helper-suppressor ratio. A lung biopsy was positive for pneumocystis carinii pneumonia (PCP), indicating a diagnosis of acquired immunodeficiency syndrome (AIDS).*
>
> *The patient's pneumonia responded to pentamidine therapy, and the patient was discharged. The patient had two additional admissions for PCP. Seventeen months after the patient was first discovered to be HIV positive, he again developed PCP but did not respond to therapy. He died 2 weeks later.*

Figure 2: Cause of Death Section of Death Certificate for Case History no. 6



32. PART I. Enter the chain of events--diseases, injuries, or complications--that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.		Approximate interval: Onset to death
IMMEDIATE CAUSE (Final disease or condition ---------> resulting in death)	a. Pneumocystis carinii pneumonia Due to (or as a consequence of):	2 weeks
Sequentially list conditions, if any, leading to the cause listed on line a. Enter the UNDERLYING CAUSE (disease or injury that initiated the events resulting in death) LAST	b. Acquired immunodeficiency syndrome Due to (or as a consequence of):	17 months
	c. HIV infection Due to (or as a consequence of):	Over 17 months
	d.	
PART II. Enter other significant conditions contributing to death but not resulting in the underlying cause given in PART I.		

Source: DHHS Publication No. (PHS) 2003-1108 03-0002 (4/2003)[4]

[9] https://www.cdc.gov/nchs/data/misc/hb_cod.pdf

Figure 2 shows an accurate completion of the decedent's death certificate.[10] The immediate cause of death was pneumocystis carinii pneumonia (PCP) and is correctly named on Part I(a). The individual's HIV infection is the last item listed in Part I and is therefore correctly identified as the underlying cause of death. Because this death certificate accurately captures the individual's underlying cause of death as the HIV infection, public health programs and policies will have accurate information to guide their actions.

When the cause of death section on the death certificate is not completed accurately, inaccurate information is introduced into the public health statistics analysis and vital information is lost, as would be the case if only "cardiac arrest" was listed as the cause of death.

Part 2 of this death certificate is left blank because there were no other known contributing factors that may have contributed to the death, but did not directly cause the death to occur.

[10] The CDC uses the US standard death certificate in this example.

Appendix C. Environmental Scan Questions

1. Is the purpose and use of the death certificate clear? Why is it important to provide more information on the death certificate than simply something like “quit breathing?”
2. Who drives the process of completing a death certificate from the point a patient passes away until it is registered with the State? How is the process of completing the death certificate handled from start to finish?
3. Are medical records considered when determining a cause of death, and if so, how? How far back do you look? Do you look up to a year back or beyond?
4. How do you know if the decedent was pregnant for completing the pregnancy checkbox? If you knew she was pregnant, how do you know the time period (e.g. pregnant at time of death, within 42 days of death, within 43 days to 1 year).
5. What structural, procedural, and technological barriers does the medical certifier perceive in determining if a death was pregnancy-related, both in terms of knowledge about the cause of death and the mechanics of completing the certificate? Does your medical facility provide administrative support for reporting deaths in TER (e.g. helping with data entry, keeping track of user accounts and passwords)?
6. Is there any pregnancy-related information that, if provided, could help formulate cause of death statements? How/what factors does a physician use to determine if a death is related to a pregnancy? If a mother passes away and her OB-GYN was the last physician she whose care she was under, is it often assumed the pregnancy influenced her death? Are prenatal records considered when determining a death was related to pregnancy?
7. What other challenges are involved in completing accurate cause of death statements on death certificates?
8. What training(s) were you provided with to determine cause of death? How widely is training available? Did you receive specialized training on pregnancy-related deaths?
9. What do you see the best way to receive training to determine if a death is pregnancy-related? Would tools, such as a mobile app or a pocket card for easy reference (or possibly both) be beneficial?
10. What would you see as the types of questions that could be included as prompts in an electronic system to get the real cause of death?

11. How do different entities (FH, JP, hospital, attending physician, etc.) work together (or do they?) to determine if a death was pregnancy-related? What could improve that part of the process?

12. How do you see your role in regard to the previous question, and how do you see the role of others?

13. How do facilities communicate with funeral homes, and what role does the funeral home play in influencing the cause of death statement?

Appendix D. Focus Group Questions

1. What training(s) were you provided with to determine cause of death? How widely is training available?

2. Are medical records considered when determining a cause of death, and if so, how?

3. Is the purpose and use of the death certificate clear? Why is it important to provide more information on a death certificate than simply something like quit breathing?

4. Who drives the process of completing a death certificate from the point a patient passes away until it is registered with the State? How is the process of completing the death certificate handled from start to finish? Do you have any administrative support at your facility to complete death certificate reporting? If so, does that administrative support also assist with reporting the cause of death data?

5. What challenges are involved in completing accurate cause of death statements on death certificates?

6. What structural, procedural, and technological barriers does the medical certifier perceive in filling out the death certificate, both in terms of knowledge about the cause of death and the mechanics of completing the certificate?

7. What do you see as the best way to receive training for completion of death certificates? Would tools such as a mobile app or a pocket card for easy reference (or possibly both) be beneficial?

8. What would you see as the types of questions that could be included as prompts in an electronic system to get to the real cause of death?

9. How do different entities (funeral home, JP, hospital, attending physician, etc.) work together (or do they) to complete death certificates? What could improve that part of the process?

10. How do you see your role in regard to the previous question, and how do you see the role of others?

11. What has traditionally been the rule for completing the death certificate in terms of collaboration, and does your facility have a standardized process in terms of collaborating with others?

12. How do facilities communicate with funeral homes, and what role does the funeral home play in influencing the cause of death statement?

13. How does a medical facility inform physicians of the manners of death in which they would certify a death versus a Medical Examiner or Justice of the Peace?

14. What is the medical facility's procedure for referring a death to a Medical Examiner or Justice of the Peace?

Appendix E. Panelist List

Participant Name	Participant Affiliation
Dr. Robert N. Anderson	National Center for Health Statistics
Dr. Tara Das	Texas DSHS Vital Statistics Section
Chris Guerrero	Texas DSHS Vital Statistics Section
Dr. Matthew Harbison	Memorial Hermann Hospital
Judge Judy Hobbs	Williamson County Justice of the Peace
Dr. John Holcomb	Texas Medical Association
Dr. Robert E. Jackson	Texas Medical Association
Carrie Kroll	Texas Hospital Association
Dr. Kimberly Molina	Bexar County Medical Examiner's Office
Dr. Karen Ruggiero	Texas DSHS Office of Child and Maternal Health
Gary Sammet	Florida Bureau of Vital Statistics
Jessica Schmidt	Williamson County Office of Judge Hobbs
Dr. Gary Sheppard	Texas Medical Association
Warren Stewart	Texas DSHS Vital Statistics Section
Shae Sutton	National Association for Public Health Statistics and Information Systems