



**Diabetes Vital Statistics Reporting on Death Certificates  
Literature Review Summary Report**

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## **I. Introduction**

### ***A. Diabetes Vital Statistics Reporting on Death Certificates Project***

The Diabetes Vital Statistics Reporting on Death Certificates Project is an initiative of the National Association of Chronic Disease Directors (NACDD), which works to improve the health of people affected by chronic diseases such as diabetes. The goal of the project is to increase the appropriateness and accuracy of diabetes reporting on death certificates by providing a continuing education opportunity for medical and hospital administrative staff on the accurate reporting of diabetes as an underlying or contributing cause of death.

### ***B. Literature Review - Purpose***

As part of the project, a literature review was conducted in order to assess current and past knowledge and evidence around issues related to the completion of death certificates in general, and the under-reporting of diabetes as a cause of death on death certificates in particular. The review further served to identify barriers that medical and hospital administrative staff experience (or might experience) with regards to reporting diabetes on death certificates as well as identify gaps in the current knowledge pertaining to death certification, specifically with regards to diabetes.

Specific issues explored through the literature review included:

- 1) Death certification protocol and procedures (e.g., process involved in completing, coding and submitting death certificates; practitioners/staff involved; standards in the completion and reporting process; oversight, quality assurance, and enforcement of policies).
- 2) Issues with death certificate reporting (e.g., common errors and inaccuracies, factors influencing these errors, additional barriers to accurate reporting, recommendations and strategies to improve reporting).
- 3) Issues with death certificate reporting of diabetes (e.g., diabetes reporting trends, possible reasons for under-reporting, recommendations and strategies to improve diabetes reporting).

## **II. Methods**

The literature review included relevant peer-reviewed journal articles, government reports and grey literature published within the last fourteen years (2000 to 2014). Older articles and publications were included only if they provided background information that elucidated the

findings of the current literature or offered a unique contribution to the scientific knowledge. Both domestic and international articles were accessed, but foreign documents were only included if they were published in English, contributed to the knowledge base, were deemed applicable and/or generalizable to the United States (U.S.), or encompassed U.S. data (e.g., cross-country comparison studies).

Internet searches, using a variety of search terms, were conducted among Medline/PubMed, American Diabetes Association (ADA) Scientific Sessions/Abstracts database, and Cochrane Reviews (The Cochrane Library). Search terms were generated for each of the three topic areas of the literature review. A list of search terms, along with the complete search strategy, is provided in Attachment A.

After an initial scan of titles for relevancy, abstracts and summaries of identified publications were reviewed for their appropriateness. Key articles highlighting findings for each area of the literature review were then selected for further accessing and review. In addition, reference lists of identified articles were scanned for additional publications that could contain relevant information. A complete list of all relevant citations found through the literature review, as well as copies of articles cited in this report, are available through the Diabetes Vital Statistics Reporting on Death Certificates Project.

### **III. Findings**

#### ***A. Death Certification Protocol and Procedures***

##### **Overview of the U.S. Death Certification and Registration System**

Registration of vital events (e.g., births, deaths, fetal deaths) in the U.S. is a state and local function.<sup>1</sup> Each state has its own vital statistics registration system, which depends largely on the efforts of the certified personnel who prepare or certify vital events records. In some states, events are reported to a local or county registrar, who then transmits these records to the state vital statistics office.<sup>1,2</sup> In other states, records may be reported directly from the reporting source (hospital, physician, or funeral director) to the state vital statistics office.<sup>1</sup>

The state office is responsible for checking each file for accuracy, completeness, and a number of other routine duties to ensure the records are properly filed.<sup>1</sup> If information on the death certificate is vague or incomplete, then querying, or contacting the person who provided the information for clarification, may occur.<sup>3</sup> Once filed, a nosologist classifies and codes the cause

of death according to the current International Classification of Diseases (ICD), released by the World Health Organization (WHO) (currently ICD-10).<sup>4-7</sup>

Death certificate data are routinely purchased by the National Center for Health Statistics (NCHS)<sup>2,8</sup> and used to compile national mortality statistics as well as generate reports.<sup>1,2,8</sup> Vital statistics data are further used to monitor morbidity and mortality; inform social service, public health, health care and government programs and policies; identify funding and research priorities; as well as conduct scientific studies.<sup>1,2,5,6,9-22</sup> The NCHS also works in collaboration with states to develop and promote model laws, standard death certificates and reporting forms, handbooks and other instructional materials, and training and quality control programs.<sup>1,23</sup> States typically adapt model legislation and standard forms to meet their own needs and may or may not alter vital statistics laws or certificates when U.S. models or standards are changed.<sup>2</sup>

#### U.S. Standard Death Certificate - What does the death certificate entail?

State death certificates vary, but generally are based on the U.S. Standard Death Certificate form.<sup>2</sup> (A copy of the U.S. Standard Death Certificate form can be found in Attachment B.) Part I of the death certificate is used to record the underlying cause of death (UCOD), defined by the WHO as “(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury.”<sup>24</sup> Part I consists of four lines (a, b, c, and d) on which the certifier lists the causal sequence of events leading to death. For example, the condition leading directly to death is to be listed on line *a*, and the condition leading to/causing that is to be listed on the line below (line *b*); the same applies to the subsequent lines.<sup>8,20,25-27</sup> The medical certifier is instructed to complete this sequence based on their best medical judgment.<sup>8</sup> The lowest line completed should list the single disease process that initiated the sequence of events culminating in death, and thus identify the UCOD.<sup>5,8,18,28</sup> Space is also provided in Part I for the certifier to provide a time frame or estimate in which each event listed occurred.<sup>8</sup>

Part II of the death certificate has space to list any other significant conditions contributing to death, but that were not part of the major train of morbid events reported in Part I.<sup>5,8,26,28</sup> This allows the certifier to list other medical conditions present that cannot be directly attributed to the UCOD.<sup>8</sup> (Key terms and definition in death certification are provided in Attachment C.)

#### Completion of the Death Certificate - Who is involved?

Completion of the death certificate may involve physicians, hospital staff, funeral directors, and the medical examiner's office.<sup>22</sup> A physician, medical examiner, or coroner typically completes the cause and circumstances of death section of the certificate and serves as the "certifier" of death.<sup>2,3,12,22</sup> Hospital staff assists with preparing the certificate and ensures it is completed in a timely manner.<sup>22</sup> The funeral director completes the sections containing demographic and burial/disposition information.<sup>2,3,12</sup> The death certificate must be completed by all parties before burial or final disposition of the deceased can take place.<sup>2,6,8,12</sup> The order of completion and transmission from one party to another depends on local needs, laws, and regulations.<sup>2</sup>

### Classification and Coding

As noted previously, the cause of death reported on the death certificate is assigned an ICD-10 code after it is filed. When more than one UCOD is listed in Part I, or errors in the cause of death sequence are detected, a set of rules developed by the WHO are applied to select an UCOD code. This may lead to identifying an UCOD different than that listed on the lowest line used in Part I of the death certificate.<sup>2,25,29-31</sup> Reselection of the UCOD occurs nationally 30% to 40% of the time.<sup>30</sup>

Given the process by which ICD codes are assigned and mortality statistics are determined, it is vitally important for certifiers to be meticulous and accurate in completing the cause of death section of the death certificate.<sup>2,8,11,14,15,26,28,32,33</sup> However, no federal statutes directly regulate the medical accuracy of death certificates in the U.S.<sup>8</sup>

### ***B. Issues with Death Certificate Completion and Reporting***

There is wide-spread agreement in the literature that death certificates are often completed inaccurately, particularly with regards to the cause of death section.<sup>2,4-6,8-11,14,15,17,19,25, 26,29,30,33-43</sup> International reports of inaccuracies range from 20% to 65%.<sup>\*13</sup> Domestically, one study found that 41% of the death certificates analyzed by the researchers contained improperly completed cause of death statements.<sup>11</sup> Another U.S. study found that 96% of death certificates reviewed had some degree of error, with 34% containing severe errors to the cause of death statement (e.g., listed the wrong cause or manner of death).<sup>14</sup> Given the relatively high rate of errors in the completion of death certificates, death certificate data must be interpreted with awareness and caution of potential problems with validity.<sup>2</sup>

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\* The literature varies somewhat in estimating the range of error rates. Lakkireddy et al. (2004) cite the range as 16% to 40%. Lu et al. (2001 March) cite a range of 25% to 78% in hospital-based studies and 16% to 56% in population-based studies.

## Death Certificate Errors and Contributing Factors

In order to address issues with death certification and reporting, it is important to understand the types of errors and inaccuracies that occur, particularly those that may be avoidable and/or amenable to intervention, along with their contributing factors. These are highlighted below.

### Common Errors

Inaccuracies in death certification can result from improper completion of the death certificate by the attending physician, coroner or medical examiner, or from the subsequent coding process.<sup>13</sup> Many of the errors cited in the literature pertain to the improper completion of parts I and II of the death certificate.<sup>2,4,5,10,11,14,15,17,18,20,21,25,27,32,33,35,37,39,42-48</sup> These errors are often categorized as being either major or minor.<sup>4,5,14,18,37</sup>

Specific errors categorized under each group vary somewhat in the literature, but generally, minor errors are considered to be those that are less likely to lead to a misclassification of the UCOD<sup>5</sup>, although they may make the coding process more difficult for the nosologist.<sup>21</sup>

Common types of minor errors include:

- Illegible writing.<sup>5,14,18,21</sup>
- Use of abbreviations.<sup>4,5,10,11,14,17,21,43,45,48</sup>
- Missing information (e.g., boxes not checked, contact information not provided, time interval between onset of condition and death not completed).<sup>5,10,14,18,21,43,45,47,48</sup>
- Inclusion of conditions unrelated to the death and/or incidental findings in Part II.<sup>5,11,42</sup>
- Listing a mechanism of death (e.g., cardiac arrest, pulmonary arrest, or other events that can be applied to every death regardless of the cause), but with a legitimate underlying cause of death.<sup>18,43</sup>

Major errors are typically those that could affect the ultimate determination and coding of the UCOD,<sup>5</sup> and consequently, impact mortality data. Common major errors documented in the literature include:

- Listing more than one disease condition per line or recording two competing causes of death (e.g., multiple causal sequences) in Part I.<sup>5,11,17,18,21,25,27,35,37,43,48</sup>

- Reporting an incorrect causal sequence.<sup>5,10,11,14,17,18,20,21,25,27,32,33,35,37,42-44,46-48</sup>
- Reporting cause of death in a nonspecific or incomplete way.<sup>2,11,14,21,27,37,39,45,47</sup>
- Listing the mode or mechanism of death *without* an explanation or sequence leading to the true underlying cause.<sup>5,10,11,15,17,21,27,32,37,39,42-44,47</sup>
- Placing immediate or underlying causes of death in Part II versus in Part I of the certificate, and/or listing other factors contributing to death in Part I rather than Part II.<sup>4,11,17,21,42</sup>
- Not listing an acceptable UCOD in Part I.<sup>5,14,18,43,48</sup>
- Listing an inaccurate cause and/or manner of death.<sup>14,18,33,45</sup>

### Contributing Factors

The literature also cites a plethora of factors that contribute to frequent errors and inaccuracies in the completion of death certificates. These factors can be considered in terms of the physician, system, and other influences.

### Physician Factors

In terms of physician factors, the most commonly mentioned issue in the literature is a lack of education, training and experience in the completion of death certificates.<sup>2,4,8,10,13,14,18,22,32,33,35,37-40,44,49-56</sup> Studies note that instruction on death certification is limited in medical school and few resident physicians receive formalized training as part of their residency program.<sup>10,18,22,33,38,57</sup>

Other frequently reported physician factors include:

- Fatigue.<sup>8,14,18</sup>
- Time constraints and competing demands.<sup>2,4,8,14,18,41</sup>
- Lack of physician reimbursement/incentive for completing death certificates.<sup>2</sup>
- Perceived lack of importance of death certificates and/or misperceptions/lack of awareness of how death certificate data are used.<sup>8,9,11,13,14,18,40</sup>

- Lack of confidence in ability to complete the death certificate and a perceived need for supervision.<sup>13,33,53</sup>
- Lack of understanding and/or awareness, or ignoring instructions for completing the cause of death statement, particularly with regards to listing a proper causal sequence.<sup>8,9,20,25,32,33</sup>
- Confusion over or misinterpretation of the various terms used on death certificates such as manner of death, UCOD, immediate cause of death, and mechanisms of death.<sup>8-10,37,43</sup>
- Difficulty in determining whether a condition caused or contributed to death and consequently, identifying a single major train of morbid events, especially when multiple diseases and complication coexist.<sup>14,16,20,25,32,42</sup>
- Unfamiliarity with the deceased patient and/or limited access to medical records.<sup>8,9,14,18,22,50</sup>
- Differences in interpretation of the decedent's medical history and in selecting the UCOD.<sup>32,52</sup>
- Concern for the family of the deceased (e.g., do not want to list a cause of death that might create embarrassment, stigma or distress for the family, or that might present legal issues such as processing insurance claims, validity of wills [as in the case of dementia], etc.).<sup>8,10,13,29,53,55,58</sup>
- Sensitivity to cultural norms, needs and/or practices surrounding death (e.g., providers may avoid an autopsy, even in light of uncertainty, if an autopsy goes against certain customs of the decedent's family).<sup>13</sup>
- Uncertainty in identifying a specific cause of death and perceived pressure from the bereaved family members to identify a definitive cause.<sup>13,53</sup>

### System Factors

The literature reviewed also notes several system factors that contribute to inaccurate death reporting. Among these is a lack of uniform guidelines and clear, specific instructions for completing death certificates.<sup>2,8,11</sup> It is also noted that there is variation in nosologic coding practices.<sup>49,59</sup> Coding a cause of death may be especially problematic when the decedent has multiple comorbidities, given that a single disease may not adequately describe the cause of

death.<sup>49</sup> There may also be limitations in state-specific certification systems. For example, Wexelman et al. (2013) found that medical certifiers in New York City encountered barriers when completing cause of death statements because certain diagnoses were not recognized by New York's death certification system.<sup>22</sup>

A couple of articles further point out that there are few incentives for the accurate completion and coding of death certificates,<sup>58</sup> no legal mechanisms for detecting or correcting mistakes, and no legal penalties for listing an invalid cause of death.<sup>8</sup>

### Other Factors

Other observations noted by the literature are that death reporting errors tend to increase with the age of the deceased. This may be due to the increased incidence of comorbid conditions among older patients, making it more difficult to establish a single cause of death.<sup>5,37</sup> It has also been found that major errors tend to increase as the number of lines used to document the cause of death sequence increases.<sup>4,5</sup> Finally, one state-based study noted that frequent errors may be due to the failure of a hospital's leadership to emphasize the importance of correct death certificate completion.<sup>55</sup>

### Physician Practices and Perspectives

In further understanding errors in the completion of death certificates and contributing factors, it is important to consider physician practices and perspectives regarding death certification. Several researchers have found that errors in death reporting may vary by the type of physician.<sup>20,27,35</sup> Physicians of different specialties manage different types of diseases and conditions with contrasting complexities in terms of the determination of the UCOD.<sup>27</sup> They may also have differing opinions in determining the causal sequence of events leading to death.<sup>20</sup>

One U.S. study found that pathologists are more likely to properly complete cause of death statements than other clinicians.<sup>11</sup> Another international study found that general practitioners may perform better in death certification than specialists, perhaps because of their greater familiarity with their patients.<sup>37</sup> Resident physicians are responsible for death certificate completion in the majority of teaching hospitals, yet studies suggest medical students, house staff, and junior physicians frequently make mistakes in the completion of death certificates.<sup>38</sup> Some studies hold that younger, more inexperienced physicians commit more errors than senior physicians,<sup>37,60</sup> though this is not always the case.<sup>10,34,40</sup>

Physician perceptions further elucidate findings with regards to death certification. A survey of resident physicians in New York City (reported by Wexelman et al., 2013) revealed that only

one-third of respondents believed the current death certification system accurately documents the correct cause of death.<sup>22</sup> Nearly half reported that they had knowingly listed an inaccurate cause of death, often at the request or advisement of a medical examiner or hospital admitting staff, or because the system would not accept what they believed to be the correct cause of death.<sup>22,61</sup> Less than a quarter were aware that they could include the qualifiers “probable,” “presumed,” or “undetermined” as part of the cause of death statement.<sup>22</sup> Only about three percent indicated that they had ever updated a death certificate when new information became available (e.g., autopsy results). Moreover, less than half reported receiving any training on death certificate completion during their residency program and less than a quarter had been directed to the New York City Board of Health’s mandatory online training module.<sup>22</sup> This study, as well as others, also found that physicians may choose the cause of death that they perceive will be the most accepted and least questioned.<sup>22,41,50,55</sup>

### Efforts to Improve Reporting

In light of the importance of accurate mortality data and numerous issues surrounding death reporting, there have been international, national and state efforts to improve death certification. Previous efforts range from development and dissemination of instructional materials (e.g., written handbooks/articles, abbreviated guidelines, pocket guides, and audio and video instructions)<sup>2,11,32,44</sup> to convening national and global conferences, work groups, and partnerships.<sup>12,58,62,63</sup>

Internationally, the WHO convened a Mortality Reference Group (MRG), with the mandate to issue authoritative instructions on the interpretation of ICD coding rules and guidelines.<sup>63</sup> The Education Committee of the WHO Family of International Classifications (WHO-FIC) Network has also developed a core curriculum for guiding the development of training for death certifiers.<sup>19,21</sup>

Domestically, problems surrounding death certificate reporting have been recognized for quite some time. Efforts to improve reporting have included:

- Convening national conferences to explore issues with death reporting and make recommendations for improvement;<sup>58,62</sup>
- Forming a national partnership among the National Association of Public Health Statistics and Information Systems (NAPHSIS), NCHS, and the Social Security Administration to improve the timeliness, quality, and sustainability of vital registration and statistics systems through the adoption of national, consensus-based standards and guidelines, and the reengineering of vital registration systems in the U.S.;<sup>12</sup> and

- Development of web-based tutorials on death certificate completion through the National Association of Medical Examiners,<sup>40</sup> and a partnership among New York City's Bureau of Vital Statistics, NAPHSIS and NCHS.<sup>55</sup>

At the local level, New York City implemented a multifaceted intervention among New York City hospitals, which addressed hospital-specific policies, practices, and education. The intervention consisted of: 1) a conference call with senior hospital staff (e.g., medical directors and medical, quality assurance, admitting, and regulatory affairs staff); 2) on-site, in-service training of medical and clerical staff involved with death certification; 3) process mapping of death certification and registration workflow; 4) medical records audit; and 5) promotion of an online learning module. Evaluation of the effort showed significant and sustained improvements in accuracy of death certification, specifically related to accurate reporting of heart disease deaths.<sup>55</sup>

Other improvement efforts implemented in New York City include issuance of cause of death quality data reports, dissemination of educational materials (e.g., pocket cards and cause of death posters), telephone assistance, and monitoring death registration rejections.<sup>55,61</sup> A 2013 article further notes that New York City plans to automate enforcement of its mandatory online death certificate training module through its Electronic Death Registration System (EDRS), which will require completion of the module before credentialing.<sup>61</sup>

Additional efforts to improve death reporting have included:

- Revisions to the death certificate form; specifically the addition of a fourth line (line d) in part I of the U.S. Standard Death Certificate in 1989. Since inclusion of this fourth line, there have been fewer incidences of certifiers reporting multiple conditions per line;<sup>51</sup> however, it may have contributed to an increase in sequencing errors.<sup>20,51</sup>
- Local or institutional quality assurance review processes to identify and rectify errors, inconsistencies, and/or incomplete information.<sup>2,45</sup>
- Querying vague, unspecific, inconsistent, or incomplete cause of death statements.<sup>3,51,64</sup>
- Implementation of electronic death certificates, which may improve completion by providing online instructions and illustrative examples of how to correctly complete a death certificate; limit errors through automatic checks; allow for quicker transmission of information and data; and strengthen security and confidentiality.<sup>56</sup>

### Training and Continuing Education

Of special note are initiatives to improve the completion of death certificates through education and training programs for practitioners. The literature shows that such efforts are generally successful in improving the knowledge, attitudes and/or skills of clinicians around death certification as well as the accuracy of death certificates.<sup>9,10,17-19,21,38-40,43,48,55,57</sup>

Salient themes and specific considerations noted in the literature regarding educational interventions include the following:

- Design and format -- The impact of training and educational efforts vary by format.
  - Education through printed materials alone slightly improves death certification practices, but is not as effective as other, more interactive methods.<sup>19,38,47</sup>
  - The use of a video as an educational tool also has a slight, but limited impact on the quality of death certification.<sup>9,19</sup>
  - Coupling an educational intervention with an audit and feedback on accuracy and adherence to death certification guidelines has been shown to improve accuracy and legitimacy of death certification.<sup>19,57</sup>
  - Use of a web-based, self-study tutorial has also been shown to improve accuracy of death certificate completion, specifically among medical students.<sup>21,40</sup>
  - Interactive workshops appear to be the most effective form of educational efforts to improve death certification.<sup>10,17-19,38,39,43,47</sup>
  
- Timing – The literature suggests that undergraduate training alone on death certification may be insufficient and should be reinforced with training during residency, given the increased relevance, greater understanding of clinical cases, and opportunities for application during the residency years.<sup>17,19</sup>
  
- Content and curriculum –As noted above, and described by Aung et al. (2010), the WHO-FIC Network has established minimum requirements for the content of death certification training. These requirements specify that training should address:
  - Medical science related to ascertaining cause(s) of death (e.g., concept of etiology and risk factors, pathophysiology, forensic medicine, autopsy);
  - Principles for certifying causes of death (e.g., format of the death certificate, concept of UCOD, importance of best medical opinion);
  - Certification rules for specific causes of death (e.g., natural vs. external causes; perinatal deaths; chronic diseases such as diabetes, cancer, asthma);
  - Legal/ethical issues (e.g., legal requirements, privacy and confidentiality, professional ethics); and
  - Uses of data on causes of death (e.g., vital statistics, medical and epidemiological research, health planning and evaluation).<sup>19</sup>

The literature also suggests that training should address practitioners' perspectives about the role of uncertainty, family interests, and cultural practices in completing death certificates;<sup>13,21</sup> provide an opportunity to practice completion of death certificates based on case studies or scenarios,<sup>10,39,48,53</sup> and provide review and feedback after completion of practice exercises.<sup>39,53</sup> Additional training topics cited by the literature are outlined in Attachment D.

### Additional Recommendations and Potential Solutions

Given the plethora of errors and contributing factors surrounding death certification, a multifaceted approach to improving cause of death reporting is recommended.<sup>14</sup>

First and foremost, there is overwhelming consensus in the literature that there is a need for increased training and continuing education for clinicians around death certification.<sup>2,4,5,6,8,10,11,14,17-20,22,26,27,29,33,35,37,40,42,43,44,47,50,53</sup> In accordance with research on past training efforts, interactive workshops are recommended as the most effective method of providing education on the completion of death certificates.<sup>17-19,43,47</sup> Additionally, appropriate use of electronic media and self-study materials coupled with interactive education and audit/feedback is recommended to achieve the wide range of coverage necessary to improve the accuracy and reliability of mortality data.<sup>19</sup> Education and training on death certification needs to be initiated in medical school and further provided to new medical graduates as well as periodically given to practicing physicians in order to reinforce knowledge.<sup>2,4-6,8,11,14,17-20,22,26,27,29,33,35,37,40,42-44,50,53,55</sup> Finally, trainings should address a variety of topics to enable medical professionals to develop the knowledge and skills needed to adequately and accurately record causes of death.<sup>19</sup>

Some researchers recommend establishing a mandatory training course for medical students and/or residents, developing minimum competencies in death certification, and including questions about death certification on specialty exams.<sup>8,10,33,58</sup>

Further, educational efforts should be aimed at physicians and institutions that are most likely to be pronouncing and certifying deaths.<sup>62</sup> Based on a study of characteristics of death certifiers and institutions in Fulton County, Ga, it is suggested that death certification education efforts may be most effective if they are hospital-based, target appropriate personal physician certifiers, and focus on certification of inpatient deaths from natural causes.<sup>62</sup> Other recommendations and potential solutions cited by the literature include:

- Provide readily available instructional resources detailing the standards of death certificate completion (e.g., instruction sheets, pocket cards, toll-free telephone helpline) at health care institutions.<sup>17,33</sup>

- Develop and implement uniform standards on death certificate completion on a national basis; require health care facilities to demonstrate compliance and adherence to policies regarding training in death certificate completion,<sup>33,46</sup> and establish expert consensus and more rigid guidelines to resolve complex causal sequence determinations, such as selection between severe complications and chronic diseases as well as among prominent comorbidities.<sup>32</sup>
- Utilize a team approach involving certifying physicians and pathologists or physicians with more training and experience in death certification, or institute a system of senior medical consultation and/or peer review.<sup>4,5,11,13,14,17,33,40,42</sup>
- Require physicians who are familiar with the deceased to participate in completion of the death certificate.<sup>6,14,32,43</sup>
- Integrate review and discussion of death certificates into daily rounds or mortality meetings with the entire physician team.<sup>4,5,14,18,19,40</sup>
- Institute quality improvement and control systems (e.g., audits, expert panel reviews) and feedback mechanisms that assess completeness and accuracy of death certificate information and ideally provide feedback to those that complete and code death certificates.<sup>10,14,17,26,29,35,58</sup>
- Implement incentives for institutions and certifiers.<sup>2,5,58</sup>
- Ensure access to information on the medical history of the decedent through linked records.<sup>65</sup>
- Continue to query inconsistent information based on NCHS procedures.<sup>3,5,19,20,27,44,51,66</sup>
- Increase the use of autopsy results to amend death certificates, when available and necessary.<sup>4,11,33,44</sup>
- Allow a category for death from natural but unspecified causes on death certificates and in coding systems.<sup>13</sup>
- Increase development and use of software programs and/or electronic death certificates with built in quality assurance mechanisms (e.g., will not accept

inappropriate causes of death and/or improper sequencing), and that have the capacity to attach additional information.<sup>2,44,56</sup>

- Explore new methods for analysis and criteria for classifying death due to multiple causes (i.e., greater use of multiple-cause-of-death data).<sup>32,35,46,52</sup>
- Convene a federal task force to re-examine national morbidity and mortality statistics, with a focus on quality assurance and control of the death certification process.<sup>33</sup>

### ***C. Issues with Death Certificate Reporting of Diabetes***

There is substantial evidence in the literature that diabetes is under-reported both domestically<sup>49,54,59,67-72</sup> and internationally.<sup>73-76</sup> Domestic studies of decedents with known diabetes have shown that diabetes is reported anywhere on the death certificate (either in Part I or II) between 34.7% and 43% of the time,<sup>49,54,59,67,70-72</sup> and as the UCOD (Part I) between 6.2% and 15% of the time.<sup>49,54,59,67,70,71</sup> Needless to say, persistent under-reporting of diabetes on death certificates underestimates the burden of the disease and the impact of diabetes on death rates.<sup>67,71</sup>

#### Trends in Diabetes Reporting

Diabetes reporting on death certificates has remained relatively stable over time,<sup>49,51,70,71</sup> despite increasing prevalence.<sup>49</sup> According to an analysis of data from the National Mortality Followback Survey, the rate of diabetes being reported anywhere on the death certificate among those with a history of diabetes was 38.2% in 1986 and 35.5% in 1993.<sup>70</sup> A more recent study of diabetes reporting among decedents that were part of the Translating Research Into Action for Diabetes (TRIAD) study found an increasing trend of recording diabetes as an UCOD over an eight year period (2000-2007), but not for the recording of diabetes anywhere on the death certificate.<sup>54</sup>

Cheng et al. (2008) in their analysis of diabetes reporting on death certificates for decedents who were enrolled in the Rancho Bernardo cohort study also found no improvement in diabetes reporting over time, but did find an improvement from 1992 to 2003 in diabetes reporting on death certificates for those who died of cardiovascular disease (CVD).<sup>71</sup> Other studies have also found that diabetes is significantly more likely to be reported on the death certificates of decedents dying of CVD than all other causes,<sup>49,54,67,75,76</sup> which could reflect increased awareness of the association between diabetes and CVD.<sup>49,54,71</sup>

#### Factors Associated with Diabetes Reporting

In general, it has been found that increased reporting of diabetes on death certificates is associated with:

- Younger age at death.<sup>30,67,68,72</sup>
- Diagnosis of diabetes under the age of 30.<sup>67,70</sup>
- Treatment with diabetes-related medications (e.g., insulin and oral agents).<sup>49,68,71,73</sup>
- Longer duration of diabetes.<sup>49,67,72,76</sup>

Of importance, Bild and Stevenson (1992) found an interaction between age and duration of disease in the frequency of reporting diabetes on death certificates. Specifically, after stratifying by duration of diabetes, they found that diabetes was more likely to be reported for younger decedents only if they had diabetes for 15 years or more; among those with diabetes for 5 years or less, diabetes was more likely to be reported for older decedents.<sup>67</sup> Andresen et al. (1993) found more frequent reporting of diabetes on death certificates among younger age groups and those who had insulin-dependent diabetes or were insulin treated.<sup>68</sup> Evans et al. (2007) who examined death certificates only among decedents with Type 2 diabetes in Scotland found that diabetes was *less* likely to be reported among younger age groups (less than age 45).<sup>76</sup> These findings may suggest that the increase in reporting of diabetes among younger age groups could reflect the presence of Type I diabetes. Therefore, people with Type I diabetes may be disproportionately represented in death certificate data.<sup>67</sup>

Regarding the association of diabetes reporting with taking diabetes-related medications, several researchers suggest that treatment with medications may raise the visibility of diabetes<sup>73</sup> or indicate a greater severity of disease.<sup>71</sup> This, in turn, could signal physicians to list diabetes as a cause or contributor of death.<sup>71,73</sup>

Some factors associated with increased reporting of diabetes are unclear. For example, several studies have found that diabetes is more likely to be reported on a death certificate if the decedent died in an outpatient versus in an inpatient setting.<sup>30,68,70,72</sup> While another study found that diabetes reporting was better among hospital deaths.<sup>71</sup>

It has also been found that decedents who had an autopsy performed were less likely to have diabetes recorded anywhere on their death certificate<sup>68,72</sup> or as an UCOD.<sup>30</sup> One study found that recording of diabetes as an UCOD was associated with having fewer comorbidities.<sup>49</sup>

The literature also notes an association between diabetes reporting and the type of medical certifier. Generally, certifying physicians who served as the decedent's primary care physician (PCP) are more likely to record diabetes on the death certificate than a clinician less familiar with the patient.<sup>68,72</sup> Studies have also found that diabetes was less likely to be mentioned on the death certificate<sup>68</sup> or recorded as an UCOD if the certifying was a coroner<sup>30</sup> or medical

examiner.<sup>68</sup> Another study found that diabetes reporting differed by physician sub-specialty, with endocrinologists more likely to report diabetes as an UCOD (especially when CVD was present) than cardiologists and nephrologists; though this study was based in Taiwan, and thus it is not known if similar patterns occur in the U.S.<sup>52</sup>

### Problems with Diabetes Death Reporting

The literature cites several issues and potential problems with regards to the reliability and validity of diabetes death reporting.<sup>54</sup> Of significance is the fact that only a fraction of decedents with known diabetes have it reported on their death certificate.<sup>65,67,69,71</sup> Even when diabetes does appear on the death certificate, its placement on the certificate (either in Part I or Part II) and appearance in the causal sequence of morbid events (if reported in Part I) can affect whether or not it is coded as the UCOD.<sup>25,65</sup>

Diabetes is considered to be particularly problematic with regards to the accurate completion of cause of death statements for several reasons. These include the following:

- Diabetes is open to a high degree of medical subjectivity and interpretation in determining its contribution to death.<sup>46,49,70,71,77,78</sup>
  - In particular, the time duration between the onset of diabetes, development of complications and death, coupled with the presence of comorbidities (for which people with diabetes have an increased risk), often makes it difficult to determine if diabetes was an UCOD or a contributing cause.<sup>7,25,51,59,65,68,79</sup>
- Diabetes may not be mentioned on the death certificate due to incomplete clinical knowledge about the decedent and/or lack of accurate medical history information.<sup>49,67,72</sup>
- Physicians also may not list diabetes due to space constraints on the death certificate, particularly if there are multiple chronic conditions to consider, which may compete for space.<sup>49,67</sup>

The literature also notes that differences in diagnostic criteria or inaccuracy of diagnosis may affect diabetes reporting on death certificates,<sup>54,71</sup> as does a lack of physician training in death certificate completion.<sup>72</sup>

### Diabetes-Specific Errors in the Cause of Death Statement

In terms of errors in cause of death statements, listing an inaccurate causal sequence of morbid events in Part I of the certificate is of particular concern in the case of diabetes.<sup>20,25</sup>

Lu et al. (2006) conducted an international comparison of errors in diabetes-related cause of death reporting among Sweden, Taiwan, and the U.S. and found that American physicians were more likely to report an incorrect causal sequence (28%) than their counterparts in Taiwan (21%) and Sweden (5%).<sup>25</sup> A later study by Lu et al. (2010 April) found that the prevalence of sequencing errors on U.S. death certificates in which diabetes was listed in Part I increased from 22% in 1985 to 33% in 2005.<sup>51,p.1074</sup> The authors' postulate that the rise in the error rate could be due to the increased reporting of multiple conditions for deaths with mention of diabetes, making it more difficult to discern a clear UCOD.<sup>51</sup>

Cheng et al. (2012 July) looked at state differences in errors involved in diabetes reporting and found that among deaths in which diabetes was reported in Part I of the death certificate, an average of 32% had an incorrect causal sequence reported. Specific error rates varied, by state with a low of 13% in Hawaii and a high of 45% in Delaware.<sup>66</sup>

Another study by Cheng et al. (2012 September) found that among U.S. death certificates in which both diabetes and hypertension were reported in Part I, 38.2% included an incorrect causal sequence; specifically, they listed hypertension on a line below diabetes, erroneously indicating that hypertension is a cause of diabetes.<sup>20</sup> It has been suggested that this is likely due to the certifying physician not being aware that diseases listed in Part I should be presented in an appropriate causal sequence versus a lack of understanding of pathophysiology.<sup>20,25</sup>

Such errors in the causal sequence of morbid events could lead to diabetes not being identified and coded as the UCOD, even if the certifying physician intended it to be.<sup>2,25,29-31</sup>

### Coding Factors

Some researchers point out that the complexity in coding rules leaves assignment of diabetes as the UCOD up to expert judgment,<sup>77</sup> and that there are ambiguities in the ICD coding rules for selecting diabetes as the UCOD, particularly when CVD is mentioned.<sup>79</sup> Indeed, a European study of the certification and coding of causes of death utilizing clinical case histories of people with diabetes found that national coding practices accounted for 35% of the variation in diabetes mortality rates among participating countries.<sup>80</sup>

### Efforts to Improve Diabetes Reporting

The literature review yielded very little in terms of previous efforts to improve diabetes reporting on death certificates. The only studies found pertain to the addition of a checkbox for diabetes on state death certificate forms in North Dakota, Kentucky and New Jersey. Previous research has shown that the inclusion of a tobacco checkbox, asking whether tobacco use contributed to an individual's death, significantly increased reporting of tobacco use as a contributor to death.<sup>81</sup> Likewise, inclusion of a diabetes checkbox may: 1) improve quality of

reporting of diabetes as an underlying or contributing cause of death, 2) provide prevalence data with regards to diabetes among decedents regardless of the cause of death, and 3) increase information on causes of death among decedents with diabetes, thus allowing for the calculation of death rates due to various causes.<sup>82</sup>

The experience of states with regards to the addition of a diabetes checkbox on death certificates has been mixed. North Dakota has found that the checkbox provides useful information on the diabetes status of decedents and has allowed the state to document the effects of diabetes on mortality.<sup>83</sup> Kentucky, which added two checkboxes (one noting if the decedent had diabetes and another asking if diabetes was an immediate, underlying, or contributing cause of death) found that since the addition of the checkboxes, diabetes reporting in Part II of the death certificate has decreased, while diabetes reporting in Part I has increased. This has resulted in a slight increase in reporting diabetes as the UCOD, but a decrease in overall diabetes reporting.<sup>84</sup> New Jersey found that since inclusion of the checkbox, reporting of diabetes as a contributing cause has increased, but it has had little effect on the coding of diabetes as an UCOD. New Jersey further found that the accuracy of the checkbox as a measure of diabetes status among decedents was questionable. Thus using checkboxes as a strategy to improve diabetes cause of death reporting is potentially problematic.<sup>82</sup>

### Recommendations and Suggested Strategies

Despite the lack of published literature on specific efforts to improve diabetes reporting, the literature does contain a number of recommendations and suggested strategies to address this issue. General recommendations include:

- Establish clear and specific guidelines for the certification of deaths in persons with diabetes. These guidelines should cover issues regarding reporting of diabetes as an underlying or associated cause of death when CVD is also reported.<sup>78</sup>
- Improve understanding of the death certificate recording process and specific understanding of the factors associated with recording of diabetes.<sup>67</sup>
- Improve and increase education on the completion of death certificates,<sup>51,71</sup> specifically with regards to determining the UCOD when diabetes and multiple comorbidities exist and the importance of proper causal sequencing.<sup>51,73,80</sup>
- Increase the use of multiple-cause-of-death (MCO) statistics as a complement to UCOD in interpreting and understanding diabetes and other cause-specific mortality trends.<sup>7,16,30,78-80</sup>

Some researchers still recommend adding check boxes on the death certificate for common conditions of interest, which may improve documentation of diabetes as a coexisting condition;<sup>49,59</sup> though, as described above, the benefit of checkboxes is unclear.

In summary, efforts to improve diabetes reporting must address incorrect certification, uncertainty and inaccuracy of causal sequences, and low reporting of diabetes for decedents with known diabetes.<sup>78</sup>

#### **IV. Research Gaps**

Despite the wealth of information in the literature on issues surrounding death certification and diabetes reporting on death certificates, several gaps in the research remain. In terms of death reporting in general, the literature points to a number of areas that need further research. These include the need to:

- Better understand patterns of death certificate completion for in-hospital deaths.<sup>50</sup>
- Conduct further research on educational/training programs that evaluates and compares the effectiveness and sustainability of outcomes of different instructional methods (including web-based tutorials), in various settings, for various types of medical professionals, and offered at various points in a practitioner's career.<sup>19,17,21,38,40</sup>
- Explore further alternative interventions, other than formal education and training, that may be effective in improving the quality of death certification.<sup>19</sup>
- Investigate further the effect of uncertainty, family interests and cultural mores on death certification.<sup>13</sup>

In addition, while the literature provides information on the percent of death certificates that contain errors in Part I (often reported by the specific type of error), there is a lack of clear aggregate data on how often Part I is filled out completely versus incompletely (e.g., percent of death certificates in which lines are skipped or information is omitted in Part I).

There also appears to be relatively few studies comparing the accuracy of electronic death certificates to paper certificates. As more states transition to electronic death registration systems, it will be important to assess whether use of electronic death certificates improves the completeness and accuracy of death reporting.

Finally, it is worth noting that many of the findings regarding general death certification are based on international studies. While U.S.-based studies are also represented, more research is

needed to assess if common reporting errors, influencing factors, and effective interventions described in the international literature also apply to practitioners and others involved in the death certification process in the U.S.

Regarding diabetes reporting on death certificates, areas needing further research, particularly in the U.S., include:

- The characteristics of physicians and health care institutions/hospitals associated with a high frequency of incorrect diabetes reporting.<sup>20</sup>
- Physicians' diabetes-related death certification practices and behaviors<sup>46</sup> (e.g. perspectives, patterns, perceived barriers, etc.).
- Effective strategies to improve diabetes reporting on death certificates (e.g., diabetes-specific education and training; state, local, and institution policies, procedures and quality assurance efforts; and other interventions).

The literature also cites the need for an international review of cause of death certification and coding practices with reference to diabetes. Such a review could lead to consensus-based guidelines for standard cause of death reporting among countries, resulting in more reliable and comparable statistics on diabetes.<sup>79</sup>

## **V. Literature Review Conclusions**

Death certification and reporting are important components of the U.S. Vital Statistics System, which is used to monitor population health, identify research and funding priorities, assess the impact of prevention and care services, conduct studies, and inform policies. However, as documented in the literature, death certificates are frequently completed inaccurately. While issues surrounding death reporting stem from a variety of factors, including coding practices and system influences, a significant number of inaccuracies are due to errors in the completion of death certificates by medical professionals. These errors may result in either over-reporting or under-reporting of specific diseases and may present a skewed picture of the causes of death within the population.

Diabetes, in particular, is under-reported as a cause of death. As the literature demonstrates, diabetes may not be listed on death certificates, even when death could have been reasonably associated with the disease.<sup>70</sup> Moreover, diabetes reporting on death certificates has remained relatively stable over time, even in light of increased prevalence of the disease.<sup>49</sup> This persistent under-reporting of diabetes significantly underestimates the burden of disease.<sup>71</sup> Improved recording of diabetes on death certificates could raise further awareness and foster greater

understanding of diabetes and its complications, possibly resulting in increased allocation of funding for further research or improved prevention and care services.<sup>16,70,78</sup>

The need for accuracy in the recording of causes of death, including diabetes, cannot be stated enough.<sup>19</sup> While there have been a number of efforts to improve death certification at the international, national, state, and local levels, more needs to be done. In particular, there is overwhelming consensus in the literature that more formalized education and training around completion of death certificates is needed for practitioners. Further, given the multitude of factors influencing death certification and diabetes reporting on death certificates, a multi-pronged approach may be needed, which couples educational interventions with other policy, systems, and practice-based efforts as well.

**V. Attachments**

**Attachment A**

Diabetes Vital Statistics Reporting on Death Certificates Project

Literature Review

Search Strategy

**General Search Parameters:**

- English language articles/documents (primarily domestic research but may include international studies if they contribute to the knowledge base, are applicable/generalizable to the U.S. or reflect U.S. data—e.g., cross-country comparison studies).
- Peer-reviewed journals
- Grey literature
- Time-frame: priority given to studies/documents published within the last 14 years (2000-2014), but include older articles/documents if they are relevant and provide a unique contribution to the knowledge-base.
- Articles/documents primarily addressing Type II diabetes

**Key search terms: reporting, underlying cause of death, cause of death, multiple-cause-of-death, death certificate(s), death certification, vital statistics, mortality statistics, procedure, death reporting, accuracy/validation, quality assurance, issues, barriers, problems, ambiguity, difficulty, education/training, clinical competence, best practices, diabetes, policy/policies, protocol(s)**

Review Elements	Suggested Databases/Websites/Search Engines	Search Term Combinations/Phrases
<p>A. Issues with death certificate reporting (e.g., barriers to accurate reporting – including general barriers and disease-specific barriers [examples of diseases other than diabetes], recommendations/strategies to improve reporting).</p>	<p>Medline/PubMed  <a href="http://www.ncbi.nlm.nih.gov/pubmed">http://www.ncbi.nlm.nih.gov/pubmed</a></p>	<ul style="list-style-type: none"> <li>• Reporting AND ("underlying cause of death" OR "cause of death" OR "multiple-cause-of-death") AND ("death certificates" OR "death certificate" OR "death certification")</li> <li>• ("death certificate" OR "death certificates" OR "vital statistics" OR "mortality statistics") AND (reporting OR procedure OR accuracy OR policy) [Note: scanned titles with a focus on those mentioning "death" in the title]</li> <li>• (Accuracy OR validation OR "quality assurance") AND reporting AND ("underlying cause of death" OR "cause of death" OR "multiple-cause-of-death")</li> <li>• (Accuracy OR validation OR "quality assurance") AND reporting AND ("death</li> </ul>

Review Elements	Suggested Databases/Websites/Search Engines	Search Term Combinations/Phrases	
		<p>certificates" OR "death certificate" OR "death certification")</p> <ul style="list-style-type: none"> <li>• (Issues OR barriers OR problems OR ambiguity OR difficulty) AND ("death certificates" OR "death certificate" OR "death certification")</li> <li>• ("death certification" OR "death reporting") AND (education OR training OR "clinical competence" OR "best practices")</li> </ul>	
	<ul style="list-style-type: none"> <li>• American Diabetes Association (ADA) Scientific Sessions/Abstracts (<a href="http://professional.diabetes.org/Default.aspx">http://professional.diabetes.org/Default.aspx</a>)</li> <li>• Cochrane Reviews (<a href="http://onlinelibrary.wiley.com/cochranelibrary/search/quick">http://onlinelibrary.wiley.com/cochranelibrary/search/quick</a>)</li> </ul> <p>(note: some quotations and parentheses may be omitted in ADA and Cochrane Reviews searches.)</p>	<p>All of the above, plus:</p> <ul style="list-style-type: none"> <li>• "death certification" OR "death certificates" OR "death certificate"</li> <li>• "vital statistics" OR "mortality statistics"</li> <li>• "cause of death" OR "underlying cause of death" OR "multiple cause of death"</li> <li>• "death certification" AND education</li> <li>• "death certificates" AND education</li> <li>• "death certificates" AND "best practices"</li> <li>• "death certification" AND training</li> <li>• "death certificates" AND training</li> </ul>	
<p>B. Issues with death certificate reporting of diabetes (e.g. reporting trends, possible reasons for underreporting, recommendations/strategies to improve reporting).</p>	<ul style="list-style-type: none"> <li>• Medline/PubMed (<a href="http://www.ncbi.nlm.nih.gov/pubmed">http://www.ncbi.nlm.nih.gov/pubmed</a>)</li> <li>• Cochrane Reviews (<a href="http://onlinelibrary.wiley.com/cochranelibrary/search/quick">http://onlinelibrary.wiley.com/cochranelibrary/search/quick</a>)</li> </ul> <p>(note: some quotations and parentheses may be omitted in ADA and Cochrane</p>	<p>"diabetes" OR "diabetes mellitus" combined with each of the following: [Using Boolean modifier AND]</p>	<ul style="list-style-type: none"> <li>• Reporting AND ("underlying cause of death" OR "cause of death" OR "multiple-cause-of-death") AND ("death certificates" OR "death certificate" OR "death certification")</li> <li>• ("death certificate" OR "death certificates" OR "vital statistics" OR "mortality statistics") AND (reporting OR procedure OR accuracy OR policy) [Note: scanned titles</li> </ul>

Review Elements	Suggested Databases/Websites/Search Engines	Search Term Combinations/Phrases	
	Reviews searches.)		<p>with a focus on those mentioning “death” or “diabetes” in the title]</p> <ul style="list-style-type: none"> <li>•(Accuracy OR validation OR “quality assurance”) AND (“underlying cause of death” OR “cause of death” OR “multiple-cause-of-death”)</li> <li>•(Accuracy OR validation OR “quality assurance”) AND (“death certificates” OR “death certificate” OR “death certification”)</li> <li>• (Issues OR barriers OR problems OR ambiguity OR difficulty) AND (“death certificates” OR “death certificate” OR “death certification”)</li> <li>• (“death certification” OR “death reporting”) AND (education OR training OR “clinical competence” OR “best practices”)</li> </ul>
	<p>American Diabetes Association (ADA) Scientific Sessions/Abstracts  <a href="http://professional.diabetes.org/Default.aspx">http://professional.diabetes.org/Default.aspx</a></p>	<p>All of the above, plus:</p> <ul style="list-style-type: none"> <li>• Diabetes AND “death certification” OR “death certificates”</li> <li>• Diabetes AND “vital statistics” OR “mortality statistics”</li> <li>• Diabetes AND “cause of death” OR “underlying cause of death” OR “multiple cause of death”</li> <li>• Diabetes AND death certification AND education</li> <li>• Diabetes AND death certificates AND education</li> <li>• Diabetes AND death certificates AND best practices</li> <li>• Diabetes AND death certification AND training</li> <li>• Diabetes AND death certificates AND training</li> </ul>	

Review Elements	Suggested Databases/Websites/Search Engines	Search Term Combinations/Phrases
<p>C. Death certification protocol (e.g., process involved, who reports, forms used, guidelines/standards, policies, etc.)</p> <p>Note: Information most likely to be gathered through environmental scan, though any articles with information on the above found through the lit review will be documented as well.</p>	<ul style="list-style-type: none"> <li>• Medline/PubMed (<a href="http://www.ncbi.nlm.nih.gov/pubmed">http://www.ncbi.nlm.nih.gov/pubmed</a>)</li> <li>• American Diabetes Association (ADA) Scientific Sessions/Abstracts (<a href="http://professional.diabetes.org/Default.aspx">http://professional.diabetes.org/Default.aspx</a>)</li> <li>• Cochrane Reviews (<a href="http://onlinelibrary.wiley.com/cochranelibrary/search/quick">http://onlinelibrary.wiley.com/cochranelibrary/search/quick</a>)</li> <li>• NAPHSIS (<a href="http://www.naphsis.org/Pages/home.aspx">http://www.naphsis.org/Pages/home.aspx</a>)</li> </ul> <p>(note: some quotations and parentheses may be omitted in ADA, Cochrane Reviews and NAPHSIS searches.)</p>	<ul style="list-style-type: none"> <li>• (“death certificates” OR “death certification” OR “death reporting”) AND (protocol OR policies)</li> <li>• (diabetes OR “diabetes mellitus”) AND (“death certificates” OR “death certification” OR “death reporting”) AND (protocol OR policies)</li> </ul>

# Attachment B

## U.S. Standard Certificate of Death Form\*

LOCAL FILE NO.	U.S. STANDARD CERTIFICATE OF DEATH				STATE FILE NO.
1. DECEDENT'S LEGAL NAME (include AKA's if any) (First, Middle, Last)		2. SEX		3. SOCIAL SECURITY NUMBER	
4a. AGE-Last Birthday (Years)		4b. UNDER 1 YEAR		4c. UNDER 1 DAY	
5. DATE OF BIRTH (Mo/Day/Yr)		6. BIRTHPLACE (City and State or Foreign Country)			
7a. RESIDENCE-STATE		7b. COUNTY		7c. CITY OR TOWN	
7d. STREET AND NUMBER		7e. APT. NO.		7f. ZIP CODE	
7g. INSIDE CITY LIMITS? <input type="checkbox"/> Yes <input type="checkbox"/> No					
8. EVER IN US ARMED FORCES? <input type="checkbox"/> Yes <input type="checkbox"/> No		9. MARITAL STATUS AT TIME OF DEATH		10. SURVIVING SPOUSE'S NAME (if wife, give name prior to first marriage)	
		<input type="checkbox"/> Married <input type="checkbox"/> Married, but separated <input type="checkbox"/> Widowed <input type="checkbox"/> Divorced <input type="checkbox"/> Never Married <input type="checkbox"/> Unknown			
11. FATHER'S NAME (First, Middle, Last)			12. MOTHER'S NAME PRIOR TO FIRST MARRIAGE (First, Middle, Last)		
13a. INFORMANT'S NAME		13b. RELATIONSHIP TO DECEDENT		13c. MAILING ADDRESS (Street and Number, City, State, Zip Code)	
14. PLACE OF DEATH (Check only one; see instructions)					
IF DEATH OCCURRED IN A HOSPITAL: <input type="checkbox"/> Inpatient <input type="checkbox"/> Emergency Room/Outpatient <input type="checkbox"/> Dead on Arrival IF DEATH OCCURRED SOMEWHERE OTHER THAN A HOSPITAL: <input type="checkbox"/> Hospice facility <input type="checkbox"/> Nursing home/Long term care facility <input type="checkbox"/> Decedent's home <input type="checkbox"/> Other (Specify):					
15. FACILITY NAME (if not institution, give street & number)		16. CITY OR TOWN, STATE, AND ZIP CODE		17. COUNTY OF DEATH	
18. METHOD OF DISPOSITION: <input type="checkbox"/> Burial <input type="checkbox"/> Cremation		19. PLACE OF DISPOSITION (Name of cemetery, crematory, other place)			
<input type="checkbox"/> Donation <input type="checkbox"/> Entombment <input type="checkbox"/> Removal from State <input type="checkbox"/> Other (Specify):					
20. LOCATION-CITY, TOWN, AND STATE			21. NAME AND COMPLETE ADDRESS OF FUNERAL FACILITY		
22. SIGNATURE OF FUNERAL SERVICE LICENSEE OR OTHER AGENT				23. LICENSE NUMBER (Of Licensee)	
<b>ITEMS 24-28 MUST BE COMPLETED BY PERSON WHO PRONOUNCES OR CERTIFIES DEATH</b>				24. DATE PRONOUNCED DEAD (Mo/Day/Yr)	
				25. TIME PRONOUNCED DEAD	
26. SIGNATURE OF PERSON PRONOUNCING DEATH (Only when applicable)				27. LICENSE NUMBER	
28. DATE SIGNED (Mo/Day/Yr)					
29. ACTUAL OR PRESUMED DATE OF DEATH (Mo/Day/Yr) (Spell Month)			30. ACTUAL OR PRESUMED TIME OF DEATH		31. WAS MEDICAL EXAMINER OR CORONER CONTACTED? <input type="checkbox"/> Yes <input type="checkbox"/> No
<b>CAUSE OF DEATH (See instructions and examples)</b>					
<b>PART I.</b> Enter the <u>chain of events</u> —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
<b>IMMEDIATE CAUSE</b> (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 <b>UNDERLYING CAUSE</b> (disease or injury that initiated the events resulting in death) <b>LAST</b>					
b. _____ Due to (or as a consequence of): _____ c. _____ Due to (or as a consequence of): _____ d. _____					
<b>PART II.</b> Enter other significant conditions contributing to death but not resulting in the underlying cause given in PART I					33. WAS AN AUTOPSY PERFORMED? <input type="checkbox"/> Yes <input type="checkbox"/> No
					34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? <input type="checkbox"/> Yes <input type="checkbox"/> No
35. DID TOBACCO USE CONTRIBUTE TO DEATH? <input type="checkbox"/> Yes <input type="checkbox"/> Probably <input type="checkbox"/> No <input type="checkbox"/> Unknown		36. IF FEMALE: <input type="checkbox"/> Not pregnant within past year <input type="checkbox"/> Pregnant at time of death <input type="checkbox"/> Not pregnant, but pregnant within 42 days of death <input type="checkbox"/> Not pregnant, but pregnant 43 days to 1 year before death <input type="checkbox"/> Unknown if pregnant within the past year		37. MANNER OF DEATH <input type="checkbox"/> Natural <input type="checkbox"/> Homicide <input type="checkbox"/> Accident <input type="checkbox"/> Pending Investigation <input type="checkbox"/> Suicide <input type="checkbox"/> Could not be determined	
38. DATE OF INJURY (Mo/Day/Yr) (Spell Month)		39. TIME OF INJURY		40. PLACE OF INJURY (e.g., Decedent's home; construction site; restaurant; wooded area)	
41. INJURY AT WORK? <input type="checkbox"/> Yes <input type="checkbox"/> No					
42. LOCATION OF INJURY: State: _____ City or Town: _____				43. DESCRIBE HOW INJURY OCCURRED:	
Street & Number: _____ Apartment No.: _____ Zip Code: _____				44. IF TRANSPORTATION INJURY, SPECIFY: <input type="checkbox"/> Driver/Operator <input type="checkbox"/> Passenger <input type="checkbox"/> Pedestrian <input type="checkbox"/> Other (Specify)	
45. CERTIFIER (Check only one): <input type="checkbox"/> Certifying physician-To the best of my knowledge, death occurred due to the cause(s) and manner stated. <input type="checkbox"/> Pronouncing & Certifying physician-To the best of my knowledge, death occurred at the time, date, and place, and due to the cause(s) and manner stated. <input type="checkbox"/> Medical Examiner/Coroner-On the basis of examination, and/or investigation, in my opinion, death occurred at the time, date, and place, and due to the cause(s) and manner stated.					
Signature of certifier: _____					
46. NAME, ADDRESS, AND ZIP CODE OF PERSON COMPLETING CAUSE OF DEATH (Item 32)					
47. TITLE OF CERTIFIER		48. LICENSE NUMBER		49. DATE CERTIFIED (Mo/Day/Yr)	
				50. FOR REGISTRAR ONLY- DATE FILED (Mo/Day/Yr)	
51. DECEDENT'S EDUCATION-Check the box that best describes the highest degree or level of school completed at the time of death. <input type="checkbox"/> 8th grade or less <input type="checkbox"/> 9th - 12th grade; no diploma <input type="checkbox"/> High school graduate or GED completed <input type="checkbox"/> Some college credit, but no degree <input type="checkbox"/> Associate degree (e.g., AA, AS) <input type="checkbox"/> Bachelor's degree (e.g., BA, AB, BS) <input type="checkbox"/> Master's degree (e.g., MA, MS, MEng, MEd, MEd, MSW, MBA) <input type="checkbox"/> Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD)		52. DECEDENT OF HISPANIC ORIGIN? Check the box that best describes whether the decedent is Spanish/Hispanic/Latino. Check the "No" box if decedent is not Spanish/Hispanic/Latino. <input type="checkbox"/> No, not Spanish/Hispanic/Latino <input type="checkbox"/> Yes, Mexican, Mexican American, Chicano <input type="checkbox"/> Yes, Puerto Rican <input type="checkbox"/> Yes, Cuban <input type="checkbox"/> Yes, other Spanish/Hispanic/Latino (Specify) _____		53. DECEDENT'S RACE (Check one or more races to indicate what the decedent considered himself or herself to be) <input type="checkbox"/> White <input type="checkbox"/> Black or African American <input type="checkbox"/> American Indian or Alaska Native (Name of the enrolled or principal tribe) _____ <input type="checkbox"/> Asian Indian <input type="checkbox"/> Chinese <input type="checkbox"/> Filipino <input type="checkbox"/> Japanese <input type="checkbox"/> Korean <input type="checkbox"/> Vietnamese <input type="checkbox"/> Other Asian (Specify) _____ <input type="checkbox"/> Native Hawaiian <input type="checkbox"/> Guamanian or Chamorro <input type="checkbox"/> Samoan <input type="checkbox"/> Other Pacific Islander (Specify) _____ <input type="checkbox"/> Other (Specify) _____	
54. DECEDENT'S USUAL OCCUPATION (Indicate type of work done during most of working life. DO NOT USE RETIRED).					
55. KIND OF BUSINESS/INDUSTRY					

REV. 11/2003

## **Attachment C**

### **Key Terms and Definitions in Death Certification**

(From Myers et al., 1998; Table 1, p. 1319)<sup>10</sup>

**Certifying physician** -- Physician completing Cause of Death statement on death certificate (may be the attending physician, his or her delegate, or the coroner).

**Cause of Death statement** - Completion of part I and part II of the death certificate.

**Underlying cause of death** - The condition that triggered the chain of events leading to death; temporally, the most remote condition; etiologically specific.

**Immediate cause of death** - The final complication resulting from the underlying cause of death, occurring closest to the time of death and directly causing death.

**Antecedent (“intervening” or “intermediate”) cause of death** - A disease or condition that occurred as a result of the underlying cause of death but was not the final complication or immediate cause of death.

**Mechanism of death** - A physiologic derangement or biochemical disturbance by which a cause of death exerts its lethal effect (e.g., cardiac arrest, respiratory arrest); must not be used as an underlying cause of death.

**Nonspecific condition** - An anatomic or functional derangement that has more than one possible cause (e.g., sepsis, hemorrhage, heart failure, renal failure); must not be used as an underlying cause of death.

**Manner of death** - A classification of death based on the type of conditions that caused death and the circumstances under which they occurred (e.g., natural [due solely to disease], homicidal, suicidal, accidental or undetermined).

## Attachment D

### Suggested Content for Death Certification Education and Training

The literature reviewed highlights a number of topics and issues that should be addressed through education and training interventions to improve the accuracy and completion of death certificates. These include the following:

- Purpose, use and significance of death certificate data.<sup>8,9,14,19,21,22,35,48,55</sup>
- Process of death certification.<sup>9,48</sup>
- Currently legislation and legal requirements of death certification, such as when to refer a case to the coroner.<sup>9,17,19,53,55</sup>
- Clarification on completion guidelines, instructions, and definitions, particularly distinction among mechanisms of death, UCOD, and contributing causes of death.<sup>8,9,10,17,19,39,43,44,48</sup>
- Instruction on cause of death identification<sup>22</sup> and completion of cause sequence including:
  - Identifying cause of death when multiple comorbid conditions are present;<sup>51</sup>
  - Importance of correct cause of death sequencing, including guidance on how to appropriately deal with uncertainty in determining the cause of death sequence,<sup>6,8</sup> as well as correct placement on the certificate,<sup>6,20,43,44,48,51</sup>
  - Importance of reporting cause of death as specifically as possible.<sup>37</sup>
- Proper placement of diseases and conditions in Part I and Part II of the certificate (e.g., when to place a chronic disease such as diabetes in Part I and when to place it in Part II; where to place other morbid conditions such as obesity).<sup>44,82</sup>
- Examples of common errors and how to correct these errors.<sup>14,17,43,55</sup>
- When and why to amend cause of death statements.<sup>22</sup>
- Information on further resources to assist clinicians in completing death certificates.<sup>14</sup>

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