Introduction:
Accurate coding of cause of death through the use of final death certificates is important to obtain valid mortality data for studies of individuals with TBI.

Purpose:
To establish standards for transmitting/storing death certificates and coding cause of death in the TBIMS National Database by the NDSC.

Scope:
All TBIMS centers including the TBIMS longitudinal follow-up centers that conduct FORM II follow-ups, and the NDSC.

Responsibilities:
All those specified in the scope will abide by this policy and procedure.

Procedural steps:
1. Upon receiving notice that a participant in the TBIMS has expired, each center must attempt to obtain a valid and final death certificate issued by the state. Regardless of when the information is received, the data collector should classify the participant as deceased in the next follow-up period for that individual (e.g. if it is identified that a person expired 3 years post injury, then a Year 5 Form II should be submitted and the date of death recorded). If the person expires during inpatient rehabilitation the death should be recorded on the Form 1.
2. To obtain a final copy of the death certificate, write or go to the vital statistics office in the State or area where the death occurred (a complete list can be found at the CDC website [http://www.cdc.gov/nchs/w2w.htm](http://www.cdc.gov/nchs/w2w.htm)). Addresses and fees are given for each certificate in the State or area concerned.
3. To ensure that you receive exactly what you request and that your request is completed expeditiously, follow the steps outlined below:
   o For all requests, make check or money order payable to the identified office, in the correct amount for the number of certificates requested. Sending cash is not recommended because the office cannot refund cash lost in transit.
   o Because all fees are subject to change, a telephone number is included in the information for each State to call and verify the current fee.
   o States provide their home webpage address to obtain current information.
   o Type or print all names and addresses in the letter.
   o Provide all the information requested, if available, such as:
     ▪ Full name of person whose certificate is requested.
     ▪ Sex.
     ▪ Parents' names, including maiden name of mother.
     ▪ Month, day, and year of death.
     ▪ Place of death (city or town, county, and State; and name of hospital, if known).
     ▪ Purpose for which certificate is needed.
     ▪ Relationship to person whose record is requested.
     ▪ Your day time telephone number with area code.

4. Upon receipt of the death certificate, the center should retain the original and make a copy to be redacted and sent to the NDSC. The following information should be redacted from the copy of the certificate sent to the NDSC:
   • Name
   • Address
   • Social security number
   • Relative’s names and information
   • State death certificate number

5. The redacted copy of the death certificate sent to the NDSC should include:
   • Date of birth
   • Date of death
   • All final causes of death
   • Manner of death
   • Date of onset of diagnoses leading to death
   • Time and place of death
   • Description of death by coroner
• Whether an autopsy was performed
• Participant’s TBI model system identification number.

6. The redacted copy of the death certificate should then be scanned to a pdf file and uploaded to the TBIMS National Database website under the MEMBERS – UPLOAD section of the TBINDSC website (www.tbindsc.org).

7. After uploading the death certificate to the NDSC, email a copy of the death certificate invoice to Donna Wolff [dwolff@craighospital.org] at the NDSC and your center will be reimbursed for the cost of obtaining the death certificate.

TBIMS NDSC will be responsible for the following upon receipt of the death certificate:
1. Storing an electronic copy of the death certificate in a secure server at the NDSC as user-ID and password protected computer files.
2. Coding the causes of death using the using the instructions below.
3. Verifying the date of birth on the death certificate matches the date of birth for the participant in the national database.
4. Verifying the date of death on the death certificate matches the date of death for the participant in the national database.
5. Adding a pdf sticky note/comment box inserted in the pdf file of the death certificate with the cause of death codes.
6. Entering the cause of death codes into the National Database.

All coding and entering into the national database of the cause of death data will occur no later than 1 quarter after the NDSC receives the death certificate. At the beginning of each quarter the NDSC will distribute a list of all cases to each center which have been coded as having died in the national database but a death certificate has not been submitted to the NDSC.

Below are the steps that the NDSC will take to ensure confidentiality and security of death certificates maintained by the NDSC:

1. Death Certificates will be destroyed in accordance with Craig Hospital’s disposal procedures. Identifiable information will be disposed of in a confidential manner upon the project’s completion or within five years of the date of the original release, whichever occurs first, unless an extension is requested of and approved by the corresponding health department from which the death certificate was obtained. Identifiable information includes: certificate numbers, OCME numbers, names, exact dates, Social Security numbers, addresses, census tracts/blocks, institution names, some exact
measure (e.g. birth weight), write-in items, and any other information that may identify an individual. Anything that contains identifiable information will be destroyed. This includes original certificate copies, computer files and/or their abstracts and any reproductions. Linkages to other datasets with identifiable information will also be destroyed.

2. As a matter of daily operations, individual worksheets or other materials containing patient information, that are not to be kept as part of the research project file, are deposited into locked shredding containers.

GUIDELINES FOR CODING PRIMARY CAUSE OF DEATH (NDSC Responsibility)

In general, death certificates will have a line that documents the immediate cause of death followed by two or three lines under the heading "due to or as a consequence of." There will also be a line to document "other significant conditions."

A. As a general rule, the primary cause of death will be the cause entered alone on the lowest line of the "due to or as a consequence of" sequence unless it is unlikely that this condition gave rise to all the other conditions listed above it. *If you are uncertain about this, consult your center's medical professionals. An "Other significant condition" would be coded as a secondary cause of death unless it can be specifically linked to the causes listed above it, in which case it might be included in a combined primary cause of death. Any mention of traumatic brain injury, head trauma, etc. (including late effects of TBI) should be ignored *unless it is a new injury (See F).

For example, consider the following cases:

1. Immediate cause: Cardiac arrest 427.5
   Due to or as a consequence of:
   Due to or as a consequence of:

   Unless additional information can be acquired, select cardiac arrest (427.5) because, unfortunately, it is the only option available.

2. Immediate cause: Cardiorespiratory arrest 427.5
   Due to or as a consequence of: Pneumonia 486
   Due to or as a consequence of:

   Select pneumonia (486) since it led to the cardiorespiratory arrest.
3. Immediate cause: Cardiorespiratory arrest 427.5
   Due to or as a consequence of: Septicemia 038.9
   Due to or as a consequence of: Pneumonia 486

Select pneumonia (486) because it led to the other conditions. List septicemia as a secondary cause.

4. Immediate cause: Cardiorespiratory arrest 427.5
   Due to or as a consequence of: Arteriosclerosis 440.9
   Due to or as a consequence of: Late effect of intracranial Injury 907.0

Select arteriosclerosis (440.9) and ignore the reference to TBI.

5. Immediate cause: Cardiorespiratory arrest 427.5
   Due to or as a consequence of: Septicemia 038.9
   Due to or as a consequence of: Renal failure 586

Select septicemia (038.9) because renal failure (which would ordinarily have been chosen) cannot cause septicemia. List renal failure as a secondary cause.

6. Immediate cause: Arteriosclerosis 440.9
   Due to or as a consequence of: Pneumonia 486

Select arteriosclerosis (440.9) because pneumonia (which would ordinarily have been chosen) cannot cause arteriosclerosis. List pneumonia as a secondary cause.

7. Immediate cause: Cardiac arrest 427.5
   Due to or as a consequence of: Hemorrhage 459.0
   Due to or as a consequence of: Peptic ulcer 533.4

Unless there is specific evidence indicating the hemorrhage was not associated with the peptic ulcer, select peptic ulcer with hemorrhage (533.4) because hemorrhage (which would ordinarily have been chosen) can be linked with peptic ulcer to identify a more specific condition. The important question is whether this death is better classified as resulting from a disease of the digestive system or a disease of veins and lymphatics. Certainly, the former seems more appropriate given the available information.
8. Immediate cause: Pernicious anemia 281.0  
Due to or as a consequence of: Cerebral hemorrhage 431  
Due to or as a consequence of: Arteriosclerosis 440.9

Select pernicious anemia (281.0). Although arteriosclerosis can cause a cerebral hemorrhage, it cannot cause pernicious anemia. Cerebral hemorrhage also cannot cause pernicious anemia. Therefore, with no apparent causal sequence leading directly to the immediate cause of death, the immediate cause is selected as the primary cause of death. The others should be listed as secondary causes.

B. In general, ill-defined conditions should not be selected as the primary cause of death unless no alternative exists. *(For exception – see H.)*

For example:

1. Immediate cause: Myocardial infarction 410.9  
Due to or as a consequence of: Tachycardia 785.0  
Due to or as a consequence of:

Select myocardial infarction (410.9) because tachycardia (which would ordinarily have been chosen) is considered a "symptom or ill-defined condition." Tachycardia can be listed as a secondary cause of death.

C. In general, trivial conditions should be ignored. If death is the result of an adverse reaction to treatment for a trivial condition (such as renal failure resulting from taking aspirin for recurrent migraines), then code the adverse reaction as the primary cause of death. If the trivial condition is not reported as the cause of a more serious complication and a more serious unrelated condition is reported, then code the more serious condition as the primary cause of death.

For example:

1. Immediate cause: Congenital anomaly of eye 743.9  
Due to or as a consequence of: Congenital heart disease 746.9  
Due to or as a consequence of:

Select congenital heart disease (746.9) even though it cannot cause a congenital anomaly of the eye because the latter is considered a trivial condition unlikely by itself to cause death.

D. When the normal selection process results in choosing a condition which is described only in general terms and a related cause is also reported which provides more precise information about the system or nature of the chosen condition, reselect the more informative cause as the primary cause of death.
For example:

1. Immediate cause: Cerebral thrombosis 434.0
   Due to or as a consequence of: Cerebrovascular accident 436
   Due to or as a consequence of:

Select cerebral thrombosis (434.0) because it is more informative and precise than cerebrovascular accident (which would ordinarily have been chosen). Cerebrovascular accident can be listed as a secondary cause.

2. Immediate cause: Pyelonephritis 590.8
   Due to or as a consequence of: Kidney stone 592.0
   Due to or as a consequence of: Renal disease 593.9

Select kidney stone (592.0). Both kidney stone and pyelonephritis are more specific than renal disease, but kidney stone would have been selected if renal disease had not been listed on the certificate. Therefore, it is preferred over pyelonephritis, which can be listed as a secondary cause of death along with renal disease.

E. It is important to consider the interval between onset and death for each condition specified on the death certificate. Acute conditions that occurred a protracted time prior to death probably will not be the primary cause of death.

For example:

Immediate cause: Congestive heart failure (3 mo) 428.0
Due to or as a consequence of: Pneumonia (1 year) 486
Due to or as a consequence of:

Select congestive heart failure (428.0) because the episode of pneumonia occurred a long time before the patient died as well as long before the symptomatic heart disease began.

F. The use of E codes is very important because it is the only way to distinguish accidents, suicides and homicides from each other as well as from natural causes of death. However, E codes should only be used to reflect injuries that occur after the original TBI producing event. *If an injury or poisoning code is reported (800-999), it should always also have an E-code (E800-E999) with it. If an E code is appropriate, it will always be treated as the primary cause of death.

The distinction between accident, suicide and homicide can be found in a separate box on the death certificate below the list of causes.
G. When the death certificate does not provide adequate information (for example when the only cause of death listed is "head trauma"), which refers to the original injury, code the cause of death as unknown.

H. "For a death due to seizure or seizure disorder, use the seizure code 780.39 as opposed to the epilepsy codes 345.90 & 345.91. Someone who dies of Post-Traumatic Seizures should be coded as cause death due to seizure.

I. "When the death certificate reports the cause of death due to cancer/neoplasm, if a site of the cancer is given (e.g., lung cancer) assume this to be the primary site, if not otherwise specified.

J. "If the death certificate lists several “Other significant conditions” or “Secondary causes”, try to select from a different diagnosis grouping, for your secondary code, to provide more information upon analysis.”

For example:

1. Immediate Cause: Adult Respiratory Distress Syndrome
   Due to or as a consequence of: Streptococcal Pneumonia
   Other significant conditions: Pseudomonas Sepsis
                                 Acute Glomerulonephritis

Select Streptococcal Pneumonia (481) because it led to the other conditions. List the acute Glomerulonephritis as your secondary code as it provides a different diagnosis grouping.

Adapted from the Spinal Cord Injury Model Systems

Updated 04/01/2011
Updated 04/09/2004
Implemented 10/1/2004

Training requirements:
Staff responsible for the Form I and Form II data collection for the TBIMS national database should be familiar with this procedure. On-going training will be conducted by quarterly data collector teleconferences and in-person data collectors meetings.
Compliance:
All centers collecting data on participants in the TBI Model Systems National Database and the NDSC are responsible for adhering to this procedure.

References:

History:

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<thead>
<tr>
<th>Date</th>
<th>Action</th>
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<tbody>
<tr>
<td>3/25/2013</td>
<td>New policy developed and approved by Project Directors</td>
</tr>
<tr>
<td>1/15/2017</td>
<td>Added section addressing destruction of Death Certificates Added “Guidelines for Coding Primary Cause of Death&quot; section (was formerly a separate linked document under “Cause of Death” syllabus page).</td>
</tr>
<tr>
<td>11/19/2019</td>
<td>Full review completed by the NDSC</td>
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Review schedule:
Every 5 years