Death Clearance Manual

By the NAACCR Death Clearance
Issues Work Group of the
Registry Operations Committee

July 2009

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Edited by
Robin Otto, CTR

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Preface

The Death Clearance Issues Work Group of the North American Association of Central Cancer Registries (NAACCR) Registry Operations Committee is pleased to present the *Death Clearance Manual* for use as standard practice by all NAACCR member registries. This manual is the comprehensive compilation of death clearance process instruction intended to provide all necessary information under one cover to successfully and consistently conduct death clearance.

The Work Group, established in 2004, includes representatives from all standard-setting organizations and a cross section of registry representatives from the United States and Canada involved in death clearance. The Work Group worked closely with the Cancer Registration Steering Committee on all critical issues.

Content of this manual is set forth as minimum requirements for death clearance performed by the NAACCR membership that includes regional, state, territorial, and provincial registries. Key points are repeated throughout the manual to provide complete, consistent guidance on process instructions. The requirements are the least common denominator for registries conducting death clearance. Registries may do more, but not less.

It is the hope of the Work Group that the degree of detail presented within the *Death Clearance Manual* for the requirements and guidelines will provide much needed instruction, eliminating the inconsistencies that have long been associated with the death clearance process in North America.

The NAACCR Board of Directors approved the *Death Clearance Manual* in February 2009. **Population-based cancer registries shall implement all minimum requirements specified in the *Death Clearance Manual* for deaths in 2010 to meet death clearance requirements for the NAACCR 2012 Call for Data.**

Chapter 1: Introduction

The purpose of the *Death Clearance Manual* is to establish minimum requirements for conducting death clearance. The minimum requirements provide a baseline, or least a common denominator, to achieve consistency among population-based cancer registries (hereafter referred to as "registries" or "registry") in performing death clearance. Registries may do more than the minimum requirements call for by implementing stricter registry-specific policies or procedures; however, registries may not do less than the minimum requirements specify. To enhance the usefulness of this resource, guidelines and standard terminology for death clearance methods, procedures, and decisions are also included.

1.1 Background

Population-based cancer registries use death certificates for two purposes: (1) to update mortality and other information on cases already in the registry database, and (2) as a casefinding source. The use of mortality files to update death information and increase reporting completeness in the registry is referred to as "death clearance." In recent years, the death clearance process has received increased emphasis due to the inclusion of the death certificate only (DCO) percentage in the registry certification process. The percentage of DCO cases is used to measure completeness of reporting within and among registries.

In 2002, the NAACCR Death Clearance Best Practices Work Group developed *Series V: Resolving Death Clearance Issues* to document guidelines and suggested operating procedures for specific aspects of the death clearance procedure. One of the controversies resulting from *Series V* related to abstracting a death certificate as a medical doctor/physician only (MDO) case. The NAACCR Registry Operations Committee (ROC) convened the Death Clearance Issues Work Group (hereafter referred to as the "Work Group") to evaluate this practice and develop a recommendation to resolve this issue.

As the Work Group began discussions, it identified other inconsistencies in determining DCO cases. As a result, the Work Group's original charge expanded to provide a recommendation on the MDO issue as well as develop a comprehensive manual documenting minimum requirements and guidelines for conducting death clearance, including terms and definitions associated with the death clearance process.

1.2 Problem

There are no documented national standards, rules, or requirements for conducting death clearance; nevertheless, all registries must complete the process to meet funding agency requirements and certification standards. This has resulted in significant variation among registries in determining what constitutes a DCO case. Without national standards, varying registry-specific procedures dictate whether a case is a DCO.

The following examples demonstrate inconsistent results that occur due to lack of standardization:

a. No information is obtained from the follow-back source. However, sufficient information regarding the interval between onset and death is documented on the death certificate to estimate a date of diagnosis. Some registries consider these MDO cases if the death certificate was signed by a physician; other registries consider these DCO cases.

b. Follow-back on a death certificate provides physician confirmation of the cancer diagnosis but no date of diagnosis. No interval information appears on the death certificate to estimate a date of diagnosis. Some registries consider these DCO cases. Others consider them physician-reported cases and use 99999999 as the date of diagnosis.

c. The only information received from the follow-back source is confirmation of the diagnosis. Some registries take this case out of DCO status. Other registries require at least confirmation of the diagnosis and the actual or estimated diagnosis date. There are other registries that require even more information to take a case out of DCO status.

d. When a non-physician coroner signs the death certificate, some registries follow-back to the coroner and use the information provided. Other registries use only information provided by a medical practitioner or obtained from a clinical record to take a case out of DCO status.

Because one of the quality measures used to evaluate registry completeness is percentage of DCO cases, uniform and consistent practices for determining DCO cases are needed. Differences in methodology and decisionmaking for death clearance impact the number of cases identified as DCOs. Defining minimum requirements governing the death clearance process will facilitate the development of comparable procedures among registries. Standardization of the death clearance process will improve the usefulness of the percentage of DCO cases as a measure of completeness of reporting for population-based registries. It will also increase the accuracy of comparisons of DCO data between and among registries.

1.3 Approach

The approach taken by the Work Group to standardize death clearance was to first identify methodology, procedures, and decisions that differed among registries when performing death clearance. The Work Group identified scenarios encountered in performing death clearance and discussed the scenarios until consensus was reached.

Work Group members then adopted a four-step process for addressing the problem by: (1) identifying and reviewing all known sources of information referencing death clearance (see Appendix A: Death Clearance Publications); (2) identifying information needed to provide consistency in conducting death clearance from each source—this involved identifying and resolving inconsistencies among documented resources; (3) determining what must be done to yield consistent results; and (4) compiling the information into one comprehensive reference source.

During this process, representatives from the National Center for Health Statistics (NCHS) provided additional insight into death certificate data collection. Work Group members presented recommendations on controversial issues identified through this process to various audiences to build consensus. The Work Group incorporated decisions into the document and submitted it to the NAACCR's ROC, Cancer Registration Steering Committee, and the NAACCR Board of Directors for approval.

1.4 Results

The efforts of the Death Clearance Issues Work Group resulted in the development of the *Death Clearance Manual*. This document: (1) identifies minimum requirements for conducting death clearance; (2) includes guidelines and rationale to facilitate understanding the process; (3) standardizes terms and definitions associated with the death clearance process; and (4) incorporates all aspects of death clearance into one resource, to the extent possible.

1.5 Minimum Requirements, Guidelines, and Glossary

This manual presents information as **minimum requirements,** guidelines, and a glossary for death clearance.

a. **Minimum Requirements:** Statements within the text of the document describing methods, procedures, and decisions that represent the least the registry must do to perform death clearance. These statements are numbered and identified in **bold text.** An example of a **minimum requirement** from Chapter 3, Death Clearance Match is: "**3.2.2 No Alteration of Underlying Cause of Death: Underlying Cause of Death from the mortality file must not be altered when entered into the NAACCR field Cause of Death [1910] even when the registry has more complete or detailed information.**"

   Registries may do more than called for in the minimum requirements by implementing stricter registry-specific policies and procedures; however, registries may not do less than a minimum requirement specifies. Before implementing a stricter version of the rule, registries should identify and assess its impact on the registry's workload and results.

b. **Guidelines:** Information and rationale provided to facilitate understanding the process. Guidelines appear in non-bolded text. An example of a guideline from Chapter 3, Death Clearance Match is: "Several data items are common to both registry and mortality files. Comparison of these data items may provide the opportunity to update additional data items and decrease unknown values. This comparison is recommended but is not required."

c. **Glossary:** Alphabetic list of terms, definitions, abbreviations, and acronyms associated with the death clearance process. The Death Clearance Glossary is included as Appendix B.

Chapter 2: Understanding Death Clearance

This chapter defines and describes death clearance to promote better understanding of the death clearance process and consistency in referencing any aspect of death clearance. (See also Appendix B: Death Clearance Glossary.)

2.1 Definition of Death Clearance

According to John Lewis Young, Jr., DrPH, CTR, Professor of Epidemiology, Rollins School of Public Health, Emory University, and former Chief of the Demographic Analysis Section, National Cancer Institute (NCI), Surveillance, Epidemiology, and End Results (SEER) Program, the term "death clearance" originated from the End Results Group, one of the predecessors of the SEER Program. The term referred to the process of linking against mortality files for the purpose of clearing out all of the deaths before beginning the follow-up process and generating accurate survival statistics. The idea of following back on non-reported cancer deaths came much later, when registries expanded to a population base and emphasis was put on complete and accurate incidence as well as survival data.

Death clearance is now defined as the process of matching registered deaths in a population against reportable conditions in the registry database for two purposes: (1) ascertainment of death information for persons in the registry (death clearance match), and (2) identification of all deaths with a reportable condition mentioned as a cause of death that are not found in the registry database (death clearance follow-back).

2.2 Purpose of Death Clearance

The purpose of death clearance is to utilize information from death certificates to improve cancer registration by: (1) enhancing data quality and usefulness by updating vital status and incorporating appropriate death information as well as other data items common to both cancer and death registration systems into the registry, and (2) improving completeness by adding previously unreported cancer cases.

Results of the death clearance process provide information to assist registries in assessing the adequacy of reporting from hospital and non-hospital sources. Analysis of these results may identify deficiencies in casefinding that can be used to improve reporting from existing sources or indicate additional sources to include in routine case reporting.

2.3 Death Clearance Process

The death clearance process in a registry includes the following two steps:

a. **Death Clearance Match:** Deaths from the official mortality file from the state, territorial, or provincial vital records office (hereafter referred to as mortality file) are linked to the registry database to identify records that match. For each patient match, the registry record is updated with death and other relevant data.

b. **Death Clearance Follow-Back:** First, non-matches from the previous step (death clearance match) that mention a reportable condition as one of the causes of death are ascertained and are used to identify potentially missed incidence cases. Second, patient matches from the previous step are reviewed for potential new primaries.

   For an unmatched (patient or tumor) cancer death occurring in a facility that reports to the registry, the registry makes a follow-back request for the facility to submit information on the case. For deaths that did not occur in a reporting facility, the registry requests follow-back information from the certifying physician or from the source identified as the place of death (provided that the registry has the legal authority to do so). If the first source does not have additional information, then that source may identify another follow-back source. When follow-back provides sufficient information, an abstract is prepared by the source or the registry, and the case is included as an incidence case. When the registry has exhausted all follow-back sources (or lacks the resources to follow-back to additional sources) and no information other than the death certificate is available, the case is entered in the registry database as a DCO case.

Death clearance match and death clearance follow-back may be performed separately or as one process. Many registries find it more efficient to perform death clearance as one process. Patient matches are used to update death information and non-matches (patient and tumor) are used in the death clearance follow-back process.

Refer to Appendix C: Flow Diagram of the Death Clearance Process. The specific section of the *Death Clearance Manual* that describes each part of the process is referenced in the flow diagram.

2.4 Cause of Death Section of the Death Certificate

Causes of death recorded on the death certificate play a critical role in death clearance. This section provides information on the Cause of Death section of the U.S. Standard Certificate of Death. Refer to the following NCHS publications for additional information:

a. *Instruction for Completing the Cause-of-Death Section of the Death Certificate*. Issued: August 2004. 04-377 (8/04) http://www.cdc.gov/nchs/data/dvs/blue_form.pdf.

b. Handbooks for Death Certificate: http://cdc.gov/nchs/vital_certs_rev.hetm.
   - *Physicians Handbook on Medical Certification of Death* (2003 revision)
   - *Medical Examiners* (2003 Revision)
   - *Funeral Directors' Handbook on Death Registration and Fetal Death Reporting* (2003 Revision)

c. U.S. Standard Certificate of Death, Rev. 11/2003 http://cdc.gov/nchs/vital_certs_rev.htm.

The medical-legal officer's primary responsibility in death registration is to complete the medical part of the death certificate. The medical certification includes information on the causes and manner of death and related factors, such as the place of death and the date and time of the legal pronouncement of death. The proper completion of this section is of utmost importance to an efficient-working medical-legal investigative system.

A cause of death is a disease, abnormality, injury, or poisoning that contributed directly or indirectly to death. The cause(s) of death entered on the death certificate are all diseases, morbid conditions, or injuries that either resulted in or contributed to death and the circumstances of the accident or violence that produced any such injuries.

The cause of death section of the death certificate is designed to elicit the opinion of the medical certifier as to the immediate cause, the antecedent causes, and the underlying cause, as well as the contributing causes of death. It consists of the following two parts:

Part I (chain of events leading directly to death from the immediate cause to the underlying cause)

a. Line (a) is used to report the immediate cause of death. This is the final disease, injury, or complication leading directly to death. It may be the only entry in the cause of death section if only one condition was present at death.

b. Lines (b), (c), and (d) are used to sequentially list conditions, if any, leading to the immediate cause of death. If the condition is believed to have prepared the way for the immediate cause, it can be considered an antecedent to the immediate cause even though a long interval of time has elapsed since its onset. The underlying cause of death is the disease or injury that initiated the chain of morbid events which led directly to death or the circumstance of the accident or violence which produced the fatal injury. The underlying cause of death is recorded as the last cause in this section.

   Note: Although the position for underlying cause of death is specified on the death certificate, it may be entered in a different position. The most accurate method to identify the underlying cause is to refer to the Underlying Cause of Death field in the electronic mortality file.

c. The approximate interval between onset and death at the end of lines (a), (b), (c), and (d) is used to record the interval between the presumed onset and the date of death. This should be entered for all causes—immediate cause, antecedent conditions, and the underlying cause. These intervals usually are established by the medical examiner or coroner on the basis of available information. In some cases the interval is estimated. The time of onset may be obscure or entirely unknown, in which case the medical-legal officer can state that the interval is "Unknown."

Part II (other significant conditions)

a. Part II is used to record any other important disease or condition present at the time of death, and that may have contributed to death but did not result in the underlying cause of death listed in Part I.

The World Health Organization (WHO) recommends that its signatory nations use the underlying cause of death for basic mortality statistics. Information on the other diseases or conditions that led to death and the other significant conditions that contributed to death is also important. The cause of death section reflects information used to examine the frequency of certain diseases or conditions being reported on the death certificate, whether or not they are the underlying cause. Analysis of all conditions reported on the death certificate is especially important in studying diseases or conditions that are rarely the underlying cause of death, but often contribute to death (e.g., pneumonia or diabetes).

2.5 Working With Vital Records Offices

When establishing access to mortality files, registries should ask the following questions:

a. **Does a formal agreement need to be established with the vital records office?** If an agreement is required, it should cover access to computer records, microfiche, and paper files; information that may be accessed; subsequent use or release of death record information; and costs.

b. **Are costs associated with accessing mortality files?** Vital records offices may charge to release their mortality files, to produce hardcopies of death certificates, or for other related activities. It is important for registries to be aware of all potential charges so that they can be included in the registry's annual budget.

c. **What death certificates do the computerized mortality files include?** The file should include: (1) death certificates of residents in the registry catchment area who die in the registry catchment area, (2) death certificates of residents in the registry catchment who die in another catchment area, and (3) death certificates of residents from another catchment area who die in the registry catchment area (optional for death clearance purposes).

   In the United States, many vital records offices have case-sharing agreements in which deaths of out-of-state residents are provided back to the state of residence. There is, however, significant variation in re-release stipulations for each state. It is important to know which states permit access by the registry and use of the death data according to the Inter-Jurisdictional Exchange Agreement for Vital Records, available at http://www.naphsis.org/index.asp?bid=986.

   In Canada, the Canadian Cancer Registry (CCR) Death Clearance is conducted annually by Statistics Canada to complete the death information submitted by provincial and territorial cancer registries (PTCRs) to the CCR. The process is supported by data-sharing agreements between the Canadian Vital Registrars and the Canadian cancer registries. Records on the Canadian CCR database are linked to death registrations on the Canadian Vital Statistics database, which is created from provincial and territorial death records. Any record that is death confirmed is sent to the PTCR that reported the case to Statistics Canada. Cases for which the cause of death is "cancer" on the Canadian Vital Statistics database, but has not been reported by a PTCR, are forwarded to the provincial or territorial cancer registry where the deceased resided.

d. **What are the timelines for completion of mortality files?** In the United States, vital records offices are required to report deaths to the NCHS on a monthly or more frequent basis and are supposed to have their mortality files complete and resolved (e.g., edit errors corrected) 6 months from the end of the death year. It is common to finalize the file much later for resident data due to the long delays in receipt of the out-of-state deaths for residents received from other states. Caution should be taken when using the mortality file prior to completion, especially the coding of underlying cause of death. The registry needs to be aware of the status of the mortality file before beginning the death clearance process.

   In addition, some death certificates for a given year may be received after submission to the NCHS. The registry needs to ask the vital records office how late submissions are handled and ensure that the file they receive contains these death records.

e. **What types of death record media can be accessed?** Examples of death record media include electronic files (including processing files such as SuperMICAR files), microfiche, and hardcopies of death certificates. Although computerized mortality files are needed to conduct the record linkage, the ability to review actual diagnoses and other uncoded information on the death certificate is essential to resolve linkage questions as well as determine reportability. If the registry is unable to obtain access to electronic files containing uncoded information, it is recommended that the registry review microfiche or hardcopy death certificates.

f. **What causes of death are coded?** It is important to find out what causes of death on the death certificate are coded, because only coded information can be electronically linked with registry files. Across jurisdictions, the number of codes kept in vital records offices may differ. At a minimum, the International Classification of Diseases (ICD) code for the underlying cause of death will be tabulated. Some agencies maintain a multiple cause of death file that includes codes for some or all of the other causes of death recorded on each death certificate.

g. **What death certificates and data items on the mortality file may be accessed by the registry?** To effectively perform death clearance match and death clearance follow-back, registries should have access to as many death certificates and data items on the death certificate as possible. At a minimum, registries should have access to all resident deaths, including residents who expire in another state/territory/province. Registries should request data items as available from the mortality file that will facilitate linkage, describe the cancer, and provide death information. Such data items include name, address, date of birth, birth place, sex, race, ethnicity, U.S. Social Security Number or Canadian Health Card Number, all causes of death, date of death, place of death, death certificate file number, duration or interval between onset and death, occupation, and industry.

h. **How are data items on the mortality file coded?** Registries must know what version of ICD is used to code causes of death and what coding systems are used by vital records offices to code data items such as race, ethnicity, birthplace, county, minor civil division, marital status, occupation, and industry. It is important for registries to have access to the vital records coding manual so that a conversion program can be written if coding systems differ. In the United States, codes used for submission of mortality files to the NCHS may differ from codes used by the vital records office.

i. **To whom may registries re-disclose death information incorporated into the registry through the death clearance processes?** The agreement between registries and vital records offices should delineate permissible re-disclosures. Examples of potential sources for re-disclosure include hospital registries, other registries (e.g., AIDS), other health department programs, researchers, NAACCR, SEER, and NPCR.

2.6 Timing for Conducting Death Clearance

The timing for performing death clearance is based on when the final mortality file is complete and when the registry database is complete for the diagnosis year corresponding to the year of deaths. Careful timing of the process to make sure that all registry and mortality records are available before final death clearance procedures begin will maximize use of staff time by minimizing the number of non-matched cases requiring follow-back and missed updates to vital status.

For the mortality file to be complete, all filed death certificates must be incorporated into the mortality file (including deaths of residents occurring outside of the registry catchment area), and the death certificate cause of death coding must be complete.

For the registry database to be complete, casefinding, abstracting, and reporting from all sources must be complete. These sources include hospitals, freestanding pathology laboratories, all non-hospital reporting sources, and data exchange with other registries, as well as cases identified from casefinding audits. Editing and consolidation should also be complete.

Registries performing active patient follow-up may find it beneficial to conduct death clearance matching on a monthly or quarterly basis. Updating vital status more frequently will reduce the number of follow-up requests. An interim mortality file may be used for this purpose; however, records on these files may undergo correction by vital records offices when the complete yearly file is edited. It is important to be able to identify and make corresponding changes to records linked prior to the yearly editing.

2.7 Record Linkage Between Cancer Registry and Mortality Files

Matching mortality records against records in the registry database is a specific application of general record linkage. Registries use a variety of methods and algorithms. Choice of record linkage method depends on the data items available for linking, the size of files being linked, sensitivity and specificity required, and system capabilities.

Regardless of method, algorithm, or software used, the linkage should produce the following three outcomes:

a. **Positive Patient Match:** Person is in both databases, and the match criteria were met. No manual review is required for patient match. Review may be required for tumor match or non-match.

b. **Possible Patient Match:** Match criteria are not completely met. Manual review must be carried out to determine if the records are indeed matches. Review of case files, phone calls to providers, or correspondence with facilities may be required to verify possible matches.

c. **Patient Non-Match:** No record in the registry database meets enough of the match criteria to be considered even a possible match.

Patient matches (matches at the patient level) are used in the death clearance match process. (See Chapter 3, Death Clearance Match for details.) Non-matches at the patient and tumor level are used in the death clearance follow-back process. (See Chapter 4, Death Clearance Follow-Back for details).

Chapter 3: Death Clearance Match

This chapter documents minimum requirements and guidelines for performing death clearance match, a process in which records in the registry database are linked to mortality records for the purpose of updating death and other available information on previously-reported cases in the registry database.

3.1 Linkage With Mortality Files for Death Clearance Match

3.1.1 <u>Annual Death Clearance Match</u>: Death clearance match must be completed at least annually for a specified year of deaths to update death and other information on cases in the registry database.

Death clearance match must be performed at least once each year. For registries conducting active follow-up, death clearance match may be performed more frequently than once per year to reduce the number of follow-up requests. If done before the mortality file is complete, registries must make sure that all changes made to the final mortality file are incorporated into the appropriate registry matched record.

3.1.2 <u>Mortality File</u>: The official mortality file from the state, territorial, or provincial vital records office that contains all deaths for the specified year must be used to match against the registry database.

Access to mortality files varies among states/territories/provinces and organizational structure of the registry and vital records office. Refer to Chapter 2, Understanding Death Clearance, for important information about mortality files.

All deaths for the specified year should include:

a. **Resident Deaths:** Persons who expire in their state/territory/province of residence.

b. **Out-of-State/Territory/Province Resident Deaths:** Persons who expire in another state/territory/ province (catchment area). Records for residents of the registry catchment area who expire in another catchment area must be included unless prohibited.

c. **Deaths of Non-Residents:** Persons who were not residents of the registry catchment area in which they died. These death certificates do not need to be included in the mortality file unless the registry includes them in the death clearance follow-back process.

3.1.3 <u>Underlying Cause of Death</u>: The mortality file used to perform death clearance match must include at least the underlying cause of death.

If the results of linkage between registry and mortality files are used by the registry solely to update death and other information, only the underlying cause of death needs to be included on the mortality file. The underlying cause of death (NAACCR data item 1910 Cause of Death) is required to be incorporated into the registry database for all patient matches to the mortality file unless the registry is prohibited from receiving this information.

When the same linkage is used for both death clearance match and death clearance follow-back, the multiple cause of death file must be used. Patient matches are used to update death information; non-matches at the patient and tumor level are used in the death clearance follow-back process.

3.2 Death Information Update

Death information is incorporated into the registry for patient matches. Some fields (e.g., vital status, cause of death, death certificate file number) are automatically entered because the death information from the mortality file(s) is expected to be more accurate for these fields. Other fields common to both mortality and registry records require best value selection based on the guidelines provided below. Whenever coded fields are incorporated into the registry database, registry staff must identify the coding system used in the mortality file and convert codes to NAACCR standard codes if a different coding scheme is used.

3.2.1 <u>Required Death Fields</u>: The following fields must be incorporated into the registry database from the mortality record for all patient matches unless the registry is prohibited from receiving the information:

NAACCR Data Item	NAACCR Item #	Comment
Date of Last Contact	1750	Enter date of death from mortality file
Vital Status	1760	Enter code 0 Dead (COC) or code 4 Dead (SEER)
Follow-Up Source Central*	1791	See *NAACCR Standards for Cancer Registries, Volume II*
Cause of Death	1910	Enter underlying cause of death from mortality file (see Minimum Requirement 3.2.2)
ICD Revision	1920	See *NAACCR Standards for Cancer Registries, Volume II*
Place of Death	1940	Enter state/territory/province of death from mortality file; convert to NAACCR standard codes if another coding system is used
DC State File Number	2380	Enter death certificate file number from mortality file

* Follow-Up Source Central [1791] is not required for SEER registries.

Data items from the mortality file pertaining to the death can be updated automatically by software without manual review once a positive match is made. Edits should be in place to make sure that any abstract linked to a record after death information has been added contains no dates of diagnosis or treatment occurring after the date of death. Abstracts failing these edits should be manually reviewed to identify potential inappropriate matches to mortality records.

3.2.2 <u>No Alteration of Underlying Cause of Death</u>: Underlying Cause of Death from the mortality file must not be altered when entered into the NAACCR field Cause of Death [1910], even when the registry has more complete or detailed information.

The Underlying Cause of Death field on the mortality file is intended to capture the official cause of death. Because this variable is important for record linkage purposes and has legal implications, the code must not be changed. Registries may choose to designate a registry-specific field to enter or retain a cause of death code considered by the registry to be more precise or accurate.

3.3 Best Value Selection for Other Information From the Death Certificate

Several data items are common to both the registry and mortality records. Comparison of these data items may provide the opportunity to update additional data items and decrease unknown values. This comparison is recommended but is not required.

Data Items: Guidelines for best value selection are provided for specific data items in the following table. Information from the registry record is compared with the mortality record and updated where appropriate. Guidelines for primary site and histology are provided in Section 3.4 Tumor Comparison.

NAACCR Item #	NAACCR Data Item	Comment
2230	Name--Last	See best value selection guidelines below
2240	Name--First	See best value selection guidelines below
2250	Name--Middle	See best value selection guidelines below
2390	Name--Maiden	See best value selection guidelines below
2390	Social Security Number	See best value selection guidelines below; preferred source is decided on a registry-specific basis
220	Sex	See best value selection guidelines below
160	Race	See best value selection guidelines below
190	Spanish/Hispanic Origin	See best value selection guidelines below
240	Birth Date	See best value selection guidelines below; preferred source is decided on a registry-specific basis
90	County at DX	See best value selection guidelines below; preferred source is decided on a registry-specific basis
250	Birth Place	See best value selection guidelines below; preferred source is decided on a registry-specific basis
270, 310	Occupation Code--Census or Text--Usual Occupation	See best value selection guidelines below; enter code or text appropriately; if “retired” enter more specific occupation if available
280, 320	Industry Code--Census or Text Usual Industry	See best value selection guidelines below; enter code or text appropriately
330	Occup/Ind Coding System	Identify coding system used when occupation and industry coding is entered from death record
290	Occupation Source	Identify when occupation information is entered from death record
300	Industry Source	Identify when industry information is obtained from death record
70	Addr At DX--City	Use death record information only when it provides a more accurate address at diagnosis than registry
2330	Addr At DX--No & Street	Use death record information only when it provides a more accurate address at diagnosis than registry
100	Addr at DX--Postal Code	Use death record information only when it provides a more accurate address at diagnosis than registry
80	Addr at DX--State	Use death record information only when it provides a more accurate address at diagnosis than registry

NAACCR Item #	NAACCR Data Item	Comment
2335	Addr at DX--Supplemental	Use death record information only when it provides a more accurate address at diagnosis than registry
390	Date of Diagnosis	Use death record information only when it provides a more accurate date of diagnosis than registry.

Best Value Selection Guidelines: The following guidelines are recommended to select the best value when inconsistencies exist between the mortality record and the registry record. Registries should consider who the informant on the death certificate is and the reliability of that source. When applying these guidelines, it is important that registries make consistent decisions and document how decisions are made as part of registry-specific procedures.

a. Defer to the record that provides information that is known versus unknown.

b. If both records provide known values, defer to the record that provides more specific information over less specific information, unless otherwise indicated (as in occupation).

c. If both records provide specific information, defer to information in the registry record over information in the mortality record.

   Exception: For fields such as social security number, race, birth date, and birthplace, preference may be given to the mortality record.

3.4 Tumor Comparison

When a patient match is identified, death information must be added to the registry record and demographic information may be updated. The final step is to compare the primary site in the registry database with the cancer cause of death on the mortality file to determine if the two conditions represent the same primary or different primaries. If determined to be the same primary, the best primary site and histology are entered. If determined to be different primaries, follow-back is required to determine if the additional primary is added as a missed incidence case or as a DCO case.

Tumor comparison guidelines are provided below to assist in making this determination and completing the following data items:

NAACCR Item #	NAACCR Data Item	Comment
400	Primary Site	Use tumor comparison guidelines below to determine same primary or different primaries. If same, use primary site from registry unless mortality record is more specific. If different, see Chapter 4, Death Clearance Follow-Back.
522	Histologic Type ICD-O-3	Use tumor comparison guidelines below to determine same primary or different primaries. If same, use histology from registry unless mortality record is more specific. If different, see Chapter 4, Death Clearance Follow-Back.

Tumor Comparison Guidelines: Less stringent criteria for determining same primary or different

primaries are used for death clearance than are used for multiple primary determination of tumors from required reporting sources.

When these guidelines state "no follow-back is required," the tumor match decision may be made without obtaining additional information through follow-back. Even though there is no requirement to conduct follow-back, registries may still choose to do so.

For the purpose of death clearance, the common metastatic sites when referenced in the guidelines below include: bone (C40-C41), brain (C71), liver (C22.0), and lung (C34).

The following guidelines should be applied to determine same primary or different primaries for death clearance:

a. If the primary site in the registry and the cause of death on the death certificate are the same condition, consider this a tumor match. No follow-back is required.

   For some comparisons, the two conditions are obviously the same, and can be determined to be a tumor match without follow-back. Other comparisons may also be considered a tumor match without conducting follow-back. Examples include:

   1. Exact same site even if laterality on the mortality file is unknown

   2. One is a cervical primary and the other is uterine cancer

   3. One is colon and the other is rectum

   4. Conditions are two different head and neck sites

   5. Primary site on the death certificate could have been regional progression or recurrence from the primary site in the registry.

b. When the registry cannot accurately make the determination with available information, follow-back must be conducted.

c. If the primary site in the registry and the cause of death on the death certificate clearly represent two different primaries, follow-back must be conducted to determine if the primary from the mortality record is added to the registry database as a missed incidence case or as a DCO.

d. If the primary site in the registry is unknown (C80.9) and the cause of death is a common metastatic site listed above, consider both to represent the same primary. No follow-back is required. The registry primary site remains coded to unknown primary (C80.9).

e. If the primary site in the registry is unknown (C80.9) and the cause of death is not included in the common metastatic sites listed above, additional information from the registry record should be taken into consideration to determine if it is the same or different primary. If registry information does not provide enough information to make the decision, follow-back must be conducted to obtain additional information.

f. If the primary site in the registry is a known primary and the cause of death is a common metastatic site listed above, consider both to represent the same primary without follow-back only when the metastatic site is commonly associated with the primary in the registry database. If it is not, follow-back is required to obtain additional information.

g. If the primary site in the registry is a known primary and the death certificate indicates an unknown primary (C80.9), additional information from the registry record should be taken into consideration to determine if it is the same or different primary. If registry information does not provide enough information to make the decision, follow-back must be conducted to obtain additional information.

h. If the primary site in the registry database is not histologically confirmed and not mentioned on the death certificate, registries are encouraged to follow-back to determine if the diagnosis may have been ruled out after the case was ascertained, either prior to death, or at the time of autopsy. Follow-back on these cases may result in deleting an unconfirmed tumor from the registry database.

Chapter 4: Death Clearance Follow-Back

This chapter documents minimum requirements and guidelines for performing death clearance follow-back to identify and incorporate deaths with reportable diagnoses not previously included in the registry database. Compliance with these requirements is essential to assure consistency and comparability of results among registries.

Death certificates included in the death clearance follow-back process are those that contain a diagnosis of *in situ* or malignant cancer, or benign or borderline intracranial or central nervous system (CNS) tumor (hereafter referred to as reportable condition) but are not found in the registry database. They are patient non-matches (i.e., the record is in the mortality file with a cause of death corresponding to a reportable condition but is not in the registry database) or tumor non-matches (i.e., the record is in the registry database but the reportable condition in the mortality file is not found in the registry database).

All non-matches must be resolved after death certificate review and/or follow-back to a clinical source or medical record either as a missed incidence case or as a DCO case, or excluded as non-reportable.

a. **Missed Incidence Case:** A reportable case first identified as a non-matched cancer death for which confirmation of the diagnosis and other information are obtained through follow-back to a clinical source(s) or medical record.

b. **Death Certificate Only (DCO) Case:** A reportable case for which the only information the registry has is a death certificate containing a reportable condition.

c. **Non-Reportable Case:** A case first identified as a non-matched cancer death that after further investigation does not meet reporting criteria.

All non-matches containing reportable causes of death must be entered into the registry database as either missed incidence cases or as DCO cases before the death clearance process is considered complete. If the follow-back source has not responded by the time the process must be completed, the case must be resolved as though no follow-back information was received.

Timing for Death Clearance Follow-Back: Timing for death clearance follow-back must be planned carefully. The goal is to include all specified records from each database while avoiding unnecessary follow-back and distributing the follow-back workload across a reasonable time. The timing for performing final death clearance follow-back is contingent on completion of the final mortality file and the registry database for the diagnosis year corresponding to the year of death.

The registry must have an adequate number of staff trained in casefinding and abstracting to perform follow-back. Factors that influence the number of staff needed to complete death clearance follow-back include number of deaths occurring annually in the catchment area, length of time the registry has performed death clearance follow-back, software used by the registry, level of automation of death clearance follow-back processes, and size of the registry database.

For new registries, the first year conducting death certificate follow-back is the most difficult and time consuming. The mortality file will contain a greater number of potential incidence cases not in the registry database in this first year than in succeeding years for a variety of reasons (e.g., the

diagnosis date was prior to the registry reference date, the reporting source was not required to report at the time of diagnosis, the facility that should have reported the case to the registry failed to report it). As the registry matures, more cases will have been diagnosed after the registry reference date, after non-hospital facilities were required to report, or will have been identified during a casefinding audit.

4.1 Linkage With Mortality Files for Death Clearance Follow-Back

4.1.1 <u>Annual Death Clearance Follow-Back</u>: Death clearance follow-back must be completed at least annually for a specified year of death to add missed incidence cases to the registry database.

Death clearance follow-back must be performed at least annually. Registries may find it beneficial to conduct death clearance follow-back more than once per year to distribute the follow-back workload over a longer period. If early linkages are performed with incomplete mortality or registry files, a final linkage must be performed after the registry file and the multiple cause mortality file are complete for the year.

4.1.2 <u>Mortality File</u>: The official mortality file from the state, territorial, or provincial vital records office that contains all deaths for the specified year must be used to match against the registry database.

All deaths for the specified year include:

a. **Resident Deaths:** Persons who expire in their state/territory/province of residence.

b. **Out-of-State/Territory/Province Resident Deaths:** Persons who expire in another state/territory/ province (catchment area). Records of residents of the registry catchment area who expire in another catchment area must be included unless the registry is prohibited from receiving them.

c. **Deaths of Non-Residents:** Persons who were not residents of the registry catchment area in which they died.

Access to mortality files varies by registry catchment area and organizational structure. The registry must check with the vital records office to determine whether any deaths are excluded from the file used for death clearance. If certain deaths are excluded, the registry must request inclusion unless prohibited by the Inter-Jurisdictional Exchange Agreement for Vital Records or other vital records laws, statutes, or agreements. If exchange of some death data is prohibited, the registry should identify which registry catchment areas are excluded and attempt to obtain the death data from these areas. This might be accomplished by: (1) working with the vital records office to get the Exchange Agreement, statute, etc. modified; (2) contacting the registry in the area not covered for assistance if a Data Exchange Agreement exists between the two registries; or (3) establishing a Data Exchange Agreement with the registry in the area. While pursuing one or more of these solutions, the registry could request a count by jurisdiction of death certificates with a cause of death of cancer that had not been provided to the registry. This would assist the registry in targeting its efforts. Refer to Chapter 2, Understanding Death Clearance, for important information about mortality files.

4.1.3 <u>Multiple Cause of Death File</u>: The mortality file used to perform the death clearance follow-back process must include all causes of death—the underlying cause and all contributing causes.

Because a reportable condition may appear in any position on the death certificate and there may be more than one reportable condition on the death certificate, the underlying cause and all contributing causes of death must be used to identify potentially missed incidence cases. The mortality file containing all causes of death (multiple cause of death file) must be used to conduct the final linkage for the death clearance follow-back process.

If the underlying cause of death is the only cause of death coded, the registry must manually review all death certificates to ensure that a reportable condition is not listed as a contributing cause of death. Some vital records data systems set a flag whenever a reportable condition is mentioned on the death certificate. This can be very helpful in eliminating the manual review of hardcopy death certificates.

4.2 Identification of Potential Incidence Cases

Potential incidence cases are death certificates containing a reportable condition for which there is no corresponding record in the registry database. Consistency in how potential incidence cases are identified among registries is the first step in assuring comparable outcomes from the death clearance follow-back process. Cases not meeting any of the following criteria are excluded from the death certificate follow-back process.

4.2.1 <u>Criteria To Identify Potential Incidence Cases</u>: All criteria listed below must be used to identify all potential incidence cases from the mortality file:

4.2.1.1 All Causes of Death

When reviewing the mortality file for reportable conditions, all causes of death, including all other contributing causes, must be reviewed to identify a cause(s) of death for follow-back.

4.2.1.2 Deaths From the Specified Year

Include all deaths from the specified year for which death clearance follow-back is being conducted.

4.2.1.3 Reportable Conditions Only: The following ICD-10 codes must be used to identify reportable conditions on death certificates:

- **C000-C979 Malignant neoplasms**
- **D000-D039 *In situ* neoplasms**
- **D050-D059 *In situ* of breast**
- **D070-D099 Other *in situ***
- **D320-D339 Benign neoplasm of brain and CNS**
- **D352-D354 Other reportable benign neoplasms**
- **D420-D439 Brain/CNS neoplasms of uncertain or unknown behavior**
- **D443-D445 Other reportable neoplasms of uncertain or unknown behavior**
- **D45 Polycythemia vera**
- **D460-D469 Myelodysplastic syndromes***

- **D471 Chronic myeloproliferative disease****
- **D473 Essential (hemorrhagic) thrombocythemia**
- **D721 Eosinophilia [Hypereosinophilic (idiopathic) syndrome]**
- **D758 Other specified diseases of blood and blood-forming organs [Refractory cytopenia with multilineage dysplasia 9985/3]**
- **D760 Langerhans' histiocytosis, not elsewhere classified [Langerhans' cell histiocytosis, disseminated 9754/3]**

* All causes of death coded to ICD10 code D46.9 are reportable except myelodysplasia NOS.
** All causes of death coded to ICD10 code D47.1 are reportable except myelofibrosis NOS and myeloproliferative disease unspecified. (Effective with cases diagnosed in January 2010 and after, myeloproliferative disease unspecified is a reportable condition.)

When a cause of death on a mortality record is coded to an ICD-10 code that includes both reportable and non-reportable conditions (e.g., D46.9 and D47.1), the mortality record must be included as a potential incidence case.

When a cause of death on a mortality record is coded to C449, skin cancer, the mortality record must be included as a potential incidence case to verify the histology.

Appendix D: Casefinding Codes for Death Clearance provides a complete list and description of ICD-10 codes required to identify reportable conditions. Additional ICD-10 codes may be used by the registry for casefinding if found to identify reportable conditions. If additional conditions are reportable by agreement for the registry, these diagnoses should also be included for follow-back.

4.2.1.4 Residents of the Registry Catchment Area

Resident deaths occurring in the registry catchment area must be included as potential incidence cases. Records of residents of the registry catchment area who expire in another catchment area must be included unless the registry is prohibited from receiving them.

Mortality files often include deaths of non-residents (i.e., persons who were not residents of the state/territory/province in which they died). The decision to include these cases in the death clearance follow-back process is optional because they will not impact incidence rates or DCO percentage. However, registries should consider the following benefits when deciding whether or not to include deaths of non-residents in their death clearance follow-back process:

a. As patients may change residence between diagnosis and death, working with a file of resident deaths only may exclude patients who were resident at diagnosis but not at death. Follow-back on such cases is the only way to assure the patient was not a resident at diagnosis.

b. Linked death information on residents as well as non-residents can be provided back to registry hospital staff for cases reported by the facility.

c. Holding non-resident deaths in a suspense file may provide the opportunity to obtain additional information on the address at diagnosis from an audit or other source submitted at a later time.

d. Death information on non-residents may assist other registries in their death clearance follow-back.

4.2.1.5 Cancer Deaths

Cancer deaths include all death certificates containing a cause of death that is a reportable condition. The phrase "cancer deaths" is used for simplicity even though it actually refers to all reportable conditions including benign brain and CNS tumors and excluding conditions such as basal and squamous cell carcinomas of the skin. Because there may be more than one reportable condition listed on a death certificate, each cause must be evaluated individually to determine if it is reportable and if reportable, whether it is in the registry database.

Cancer deaths are identified as potential incidence cases from two aspects of the matching process:

a. **Patient Non-Matches:** Records included in the mortality file that are not in the registry database. Patient non-matches that contain a reportable cause of death are potential incidence cases and must be included in follow-back. Patient non-matches that do not contain a reportable cause of death are excluded from the death clearance follow-back process.

b. **Patient Matches:** Records included in the mortality file that are also in the registry database. If the records match at the patient level, this match does not mean that the diagnoses indicate the same reportable condition. Tumor comparison must be performed to determine if they are the same condition or different reportable conditions. This may be performed manually or by computer algorithm.

Guidelines for comparing reportable conditions on the mortality file with primaries in the registry database are provided in Section 3.4, Tumor Comparison.

4.3 Death Certificate Review

Death certificate review is the review of the causes of death and other information exactly as it is recorded on the death certificate rather than as it appears in coded form. This is accomplished by reviewing copies of actual death certificates, death certificates on microfiche, or electronic files from vital records processing procedures such as SuperMICAR files. The purpose of death certificate review is to provide additional information on potential incidence cases beyond what is coded and to prevent non-reportable cases from being added as DCO cases.

Reviewing death certificates is the only way that certain types of non-reportable cases can be eliminated. If the death certificate is not reviewed, the case will be incorrectly entered as a DCO. For example, if the underlying cause of death is incorrectly coded to cancer, the registry will identify this error during death certificate review and eliminate the case. However, if no death certificate review is performed and no information is obtained during follow-back, the certificate will be entered as a DCO.

There is a standard practice within vital records offices to "query" death record entries based upon standard record query rules issued by the NCHS. These query rules require follow-back on the cause of death in certain instances relative to malignancies and the clarification of abbreviated terms. It is important to note, however, that the information obtained through follow-back is rarely used to change the actual death certificate as filed. These data are available in the vital records office and, for SuperMicar states, may be readily available as text through their additional or "AI" SuperMicar export files. For example, most states will query a death record with a tumor of unspecified behavior but may not update the death certificate with the findings as it has little legal significance. The key in these situations is that AI information will cause the death certificate coding to disagree with the medical section on the death record as originally filed. Any deaths that appear miscoded should be referred to the vital record office for clarification.

When reviewing death certificates, be aware of the following information taken from the *NCHS Instruction Manual:*

a. **Abbreviation Ca, CA:** This abbreviation on a death certificate must be interpreted according to the NCHS as defined in the *NCHS Instruction Manual*, Appendix D, Standard Abbreviations and Symbols. "Ca" is an abbreviation meaning cancer; "CA" is an abbreviation meaning cancer, cardiac arrest, or carotid arteriogram. Because "CA" represents numerous life-threatening conditions, the abbreviation should not be interpreted as specific to cancer without further query.

b. **History of:** Causes of death with "history of" are coded as though the term "history of" is not present. Instructions for coding causes of death prefaced with "history of" are provided in Part 2b, Instructions for Classifying the Multiple Causes of Death, 2008, Section II, Part E of the *NCHS Instruction Manual.*

Death certificate review should be conducted on all potential incidence cases either prior to follow-back or after all follow-back efforts have been completed but before entering the case as a DCO.

Performing this review prior to follow-back eliminates unnecessary requests for additional information. Performing it after follow-back reduces the number of death certificates to be reviewed to only those cases where no or insufficient follow-back is received.

Death certificate review is strongly recommended but is not considered a minimum requirement. It may not be possible to conduct death certificate review due to reasons such as the registry being denied access to death certificates by vital records office policy or state/territory/province law, or the registry lacking the staff/resources to conduct such a review. For these reasons, death certificate review is not a requirement in the death clearance follow-back process. Because it eliminates non-reportable cases and provides additional information that is not available in an electronic mortality file, registries should strive to incorporate death certificate review into death clearance follow-back procedures whenever possible.

Although not a requirement, when death certificate review is conducted, the following minimum requirements regarding types of cases to be excluded and included for follow-back based on review of the death certificate must be applied.

4.3.1 <u>Death Certificates Excluded Based on Death Certificate Review</u>: When death certificates are reviewed, the following types of cases may be excluded as potential incidence cases without follow-back. If a diagnosis is not described in this section, the death certificate must be included for follow-back.

Note: The phrase "may be excluded" is used to provide the option to follow-back if deemed necessary.

4.3.1.1 <u>Coding Error</u>: When the cause of death documented on the death certificate is miscoded as a reportable condition, the death certificate may be excluded without follow-back.

The death certificate is excluded because the cause of death documented on the death certificate was incorrectly coded to a reportable condition and there is no reportable diagnosis documented on the death certificate.

Example: A diagnosis code of C50 (breast cancer) is in the mortality file. The death certificate is reviewed, and there is no diagnosis of breast cancer or any other reportable condition on the certificate. The death certificate may be excluded.

4.3.1.2 <u>Non-Reportable Condition</u>: When the condition on the death certificate is not reportable based on the registry list of reportable conditions, the death certificate may be excluded without follow-back.

Exception: When skin cancer is documented as a cause of death on the death certificate, the mortality record must be followed back to obtain information from a clinical source or medical record to confirm the histology.

The death certificate is excluded because the cause of death diagnosis is not included on the registry reportable list. Follow-back must be conducted when the condition might be reportable if additional information is obtained.

Examples: A death certificate with a diagnosis documented as basal or squamous cell carcinoma of the skin may be excluded. Diagnoses documented as myeloproliferative disease NOS or anemia NOS on the death certificate may be excluded.

4.3.1.3 <u>Tumor or Neoplasm</u>: When the diagnosis on the death certificate is documented as tumor or neoplasm with no reference to being malignant, the death certificate may be excluded without follow-back.

Exception: A diagnosis of brain or CNS tumor or neoplasm on a death certificate for a death occurring on or after January 1, 2004, must be included for follow-back because the condition is reportable whether benign or malignant.

Although this minimum requirement permits eliminating these cases based solely on death certificate review, it is strongly recommended that each registry conduct follow-back on these cases at least once as a study to determine if their results confirm these cases to be non-reportable after additional information is obtained. The study results should be used to describe registry-specific experience and dictate whether follow-back should or should not be conducted routinely for these cases.

Examples: A death certificate with a diagnosis documented as liver neoplasm or pancreatic tumor may be eliminated during death certificate review. A diagnosis of brain tumor or CNS neoplasm documented on the death certificate must be followed back for additional information.

4.3.1.4 <u>Non-Reportable Ambiguous Terminology</u>: When the diagnosis documented on the death certificate includes ambiguous terminology not considered diagnostic of cancer, the death certificate may be excluded without follow-back.

See *NAACCR Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary, Chapter III: Standards for Tumor Inclusion and Reportability* for list of Ambiguous Terminology Not Considered as Diagnostic of Cancer.

Examples: A death certificate with a diagnosis documented as possible pancreatic cancer may be eliminated during death certificate review. A death certificate with a diagnosis documented as suggestive of ovarian cancer may be eliminated during death certificate review.

Because medical practitioners are not aware of the significance of the ambiguous terms relative to their impact on reportability, it is strongly recommended that each registry conduct follow-back on death certificate diagnoses with non-reportable ambiguous terms at least once as a study to determine if their results confirm these cases to be non-reportable after additional information is obtained. The study results should be used to describe registry-specific experience and dictate whether follow-back should be conducted routinely for these cases.

4.3.1.5 <u>Diagnosed Prior to Being Reportable</u>: When the diagnosis on the death certificate was made prior to the registry reference date or prior to the date the condition became reportable based on information on the death certificate, the case may be excluded without follow-back.

Examples:

a. If the information on the death certificate provides 1990 as the year of diagnosis for a cancer diagnosis and the registry reference date is 1994, the case may be excluded without follow-back.

b. If the cause of death is a benign brain tumor with information on the death certificate that provides a diagnosis date prior to 2004, the case is not reportable and may be eliminated without follow-back if the registry did not collect benign brain tumor diagnoses prior to 2004.

c. If the cause of death is polycythemia vera with information on the death certificate that provides a diagnosis date prior to 2001, the case is not reportable and may be eliminated without follow-back if the registry did not collect this diagnosis prior to 2001.

4.3.1.6 <u>Non-Resident</u>: When the death certificate provides information to establish decedent was not a resident of the registry catchment area at the time of diagnosis, the death certificate may be excluded.

Death certificates of non-residents may be included for follow-back and entered into the registry if the registry finds it beneficial to do so. Refer to Section 4.2.1.4 Residents of the Registry Catchment Area, for benefits of including death certificates for non-residents.

4.3.2 <u>Death Certificates Included for Follow-Back Based on Death Certificate Review</u>: When death certificates are reviewed, the following types of cases must be followed back to obtain information from a clinical source or medical record before a final determination can be made.

4.3.2.1 <u>Reportable Condition</u>: When the diagnosis documented on the death certificate is a reportable condition and does not meet any of the criteria for exclusion as specified in Section 4.3.1, follow-back must be conducted to obtain information from a clinical source or medical record before determining final disposition.

Exception: When skin cancer is documented as a cause of death on the death certificate, the mortality record must be followed back to obtain information from a clinical source or medical record to confirm the histology.

Examples: A death certificate with a diagnosis of breast cancer 2 years ago must be included for follow-back as a potential incidence case. A death certificate with a diagnosis of leukemia with no information to estimate a diagnosis date must be included for follow-back as a potential incidence case.

<u>CA or Ca (Excluding Skin CA)</u>: Both CA or Ca coded to cancer with or without mention of a primary site are considered reportable conditions and require follow-back. According to the *NCHS Instruction Manual*, "Ca" is interpreted as cancer and "CA" as cancer, cardiac arrest, or carotid arteriogram. Because "CA" represents numerous life-threatening conditions, registry staff should find out from their vital records office how "CA" in the absence of any primary site is coded. Some vital records offices (but not all) assign a cancer code only after a physician query confirms the diagnosis as cancer. When a query is made to confirm the diagnosis, many vital records offices document the confirmation. Registry staff should be aware of such a policy and have access to the query information. If "CA" is confirmed by the vital records office to be cancer, the case requires follow-back. If no query is performed by the vital records office, the case is potentially reportable and must be included for follow-back to obtain additional information to confirm or reject the cancer diagnosis.

4.3.2.2 <u>Reportable Ambiguous Terminology</u>: When the diagnosis documented on the death certificate includes ambiguous terminology considered diagnostic of cancer, the death certificate must be included for follow-back as a potential incidence case.

See *NAACCR Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary, Chapter III: Standards for Tumor Inclusion and Reportability* for list of Ambiguous Terminology Considered as Diagnostic of Cancer.

Examples: A death certificate with a diagnosis documented as probable pancreatic cancer must be included for follow-back. A death certificate with a diagnosis documented as suspected ovarian cancer must be included for follow-back because these terms are included on the list of reportable ambiguous terms.

4.3.2.3 <u>History of</u>: When the diagnosis documented on the death certificate includes the term "history of," follow-back must be conducted before determining final disposition.

Because medical practitioners vary in their use of the phrase "history of," any reportable condition that includes the term "history of" requires follow-back before determining final disposition.

Example: A death certificate with a diagnosis documented as history of prostate cancer must be included for follow-back.

4.3.2.4 <u>When in Doubt</u>: When uncertain whether to include or exclude a death certificate based on the diagnosis documented on the death certificate, default to including the case for follow-back.

4.4 Follow-Back on Potential Incidence Cases

Follow-back is the process of actively searching for additional information from a clinical source or medical record such as hospitals, certifying physicians, nursing homes, other health care practitioners and facilities to determine if the case meets registry reporting requirements and to provide additional information on established cases.

Information from a clinical source or medical record obtained from death clearance follow-back is used to:

a. Identify an incidence case to be added to the registry

b. Identify additional primaries to be added to existing records in the registry

c. Identify non-reportable cases coded to a reportable condition on the mortality file

d. Resolve discrepancies in data elements, such as primary site and histology

e. Confirm diagnoses for registry cases not microscopically confirmed or with ambiguous terminology.

The following section describes minimum requirements for follow-back. Establishing consistency in follow-back among registries is a critical step in assuring comparable outcome from the death clearance follow-back process.

4.4.1 <u>Cases Requiring Follow-Back</u>: All potential incidence cases require follow-back to determine if they can be taken out of DCO status. Potential incidence cases include:

4.4.1.1 All potential incidence cases not eliminated by death certificate review according to minimum requirements in Section 4.3, Death Certificate Review.

4.4.1.2 All potential incidence cases (as described in Section 4.2) when death certificate review is not performed or not performed prior to follow-back.

If a registry elects not to conduct follow-back for a potential incidence case, the final disposition is determined using minimum requirements specified in Section 4.6.2, No or Insufficient Follow-Back Information Received.

Example: The cause of death on a death certificate is breast cancer with no diagnosis date information on the death certificate. The place of death was a skilled nursing facility that never provided useful information when follow-back was requested in the past. The registry elects not to conduct any follow-back on this case. The registry must enter the case as a DCO because the cause of death is reportable and there is no date of diagnosis on the death certificate to indicate diagnosis prior to registry reference date.

4.4.2 <u>Follow-Back Source</u>: When follow-back is performed, the information to determine if a potential incidence case can be taken out of DCO status must be provided by at least one clinical source or medical record.

At Least One Source: Follow-back information to confirm a diagnosis and provide additional information to use in abstracting a case must come from at least one clinical source or medical record for the case to be taken out of DCO status. Because information provided from follow-back is used to abstract an incidence case, the information must be from a clinical source or medical record so that incidence cases (cases not entered as DCOs) added from the death clearance follow-back process have the same medical validity as incidence cases entered routinely from reporting facilities.

Multiple Sources: To the extent that time, resources, and policy permit, follow-back to more than one clinical source or medical record is encouraged to obtain the most complete and accurate information regarding the reportable case

Follow-back information from a clinical source or medical record may be obtained from:

a. Medical facility where the death occurred, such as a hospital or nursing home.

b. Physician who signed the death certificate, or family physician if listed, when death occurs at home.

    1. Non-physician Coroner: When the only follow-back source initially available is a non-physician coroner who signed the death certificate, the follow-back query may request the name of a physician or hospital where additional information may be obtained. Follow-back information used to confirm a diagnosis and/or provide information to abstract a case must be from a clinical source or medical record.

c. A clinical source or medical record identified from another follow-back source (e.g., a follow-back query to a physician may reveal the name of the hospital where diagnosis and/or treatment occurred). Additional information may be obtained from the hospital.

d. Another registry through a case-sharing agreement when residents expire outside of the catchment area.

e. A medical facility(ies) that reported another primary to the registry for the same patient. Hospital cancer registries that perform lifetime follow-up may have diagnostic or follow-up information on the reportable condition listed on the death certificate.

Requests to follow-back sources for additional information should include:

a. A cover letter explaining the DCO process, the information being requested, and the provisions, such as reporting law or statute, to cover the release of information to the registry

b. Report form or electronic abstract or link containing data from the death certificate already entered

c. Method for the follow-back source to provide the following information:

    1. Confirmation of the diagnosis by a recognized medical practitioner

    2. Exact or estimated date of diagnosis (*Note*: Requests for diagnosis date should encourage follow-back sources to provide a general approximation if the exact date is not known [e.g., approximately 2 months, 3 years ago, more than 5 years, etc.])

    3. Place where the diagnosis was made (*Note*: Space should be provided for facility name, physician name, date admitted, date discharged, etc.)

    4. State/territory/province of residence at diagnosis

    5. Name of a physician or facility that may provide additional information

    6. Confirmation of information already known from the death certificate as well as additional information to complete other registry data items

    7. Treatment (*Note*: Provide an area or space on the form or abstract for surgery [type and date], radiotherapy [external or internal and date], chemotherapy [type and date], hormones [type and date], and other treatment [type and date])

    8. Stage at diagnosis.

d. Copy of the death certificate if permitted by the vital records office.

No or Limited Follow-back Information: Even though a registry conducts follow-back, the registry may receive no or limited information from the follow-back source. Reasons may include:

a. Follow-back source responded but did not provide enough information to resolve the case(s).

b. Follow-back source was contacted, but no response was received.

c. Follow-back source was contacted, but medical record was not available or there was no record of the patient.

d. Follow-back source could not be contacted due to invalid, illegible, or missing facility or physician name or identification number; no current address could be found; physician had retired or facility had closed and records could not be obtained; or resident expired in another state/territory/province and the registry had no access to follow-back information.

e. No follow-back attempt was made because the follow-back source does not provide useful information and the registry elected not to invest the time.

f. No follow-back attempt was made due to law or regulations prohibiting contact.

g. No follow-back attempt was made due to insufficient registry resources or staff.

4.5 Interpreting Death Clearance Follow-Back Information

Consistency among registries in interpreting follow-back information is another critical step in assuring comparable outcomes from the death clearance follow-back process. The goal of following back on potential incidence cases is to determine if the case is reportable, and if it is reportable, to use information from a clinical source or medical record to complete as many fields as possible when abstracting the case.

Because complete information is not always available, the following minimum requirements define the least amount of information that must be obtained to take a case out of DCO status. When interpreting information in the death clearance follow-back procedure, the determining factor for a case to be abstracted as a DCO is not whether the death certificate contains information to estimate the diagnosis date but whether or not the death certificate is the only source of information to abstract the case.

4.5.1 <u>Sufficient Follow-Back</u>: Information received from follow-back is considered sufficient to take a case out of DCO status when, at a minimum, the information from a clinical source or medical record provides both confirmation of the diagnosis by a medical practitioner and the exact or estimated diagnosis date.

If both confirmation of a reportable diagnosis and diagnosis date as described below are obtained, the case is abstracted as a missed incidence case. If neither is obtained, the final disposition is determined using minimum requirements specified in Section 4.6.2, No or Insufficient Follow-Back Information Received.

If follow-back information confirms the diagnosis but does not provide a diagnosis date, a diagnosis date provided on the death certificate can be used to satisfy the diagnosis date requirement.

Although residence at diagnosis is important to ascertain through follow-back, a case may be taken out of DCO status without it. In its absence, address at death should be used as the address at diagnosis.

4.5.1.1 <u>Confirmation of Diagnosis</u>: Confirmation of a diagnosis means that the diagnosis was made by a recognized medical practitioner and is supported by information from a clinical source or medical record.

The physician may be the same physician who signed the death certificate or another physician identified through follow-back. Confirmation of the diagnosis may not be provided by a non-physician coroner unless documentation from a clinical source or medical record is provided.

If the follow-back source has no knowledge of the person having the condition, the diagnosis is considered unconfirmed unless additional follow-back confirms the diagnosis.

4.5.1.2 <u>Diagnosis Date</u>: Information is provided from a follow-back source or the death certificate to establish the exact or estimated date of diagnosis.

Apply the following minimum requirements when determining a diagnosis date:

4.5.1.2.1 <u>Exact Date</u>: Use information provided from follow-back or death certificate to determine an exact date of diagnosis.

4.5.1.2.2 <u>Estimated Date of Diagnosis</u>: If an exact date of diagnosis is not available, the date may be estimated from information provided by the follow-back source(s) and/or the death certificate according to the following instructions. Use the following table to estimate date of diagnosis when described vaguely as:

Term	Estimate As:
Spring of	April
Summer	July
Middle of year	July
Fall or autumn	October
Winter	Try to determine whether reference is to first of year (interpret as January) or end of year (December). If part of year cannot be determined, interpret as January.
Early in year	January
Late in year	December
Recently	Use month and year of death and unknown for day. If death occurred during the first week of a month, enter the previous month.
A couple	Two • A couple days ago is two days prior to death. Use month, day, and year. • A couple weeks ago is two weeks prior to death. Use month and year with day of diagnosis unknown. • A couple of months ago is 2 months prior to death. Use month and year with day of diagnosis unknown. • A couple years ago is 2 years prior to death. Use month and year with day of diagnosis unknown.

Term	Estimate As:
A few	Three • A few days ago is 3 days prior to death. Use month, day, and year. • A few weeks ago is 3 weeks prior to death. Use month and year with day of diagnosis unknown. • A few of months ago is 3 months prior to death. Use month and year with day of diagnosis unknown. • A few years ago is 3 years prior to death. Use month and year with day of diagnosis unknown.
Several	Four • Several days ago is 4 days prior to death. Use month, day, and year. • Several weeks ago is 4 weeks prior to death. Use month and year with day of diagnosis unknown. • Several months ago is 4 months prior to death. Use month and year with day of diagnosis unknown. • Several years ago is 4 years prior to death. Use month and year with day of diagnosis unknown.
Range of weeks, months, or years ago	Take the middle of the range (e.g., 2 to 4 months ago is 3 months from the date death, with day of diagnosis unknown).

When information is available to calculate the month and/or year of diagnosis, use the information to calculate as much of the diagnosis date as possible with day of diagnosis unknown.

Example 1: Follow-back information or death certificate state diagnosed 7 years ago. Subtract 7 from the year of death. Use calculated year, use month of death for month of diagnosis, with day of diagnosis unknown.

Example 2: Follow-back information or death certificate state diagnosed 6 months ago. Subtract 6 months from date of death. Use calculated month and year, with day of diagnosis unknown.

Example 3: Follow-back provides information on a particular admission (e.g., admitted October 2007). History states diagnosed 7 months ago. Subtract 7 from the month of admission. Use calculated month and year, with day of diagnosis unknown.

Example 4: Follow-back provides information on an outpatient bone scan performed in January 2007 that states history of prostate cancer. The physician says the patient was diagnosed in 2007. Assume bone scan was part of initial work-up. Use the month and year of the bone scan, with day of diagnosis unknown.

Example 5: Follow-back provides information regarding the patient's diagnosis from a particular admission to the facility. No diagnosis date is provided but the information specifies an admission date. Use the month and year of admission with day of diagnosis unknown.

Registries may elect to implement a stricter version of this minimum requirement by including more information from follow-back than confirmation of the diagnosis by a recognized medical practitioner and diagnosis date to take a case out of DCO status. If so, the registry must include documentation of the additional required information and must apply the stricter rule consistently to all cases.

Registries must also determine procedures to address situations in which some but not all of the required information is received. If the follow-back information is not considered sufficient by the stricter requirement, the case cannot be taken out of DCO status and must be abstracted as a DCO. If some but not all of the information requirements are met under the stricter requirement, the registry must determine how the information received will be used (see Section 4.5.2). After these decisions are made, the registry should assess the impact on the DCO percentage and other aspects of the death clearance follow-back process.

4.5.2 <u>Insufficient Follow-Back Information</u>: Information received from follow-back is considered insufficient to take a case out of DCO status when at a minimum the information from a clinical source or medical record does not provide both confirmation of a reportable diagnosis by a medical practitioner and the exact or estimated diagnosis date.

Exception: If follow-back information confirms the diagnosis but does not provide a diagnosis date, a diagnosis date on the death certificate can be used to satisfy the diagnosis date requirement.

Note: If the diagnosis cannot be confirmed from follow-back but the date of diagnosis is available from information on the death certificate, follow-back information is considered insufficient. Final disposition is determined using minimum requirements specified in Section 4.6.2, No or Insufficient Follow-Back Information Received.

4.5.2.1 <u>Date Too Vague</u>: When the information provided from a follow-back source or from the death certificate is too vague to estimate a diagnosis date using 4.5.1.2.2, the diagnosis date must be considered unknown. The date of diagnosis is defaulted to the date of death.

Final disposition is determined using minimum requirements specified in Section 4.6.2, No or Insufficient Follow-Back Information Received.

4.5.2.2 <u>Unknown Diagnosis Date</u>: The date of diagnosis cannot be entered as unknown on any case included in the registry database from the death certificate follow-back process. When the diagnosis date cannot be estimated from information provided on the death certificate or from a follow-back source, the date of diagnosis is defaulted to the date of death.

Final disposition is determined using minimum requirements specified in Section 4.6.2, No or Insufficient Follow-Back Information Received.

The purpose of entering cases from the death certificate follow-back process is to assign previously unreported cases to an incidence year so that they can be counted. When no diagnosis date is available, the case must be considered a DCO and the date of death is entered as the diagnosis date. The date of death is used as an arbitrary designation or default for diagnosis date to enable the case to be assigned to an incidence year.

4.5.3 Final Authority

4.5.3.1 <u>Death Certificate Review Versus Information From Follow-Back</u>: When there is a discrepancy between information on the death certificate and information provided from follow-back to a clinical source or medical record, the registry should default to the information provided from follow-back as the final authority.

Exception: If the registry determines information from the death certificate is more accurate, then the registry should use the information from the death certificate.

Before defaulting to the diagnosis provided by the follow-back source, a determination must be made that the death certificate and follow-back source are referring to the same primary. It is possible that the follow-back source provided information on a different primary. If so, this new primary must also be entered.

4.5.3.2 <u>Death Certificate Versus Mortality File</u>: When there is a discrepancy between information on the death certificate and the coded mortality file, the registry should default to the information obtained during death certificate review.

4.6 Final Disposition of Potential Incidence Cases

Consistent application of minimum requirements is needed to achieve comparability of the results in the death clearance follow-back process. Final disposition of potential incidence cases from the process results in one of three results: (1) missed incidence case, (2) DCO, or (3) exclusion as non-reportable. If multiple reportable conditions appear on the same death certificate, each condition must be resolved individually. It is possible for one death certificate to result in more than one DCO or any combination of the above three results.

Determining final disposition of potential incidence cases is based on whether or not sufficient information was received from follow-back source(s) as described in Section 4.5. Potential incidence cases can be divided into the following categories after follow-back procedures are complete. The minimum requirements included in this section must be used to determine final case disposition.

a. **Sufficient Follow-Back Information Received:** If sufficient follow-back information is received, then Section 4.6.1 is applied to determine final disposition. The final disposition of cases in this category is either missed incidence case or exclusion as non-reportable.

b. **No or Insufficient Follow-Back Information Received:** If no or insufficient follow-back information is received, then Section 4.6.2 is applied to determine final disposition. The category includes cases for which no follow-back attempt was made. Final disposition is either DCO or exclusion as non-reportable.

4.6.1 <u>Sufficient Follow-Back Information Received</u>: When sufficient information is received from follow-back according to Section 4.5.1 above, the following minimum requirements are used to determine final disposition of the case.

The reference to “reportable condition” below means that the diagnosis is reportable according to registry-specific policies and the List of Reportable Conditions.

4.6.1.1 <u>No Documentation of the Condition</u>: When follow-back information is received and a clinical source or medical record has no documentation of the reportable condition, the case is excluded.

4.6.1.2 <u>Non-Reportable Condition</u>: When sufficient follow-back information is received that the confirmed diagnosis is not a reportable condition, the case is excluded.

4.6.1.3 <u>Diagnosed Prior</u>: When sufficient follow-back information is received and the diagnosis date provided from follow-back is prior to the registry reference date or prior to the condition being reportable, the case is excluded.

4.6.1.4 <u>Non-Resident</u>: When sufficient follow-back information is received and the information indicates that the person was not a resident of the registry catchment area at diagnosis, the case may be abstracted or excluded.

The registry may choose to abstract as a missed case to assist in responding to follow-back queries from other registries or in case-sharing agreements.

4.6.1.5 <u>Reportable Condition</u>: When sufficient follow-back information is received and the confirmed diagnosis is a reportable condition with a date of diagnosis after the registry reference date or after the condition became reportable, the case is entered as a missed incidence case using the diagnosis date provided from follow-back.

The reference to "reportable condition" means that the diagnosis is reportable according to registry-specific policies and list of reportable conditions.

4.6.1.6 <u>Vague Diagnoses</u>: When sufficient follow-back information is received, process cases with vague diagnoses according to the following minimum requirements:

4.6.1.6.1 <u>Tumor or Neoplasm (Except Brain)</u>: When sufficient follow-back information is received and the confirmed diagnosis is a tumor or neoplasm, interpret the behavior as uncertain whether benign or malignant (/1) and apply registry reporting requirements. If reportable, then the case is entered as a missed incidence case using the diagnosis date provided from follow-back; if not reportable, then the case is excluded.

Example: If the cause of death is confirmed as pancreatic tumor and pancreatic tumors with a behavior of /1 (uncertain whether benign or malignant) are not required to be reported to the registry, the case is excluded.

4.6.1.6.2 <u>Brain Tumor</u>: When sufficient follow-back information is received and the confirmed diagnosis is a brain tumor, interpret the behavior as uncertain whether benign or malignant (/1). If the diagnosis date is 2004 or after, enter as a missed incidence case using the diagnosis date provided from follow-back; if diagnosed before 2004, exclude the case unless it is reportable to the registry prior to 2004.

4.6.1.6.3 <u>CA or Ca (excluding Skin CA)</u>: When sufficient follow-back information is received and the confirmed diagnosis is cancer stated "Ca" or "CA," interpret the abbreviations to mean cancer (8000/3), not carcinoma (8010/3), and code primary site as specified. If the primary site is not provided, then code the primary site to unknown (C809). These cases are entered as missed incidence cases using the diagnosis date provided from follow-back.

4.6.1.6.4 <u>Skin Cancer or Skin CA</u>: When sufficient follow-back information is received and the confirmed diagnosis is a skin cancer with no other information available, interpret the histology as cancer (8000/3). The case is excluded unless it is reportable according to registry reporting requirements. If it is reportable, then the case is entered as a missed incidence case using the diagnosis date provided from follow-back.

4.6.1.6.5 <u>Unknown Primary</u>: When sufficient follow-back information is received and the confirmed diagnosis is stated as unknown primary with no other information available, code unknown primary site. The case is entered as a missed incidence case with an unknown primary site using the diagnosis date provided from follow-back.

4.6.1.6.6 <u>Ambiguous Terminology</u>: When sufficient follow-back information is received and the diagnosis includes an ambiguous term, final disposition is based on whether or not the term is considered diagnostic of cancer.

See *NAACCR Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary, Chapter III: Standards for Tumor Inclusion and Reportability* for the list of Ambiguous Terminology Considered as Diagnostic of Cancer and the list of Ambiguous Terminology NOT Considered Diagnostic of Cancer by standard-setting organization.

4.6.1.6.6a <u>Ambiguous Term on List Considered Diagnostic</u>: When sufficient follow-back information is received and the diagnosis includes an ambiguous term on the list of Ambiguous Terminology Considered Diagnostic of Cancer, the case is reportable and entered as a missed incidence case using the diagnosis date provided from follow-back.

4.6.1.6.6b <u>Ambiguous Term on List Not Considered Diagnostic</u>: When sufficient follow-back information is received and the diagnosis includes an ambiguous term on the list of Ambiguous Terminology NOT Considered as Diagnostic of Cancer, the case is not reportable and excluded.

Note: The final disposition is based on the diagnosis from the follow-back source unless the registry determines that information from the death certificate is more accurate. The case is entered as a missed incidence case.

4.6.1.6.6c <u>Ambiguous Term not on Either List</u>: When sufficient follow-back information is received and the diagnosis includes an ambiguous term not included on either list of ambiguous terminology, consider the term not diagnostic of cancer. The case is excluded.

4.6.1.6.7 History of: When sufficient information is received from follow-back and the phrase "history of" is included in the confirmed diagnosis, the case is reportable and entered as a missed incidence case using the diagnosis date provided from follow-back.

4.6.2 No or Insufficient Follow-Back Information Received: When no follow-back information is received or when follow-back sources responded but were unable to provide sufficient information according to Section 4.5.1, the following minimum requirements are used to determine the final disposition of the case.

No or insufficient follow-back information may be due to many reasons (e.g., no follow-back attempted by the registry due to staffing, financial, or regulatory constraints; no follow-back source was identified; no response was received; source had no knowledge of the patient; source had no information to provide; source was never able to provide useful information; source could provide only confirmation of the diagnosis but no diagnosis date). For cases in this category, the registry relies on information obtained during death certificate review to determine the outcome.

If confirmation of a reportable diagnosis is received from follow-back but there is no diagnosis date, the case does not have sufficient follow-back information and must be abstracted as a DCO case. The information from follow-back that confirmed the diagnosis should be added to the text fields of the abstract.

4.6.2.1 Reportable Condition: When no or insufficient follow-back information is received and the cause of death on the death certificate represents a reportable condition, the case is a DCO. because the death certificate is the only source of information available to abstract the case.

* *Important Clarification:* This represents a change from abstracting practices documented in *Series V: Resolving Death Clearance Issues 2002*, developed by the NAACCR Death Clearance Best Practices Work Group. In that document, a case was considered an MDO if the death certificate contained sufficient information to determine or estimate a date of diagnosis and the death certificate was signed by a medical practitioner. This type of case must be entered as a DCO because the death certificate is the only source of information available to abstract the case.

4.6.2.1.1 Date of Diagnosis: The date of diagnosis for a DCO is entered according to the following:

4.6.2.1.1a Estimated Date of Diagnosis: When there is information on the death certificate to estimate a date of diagnosis, the estimated date is entered as the date of diagnosis for the DCO.

This is another change in DCO practices designed to utilize the information provided on the death certificate while still preserving the definition of a DCO.

4.6.2.1.1b Date of Death: When there is no information on the death certificate to estimate a diagnosis date, the date of death is entered as the date of diagnosis for the DCO.

4.6.2.2 <u>Non-Reportable Condition</u>: When no or insufficient follow-back information is received and the cause of death as stated on the death certificate is not reportable, the case is excluded.

The reference to "reportable condition" means that the diagnosis is reportable according to registry-specific policies and the list of reportable conditions.

If death certificate review was performed before follow-back, all non-reportable causes of death may have been excluded during this review; however, if the registry followed-back on a non-reportable cause of death for further clarification and received no or insufficient follow-back information, the case can be excluded. If death certificate review is deferred until after follow-back, non-reportable cases should be excluded at this point. See the introduction to Section 4.3.

If the diagnosis is confirmed from follow-back as not reportable, the case is excluded based on the follow-back diagnosis.

4.6.2.3 <u>Vague Diagnoses</u>: When no or insufficient follow-back information is received, vague diagnoses provided by death certificate review are interpreted according to the following minimum requirements:

4.6.2.3.1 <u>Tumor or Neoplasm (Except Brain)</u>: When no or insufficient follow-back information is received and the diagnosis on the death certificate states tumor or neoplasm, interpret the behavior as uncertain whether benign or malignant (/1) and apply registry reporting requirements. If it is reportable, the case is a DCO; refer to Section 4.6.2.1.1 for date of diagnosis. If it is not reportable, the case is excluded.

Example: If the cause of death is a pancreatic tumor and non-malignant pancreatic tumors are not required to be reported to the registry, the case is excluded.

4.6.2.3.2 <u>Brain Tumor</u>: When no or insufficient follow-back information is received and the diagnosis on the death certificate states brain tumor, interpret the behavior as uncertain whether benign or malignant (/1) and apply registry reporting requirements. If the diagnosis date can be estimated from information on the death certificate and is reportable to the registry, enter it as a DCO; if the estimated diagnosis date is prior to being reportable, the case is excluded. If the diagnosis date is unknown, the case is a DCO with date of death entered as the date of diagnosis (provided the date of death is 2004 or later).

4.6.2.3.3 <u>CA (Excluding Skin CA)</u>: Because the *NCHS Instruction Manual* interprets "Ca" as cancer and "CA" as cancer, cardiac arrest, or carotid arteriogram, when no or insufficient follow-back information is received and the diagnosis on the death certificate is "CA":

4.6.2.3.3a <u>Associated With a Primary Site (Except Skin)</u>: Interpret abbreviation as cancer (8000/3) not carcinoma (8010/3) and code primary site as specified. The case is a DCO; refer to Section 4.6.2.1.1 for date of diagnosis.

4.6.2.3.3b <u>With No Reference to Primary Site</u>: Do not interpret as cancer unless documentation on or associated with the death certificate supports a cancer diagnosis (even if it is coded to cancer). If confirmed as cancer by the vital records office documentation, the case is a DCO. Refer to Section 4.6.2.1.1 for date of diagnosis. If not confirmed as cancer by the vital records office, the case is excluded.

4.6.2.3.4 <u>Skin Cancer or Skin CA</u>: When no or insufficient follow-back information is received and the diagnosis on the death certificate states skin cancer with no other information available, interpret the histology as cancer (8000/3). The case is excluded unless reportable according to registry reporting requirements. If reportable, the case is entered as a DCO; refer to Section 4.6.2.1.1 for date of diagnosis.

4.6.2.3.5 <u>Unknown Primary</u>: When no or insufficient follow-back information is received and the diagnosis on the death certificate states unknown primary with no other information available, code to unknown primary site (C809). The case is entered as a DCO; refer to Section 4.6.2.1.1 for date of diagnosis.

4.6.2.3.6 <u>Ambiguous Terminology</u>: When no or insufficient follow-back information is received and the diagnosis on the death certificate includes an ambiguous term, final disposition is based on whether or not the term is considered diagnostic of cancer.

See *NAACCR Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary, Chapter III: Standards for Tumor Inclusion and Reportability* for the list of Ambiguous Terminology Considered as Diagnostic of Cancer and the list of Ambiguous Terminology NOT Considered Diagnostic of Cancer by standard-setting organization.

4.6.2.3.6a <u>Ambiguous Term on List Considered Diagnostic</u>: When no or insufficient follow-back information is received and the diagnosis on the death certificate includes an ambiguous term on the list of Ambiguous Terminology Considered Diagnostic of Cancer, the case is reportable and entered as a DCO; refer to Section 4.6.2.1.1 for date of diagnosis.

4.6.2.3.6b <u>Ambiguous Term on List Not Considered Diagnostic</u>: When no or insufficient follow-back information is received and the diagnosis on the death certificate includes an ambiguous term on the list of Ambiguous Terminology NOT Considered as Diagnostic of Cancer, the case is not reportable and excluded.

4.6.2.3.6c <u>Ambiguous Term not on Either List</u>: When no or insufficient follow-back information is received and the diagnosis on the death certificate includes an ambiguous term not included on either list of ambiguous terminology, consider the term not diagnostic of cancer. The case is excluded.

4.6.2.3.7 <u>History of</u>: When no or insufficient follow-back information is received for causes of death qualified by "history of," the final disposition is based on whether or not the malignancy is the underlying cause of death.

a. **Underlying Cause of Death:** The most accurate way to identify the underlying cause of death is to refer to the cause of death entered in the "Underlying Cause of Death" field in the mortality file. The selection of the underlying cause is based on the application of complex rules, causal relationships, and modification tables developed by the WHO and NCHS. Vital records offices apply these rules then records underlying cause in the appropriate field on the mortality file.

Although the underlying cause of death is designated as the first condition on the lowest used line in Part I of the death certificate, there are many circumstances in which the underlying cause would not be the condition recorded in this position. For example, there are categories for combinations of conditions, there are codes more suitable for expressing the underlying cause in tabulation, or there may be overriding epidemiological reasons for giving precedence to other conditions on the certificate that may be reported in Part II or somewhere other than the first condition on the lowest used line in Part I.

4.6.2.3.7a When no or insufficient follow-back information is received and the phrase "history of" is included in the underlying cause of death, the case is a DCO; refer to Section 4.6.2.1.1 for date of diagnosis.

According to the NCHS manual, *Instructions for Classifying the Multiple Causes of Death,* a cause of death that includes "history of" is coded as though not qualified by the term.

"History of" cases must be included in the registry database when determined to be the underlying cause of death because: (1) designation as the underlying cause of death by the vital records office implies this condition was not in the past but was the disease that initiated the chain of events leading directly to death, and (2) the underlying cause of death is used to calculate standard mortality statistics.

4.6.2.3.7b When no or insufficient follow-back information is received and the phrase "history of" is associated with a contributing cause of death, not the underlying cause of death, the case may be excluded.

When the "history of" diagnosis is not the underlying cause of death, the registry may choose to enter it as a DCO; refer to Section 4.6.2.1.1 for date of diagnosis.

4.6.2.3.8 When no or insufficient follow-back information is received, the ICD10 cause of death code contains a reportable and non-reportable condition (e.g. D46.9, D47.1), and death certificate review was not performed to identify the exact cause of death, the case is excluded.

4.7 Completion of Death Clearance Follow-Back

4.7.1 <u>Death Clearance Follow-Back Complete</u>: For the death clearance follow-back process to be complete for a specified year, both of the following conditions must be met:

4.7.1.1 All potential incidence cases must be resolved as a missed incidence case, DCO case, or excluded as non-reportable based on registry reporting requirements; and

4.7.1.2 All cases determined to be a missed incidence case or DCO case must be entered into the registry database.

4.7.2 <u>Follow-Back Response Not Received by Deadline</u>: If the follow-back source has not responded by the time the process must be completed, the case must be resolved as though no follow-back information was received.

If sufficient follow-back information is received after the death clearance follow-back process has been completed, the case may be changed from a DCO to a missed incidence case or excluded as non-reportable based on the information.

4.7.3 <u>Abstracts Not Received by Deadline</u>: If the case has been determined to be a missed incidence case but the abstract or information to abstract the case has not been received from the follow-back source, the case must be entered as a DCO case.

A case entered as a DCO case may be deleted or the record consolidated and the status changed if an abstract for the same patient and same primary is added to the registry database as a missed incidence case. This can occur for several reasons:

a. A match missed during the record linkage step is found

b. A case reported after the non-match status was determined

c. A case entered as a DCO case because the appropriate abstract or information to abstract the case had not been received from the follow-back source by the time the death certificate follow-back process had to be completed.

If the registry deletes the DCO record, the incident case abstract needs to be updated with information from the death certificate.

4.7.4 <u>Cases Not Entered Into Registry Database by Deadline</u>: If follow-back has been completed but the registry has not entered all reportable cases as either a DCO case or a missed case into the registry database, the death clearance follow-back process is not considered complete.

4.8 Abstracting Reportable Cases

Two types of reportable cases are identified from the death clearance follow-back process: (1) missed incidence cases, and (2) DCO cases. This section provides minimum requirements and guidelines to use in abstracting reportable cases.

4.8.1 <u>Abstracting Missed Incidence Cases</u>: After final disposition of all potential incidence cases has been determined, missed incidence cases must be abstracted and entered into the registry database using the appropriate version of the *NAACCR Standards for Cancer Registries, Vol. II: Data Standards and Data Dictionary* according to the following:

4.8.1.1 <u>Information from Follow-Back Source(s)</u>: Information from a clinical source or medical record received from follow-back should be the primary source for completing an abstract for a missed incidence case.

To be comparable to incidence cases routinely submitted by mandated reporting sources, the information must be obtained from a clinical source or medical record.

Exception: The death certificate is the primary source for death information entered in the fields specified in Section 4.8.1.2.

4.8.1.2 <u>Information From Death Certificate</u>: The death certificate is the primary source of information for completing the fields specified below on a missed incidence case.

NAACCR Data Item	NAACCR Item #	Comment
Date of Last Contact	1750	Enter date of death from mortality file
Vital Status	1760	Enter code 0 Dead (COC) or code 4 Dead (SEER)
Follow-Up Source Central	1791	See *NAACCR Standards for Cancer Registries, Volume II*
Cause of Death	1910	Enter underlying cause of death from mortality file
ICD Revision	1920	See *NAACCR Standards for Cancer Registries, Volume II*
Place of Death	1940	Enter state/territory/province of death from mortality file; convert to NAACCR standard codes if another coding system is used.
DC State File Number	2380	Enter death certificate file number from mortality file

<u>4.8.1.2.1 No Alteration of Underlying Cause of Death</u>: Underlying cause of death from the mortality file must not be altered even when registries have more complete or detailed information.

The Underlying Cause of Death field on the mortality file is intended to capture the official cause of death. Because this variable is important for record linkage purposes and has legal implications, the code must not be changed. Registries may choose to designate a registry-specific field to retain a cause of death code altered/corrected by the registry as a result of the death clearance process.

4.8.1.3 <u>Other</u>: Appropriate values must be entered for other required fields not provided from follow-back or from the death certificate.

Examples: NAACCR Record Version, Record Type, Date Case Completed.

To assist in the analysis of death clearance follow-back results, the following NAACCR data items and codes should be included in the abstract:

a. Casefinding Source [501] – code 80 Death Certificate (case identified through death clearance)

b. Type of Reporting Source [500] – code to reflect the type of facility providing the follow-back information.

4.8.1.4 <u>Unknown</u>: Appropriate values for unknown must be entered when information for required fields is not provided from follow-back, the death certificate, or cannot be entered as referenced in Other above.

Examples: Specific values referenced in Collaborative Stage (CS) fields, unknown values for treatment fields.

4.8.2 <u>Abstracting DCOs</u>: By definition, the only source of information to abstract a DCO is the death certificate. Cases determined to be DCO cases must be entered into the registry database using values for data items as specified in the instructions below:

4.8.2.1 <u>Death Certificate</u>: Data items pertaining to demographics, death, and cancer should be abstracted from the death certificate.

4.8.2.1.1 <u>Date of Diagnosis</u>: Enter the date of death.

Exception: A date other than the date of death may be used when interval or other information is provided on the death certificate to estimate the diagnosis date.

4.8.2.1.2 <u>No Alteration of Underlying Cause of Death</u>: Underlying cause of death from the mortality file must not be altered even when registries have more accurate, complete, or detailed information.

The Underlying Cause of Death field on the mortality file is intended to capture the official cause of death. Because this variable is important for record linkage purposes and has legal implications, the code must not be changed. Registries may choose to designate a registry-specific field to retain a cause of death code altered/corrected by the registry due to the death clearance process.

4.8.2.2 <u>NAACCR Standard</u>: Data item values for DCO cases as provided in the appropriate version of *NAACCR Standards for Cancer Registries, Vol. II: Data Standards and Data Dictionary* must be used in abstracting a DCO.

To assist in the analysis of death clearance follow-back results, the following NAACCR data items and codes should be included in the DCO abstract:

a. Casefinding Source [501] – code 80 Death Certificate (case identified through death clearance)

b. Type of Reporting Source [500] – code 7 Death Certificate Only.

4.8.2.3 <u>Collaborative Stage Manual</u>: Instructions for recording collaborative stage values for DCO cases are provided in the *Collaborative Staging Manual and Coding Instructions, Part 1, General Instructions, Death Certificate Only Cases.*

4.8.2.4 <u>Unknown</u>: When the death certificate does not provide applicable information and the *NAACCR Standards for Cancer Registries, Vol. II: Data Standards and Data Dictionary,* does not provide a specific DCO value, enter the most appropriate *Volume II* value for unknown for the data item.

Note: For the NAACCR field Reporting Facility [540], registries should assign a number to use for all DCO cases.

4.9 Death Certificate Only (DCO) Percentage

This section provides a detailed description of the formula used to calculate the DCO percentage, specific case inclusion requirements for each of the standard-setting organizations for the calculation, and DCO percentage requirements for each standard-setting organization.

4.9.1 Death Certificate Only (DCO) Percentage Calculation

The DCO percentage represents the percent of cases reported by death certificate only in a specified year. This percentage is used as a measure of completeness. Compliance with these minimum requirements will ensure consistent and comparable results and correct assumptions from analysis of DCO statistics.

4.9.1.1 <u>Complete Process According to Minimum Requirements</u>: To calculate the DCO percentage, registries must first complete the death clearance follow-back process according to the minimum requirements documented in Chapters 3 and 4.

4.9.1.2 <u>DCO Percentage Calculation</u>: The following formula must be used to calculate the DCO percentage.

$$\left(\frac{\textbf{Total \# of DCO cases for the Year}}{\textbf{Total \# of Incidence Cases* for the Year}} \right) \textbf{ X 100 = DCO Percentage}$$

***** See below for case inclusion requirements for each standard-setting organization.

a. **Total # of DCO cases for the Year:** The numerator used to calculate DCO percentage includes all DCO cases included in or added to the registry file after the follow-back process has been completed. These cases are identified by Type of Reporting Source, NAACCR Item # 500 equal to 7 "Death Certificate Only." Cases not included in the denominator as specified by each standard-setting organization (e.g., *in situ* breast cancers for NAACCR) must also be eliminated from the numerator.

b. **Total # of Incidence Cases for the Year:** The denominator used to calculate DCO percentage includes the number of incidence cases for a given year plus the number of cases for the year classified as DCO cases. Eliminate those cases not included by the respective standard-setting organization from the total number of incidence cases for the year.

4.9.1.3 <u>Cases Included in the Calculation</u>: Cases included in the numerator and denominator shall conform to requirements of the applicable standard-setting organization.

a. **Surveillance, Epidemiology, and End Results (SEER) Program:** All reportable incidence cases in the catchment areas are included in the numerator and denominator for SEER's calculation of DCO percentage.

b. **National Program of Cancer Registries (NPCR):** All invasive cancers plus *in situ* bladder cancers for residents of the registry catchment area are included in the numerator and denominator for NPCR's calculation of DCO percentage. Effective with the NPCR-CSS 2010 Data Submission, benign CNS DCO cases are included in the numerator and denominator.

North American Association of Central Cancer Registries (NAACCR): All in*vasive c*ancers plus *in situ* bladder cancers for residents of the registry catchment area are included in the numerator and denominator for NAACCR's calculation of DCO percentage.

c. **Statistics Canada:** All invasive cancers for provincial residents are included in the nume**rator and denominator for Statistics Canada's calculation of DCO** percentage.

4.9.2 Death Cer*tificat*e Only (DCO) Percentage Standards

4.9.2.1 <u>DCO Percentage Standards</u>: Registries must strive to meet DCO percentage standards as established by applicable standard-setting organizations.

a. **Surveillance Epidemiology End Results (SEER):** The percentage of cases diagnosed only by a death certificate shall not exceed 1.5 percent of all cancers registered in a given year after follow-back.

b. **National Program of Cancer Registries (NPCR):** The percentage of included cases* from data evaluated for the National Data Quality Standard (formerly known as the 24-month data) diagnosed only by a death certificate shall be less than or equal to 3.0 percent of the total after follow-back.

c. **North American Association of Central Cancer Registries (NAACCR):** The percentage of included cases* from 24-month data diagnosed by a death certificate shall be less than or equal to 5.0 percent of the total after follow-back for silver certification and less than or equal to 3.0 percent for gold certification.

d. **Statistics Canada:** The percentage of included cases* from 24-month data diagnosed by a death certificate shall be less than or equal to 5.0 percent of the total after follow-back for silver certification and less than or equal to 3.0 percent for gold certification.

* Included cases refers to cases included in the DCO calculation by each standard-setting organization as described in Section 4.9.1.3.

4.10 Analysis of Death Clearance Follow-Back Results

Conducting a comprehensive death clearance follow-back process provides useful information regarding the quality of the registry casefinding system. The most obvious reasons to conduct death clearance follow-back are to be able to calculate a DCO percentage as an overall measure of completeness and to add reportable cases to the registry database. However, registries can obtain additional value from this very labor-intensive process by analyzing the results after all cases have been added to the database.

a. **Quantifying Death Clearance Follow-Back Results:** When discussing the value of death clearance follow-back, the term Death Certificate Notification (DCN) is often used to quantify and describe results. The term DCN refers to a reportable case added to the registry database as a missed incidence or DCO case from the death clearance follow-back process. The case was not previously reported by any reporting source, and the first time the registry is made aware or notified of the case is during the death clearance follow-back process. Had it not been for conducting death clearance follow-back, these cases would not be entered into the registry

database. The number of cases included in the registry database as DCN cases is directly affected by the timing of death clearance follow-back. (Refer to the introduction to Chapter 4, Death Clearance Follow-Back.)

By quantifying the results, the registry can specifically describe cases added to the registry database from the death clearance follow-back. For example, if a registry had 500 non-matches and 300 resulted in adding a missed incidence case to the registry incidence file, 100 were added as a DCO, and 100 were eliminated as non-reportable, the net gain to the registry is 400 cases (100 DCOs and 300 missed incidence cases). If the registry generally has a caseload of 10,000 cases, then the DCOs constitute 2 percent of the database, and the DCNs or total number of cases added through the death clearance follow-back process (DCOs being a subset of DCNs) constitute 4 percent of the database.

The numbers used to quantify DCN cases can be identified from registry death clearance tracking systems or through data items included in abstracting missed incidence and DCO cases in the registry database. DCNs can identified from NAACCR data items as follows:

1. **Total DCNs:** Number of incidence cases for a given diagnosis year with Casefinding Source equal to 80, Death Certificate (case identified through death clearance).

2. **Total DCO Cases:** Number of incidence cases for a given year with Type of Reporting Source equal to 7, Death certificate only.

3. **Total Missed Incidence Cases:** Number of incidence cases for a given year with Casefinding Source equal to 80 and Type of Reporting Source not equal to 7. To identify specific facilities and volume of cases by facility reported as missed cases, Type of Reporting Source 1 can be broken down by Reporting Facility.

b. **Improving Casefinding:** The new incidence cases identified during death clearance follow-back provide important information for both the central and hospital registries that can improve casefinding. Reviewing the characteristics and circumstances of DCOs and missed incidence cases can lead to a better understanding of systemic issues that can be addressed operationally or through training to improve casefinding.

Examples of valuable information to analyze from death clearance follow-back results include:

1. Percentage of missed incidence cases by type of reporting source and/or physician specialty to determine the adequacy of reporting from required sources and justification for requiring additional sources to report.

2. Percentage of missed incidence cases by type of diagnostic confirmation (clinical, path, scans, etc.).

3. Percentage of missed incidence and DCO cases by primary site.

4. Patterns of missed incidence and DCO cases in various geographic areas of the registry catchment area.

c. **Improving the Record Matching Process:** Registries can monitor the effectiveness of the matching algorithm used for death clearance follow-back by tracking the total number of false non-matches. False non-matches become apparent when cases added to the database as DCO or missed incidence cases link to a tumor already in the database. If the false non-match is due to missing data in fields used for matching, there are few options to reduce this problem. If the false non-match is due to the matching algorithm not being robust enough to find the matches, the match criteria should be revised or a more robust algorithm used. False non-matches may also be due to incompleteness of the registry database at the time the linkage is performed. Adjusting the timing for beginning the death clearance follow-back process may be beneficial.

d. **Confirming DCO Cases:** The registry should have a quality assurance procedure in place to confirm that the DCO is the only abstract for the tumor. This procedure should be carried out after the death clearance follow-back procedure is complete and before the DCO percentage is calculated. Running a program to identify any records having a DCO and non-DCO abstract associated with the same primary will provide the opportunity to investigate the matching process and also delete the DCO.

e. **Sharing National Death Index (NDI) Information:** When U.S. registries apply the results of NDI linkage to update their respective databases, they are able to identify patients diagnosed in their state but who died in another state. These deaths may result in DCOs for the state in which they died. The Centers for Disease Control and Prevention includes a provision in the NPCR-National Death Index application that allows registries to share information obtained from the NDI for the purpose of identifying and removing duplicate cases including DCO cases. This exchange of information is a way for registries to assist each other in eliminating this type of DCO.

   For example, when Registry A and Registry B conducted NDI linkages, Registry A found a number of former residents from their state who moved to Registry B's state and died as residents of Registry B's state. Registry A is permitted to provide information obtained from the NDI linkage to Registry B to enable Registry B to clear out cases that Registry B reported as DCOs.

Appendix A: Death Clearance Publications

Cormier M. Canadian Cancer Registry Manual: Guidelines for Abstracting and Determining Death Certificate Only (DCO) Cases for Provincial/Territorial Cancer Registries (PTCRs) in Canada, 2006 Edition. Ottawa, Canada: Statistics Canada, July 2006.

Havener L (ed). Standards for Cancer Registries, Volume III: Standards for Completeness, Quality, Analysis, and Management of Data. Springfield (IL): North American Association of Central Cancer Registries, October 2004.

Hutchison CL, Menck HR, Burch M, Gottschalk R (eds). Cancer Registry Management, Principles and Practice, 2nd Edition. Dubuque, IA: Kendall/Hunt Publishing Company, 2004.

Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG (eds). IARC Scientific Publications No. 95: Cancer Registry Principles and Methods. Lyon, France: International Agency for Research on Cancer, 1991.

Menck HR, Deapen D, Phillips JL, Tucker TC (eds). Central Cancer Registries Design, Management and Use, 2nd Edition. Dubuque, IA: Kendall/Hunt Publishing Company, 2007.

NAACCR. Standards for Cancer Registries, Volume III: Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

NAACCR Death Clearance Best Practices Work Group (eds). Series V: Resolving Death Clearance Issues, 2002. Procedure Guidelines for Cancer Registries. Springfield, IL: North American Association of Central Cancer Registries, January 2003.

NAACCR Registry Operations Committee. Series II: Calculating the Death Certificate Only (DCO) Rate. Procedure Guidelines for Cancer Registries. Springfield, IL: North American Association of Central Cancer Registries, June 2000.

Riddle, BR. A Review of Death Clearance in Central Cancer Registries and Proposal for a New Regime. *Journal of Registry Management* 2004; 31(2):67-74.

Appendix B: Death Clearance Glossary

Approximate Interval Between Onset and Death: Data item at the end of lines (a), (b), (c), and (d) on death certificate used to record the interval between the presumed onset and the date of death. This should be entered for all causes—immediate cause, antecedent conditions, and the underlying cause. These intervals usually are established by the medical examiner or coroner on the basis of available information.

Cancer Deaths: For the purpose of this manual, cancer deaths refers to all death certificates containing a cause of death that is a reportable condition including benign brain and CNS tumors and excluding conditions such as basal and squamous cell carcinomas of the skin.

Catchment Area: For the purpose of this manual, catchment area refers to the geographical area and/or population served by the registry.

Cause of Death: A disease, abnormality, injury, or poisoning that contributed directly or indirectly to death. Causes of death that are coded include Immediate Cause, Cause Leading to Immediate Cause, Next Antecedent Cause, and Underlying Cause.

Clearing Deaths: The process of carefully examining all non-matched cancer deaths to determine whether they meet registry reporting requirements based on additional follow-back information, and if so, abstracted as a missed incidence case or included as a DCO case.

Death Certificate: The official legal document and vital record, signed by a licensed physician or other designated authority, that includes cause of death, decedent's name, sex, place of residence, date of death; other information (e.g., birth date, birth place, occupation) may be included. The immediate cause of death is recorded on the first line of the certificate, followed by the condition(s) giving rise to this, with the underlying cause on the last line. The underlying cause is coded and tabulated in official publications of mortality.

Death Clearance: The process of matching registered deaths in a population against reportable conditions in the registry database for two purposes: (1) ascertainment of death information for persons in the registry (death clearance match), and (2) identification of all deaths with a reportable condition mentioned as a cause of death that are not found in the registry.

Death Certificate Review: The review of the causes of death and other information exactly as it is recorded on the death certificate rather than in coded form. This is accomplished by reviewing copies of actual death certificates, death certificates on microfiche, or electronic files from vital records office processing procedures such as SuperMICAR files.

Death Certificate Only (DCO) Case: A reportable case for which the only information the registry has is a death certificate containing a reportable condition.

Death Certificate Notification (DCN) Case: A reportable case added to the registry database as a missed incidence or DCO case from the death clearance follow-back process. The first time the registry is made aware or notified of the case is during the death clearance follow-back process. The case was not previously reported by any other reporting source. Had it not been for conducting death clearance follow-back, these cases would not be entered into the registry database.

Death Clearance Match: Linkage of deaths from the mortality file to the registry database to identify records that match. For each match, the registry record is updated with death and other relevant data.

Death Clearance Follow-Back: Process used to: (1) identify potentially missed incidence cases by taking patient and tumor non-matches from the death clearance match that mention a reportable condition as one of the causes of death, (2) request additional information from potential sources, and (3) abstract the missed case.

Death File: Same as Mortality File.

Deaths of Non-Residents: Persons who were not residents of the catchment area in which they died.

Follow-Back Process: The process of actively searching for additional information on potential incidence cases from sources such as hospitals, certifying physicians, nursing homes, other health care practitioners and facilities. See Death Clearance Follow-Back.

DCO Percentage (Percent DCO): Total number of DCO cases for a given year divided by total number of incident cases for the year. The denominator is determined by the standard setter for that particular registry.

Guidelines (for Death Clearance): Information and rationale within the text of the manual provided to facilitate understanding the death clearance process. Guidelines appear in non-bolded text.

Immediate Cause of Death: The final disease, injury, or complication leading directly to death. It may be the only entry in the cause of death section if only one condition was present at death. It is recorded on the first line of the certificate, followed by the condition(s) giving rise to this, with the underlying cause on the last line.

Minimum Requirements (for Death Clearance): Statements within the text of this manual describing methods, procedures, and decisions that represent the least a registry must do to perform death clearance match and death clearance follow-back.

Missed Incidence Case: A reportable case first identified as a non-matched cancer death for which confirmation of the diagnosis and other information are obtained through follow-back to a clinical source(s) or medical record.

Mortality File: The official state, territorial, or provincial data file containing all registered deaths in the catchment area for a specified period of time as reported to the vital records office. Two types of mortality files are used by cancer registries for death clearance: (1) underlying cause of death file containing only the underlying cause of death, and (2) multiple cause of death file containing all causes of death.

Multiple (Contributing) Cause of Death File: The official state, territorial, or provincial mortality file containing both underlying cause of death and all contributing causes of death. This is the file required for death clearance follow-back.

Non-Matched Cancer Death: A death certificate containing a potentially reportable condition that cannot be matched to the registry database. Two types of non-matches are identified when mortality files are matched against the registry database: (1) non-match at the patient level, and (2) non-match at the tumor level for a matched patient.

Non-reportable Case: For the purpose of the death clearance follow-back procedure, a non-reportable case is a case first identified as a non-matched cancer death but after further investigation does not meet registry reporting requirements.

Out-of-State/Province/Territory Resident Deaths: Persons who expire in another state/territory/ province (catchment area). Records of residents of the registry catchment area who expire in another catchment area must be included in the mortality file used to conduct death clearance unless prohibited.

Patient Match: A death certificate with a potentially reportable condition that matches to a patient in the registry database.

a. **Positive Patient Match:** Match criteria are met, therefore no further manual review is required.

b. **Possible Patient Match:** Match criteria are incompletely met and must be manually reviewed to determine if the records are indeed matches. Review of case files, phone calls to providers, or correspondence with facilities may be required to verify possible matches.

Patient Non-Match: A death certificate with a potentially reportable condition that does not match to a patient in the registry database.

Registry or Registries: For the purpose of this manual, registry or registries is the term used to refer to any population-based cancer registry in the United States and Canada that performs death clearance. These population-based cancer registries may be referred to using terms such as state cancer registries, provincial and territorial cancer registries, and central cancer registries.

Resident Deaths: Persons who expire in their state/province/territory of residence.

Reportable Condition: The cause of death is reportable according to registry-specific policies and the list of reportable conditions.

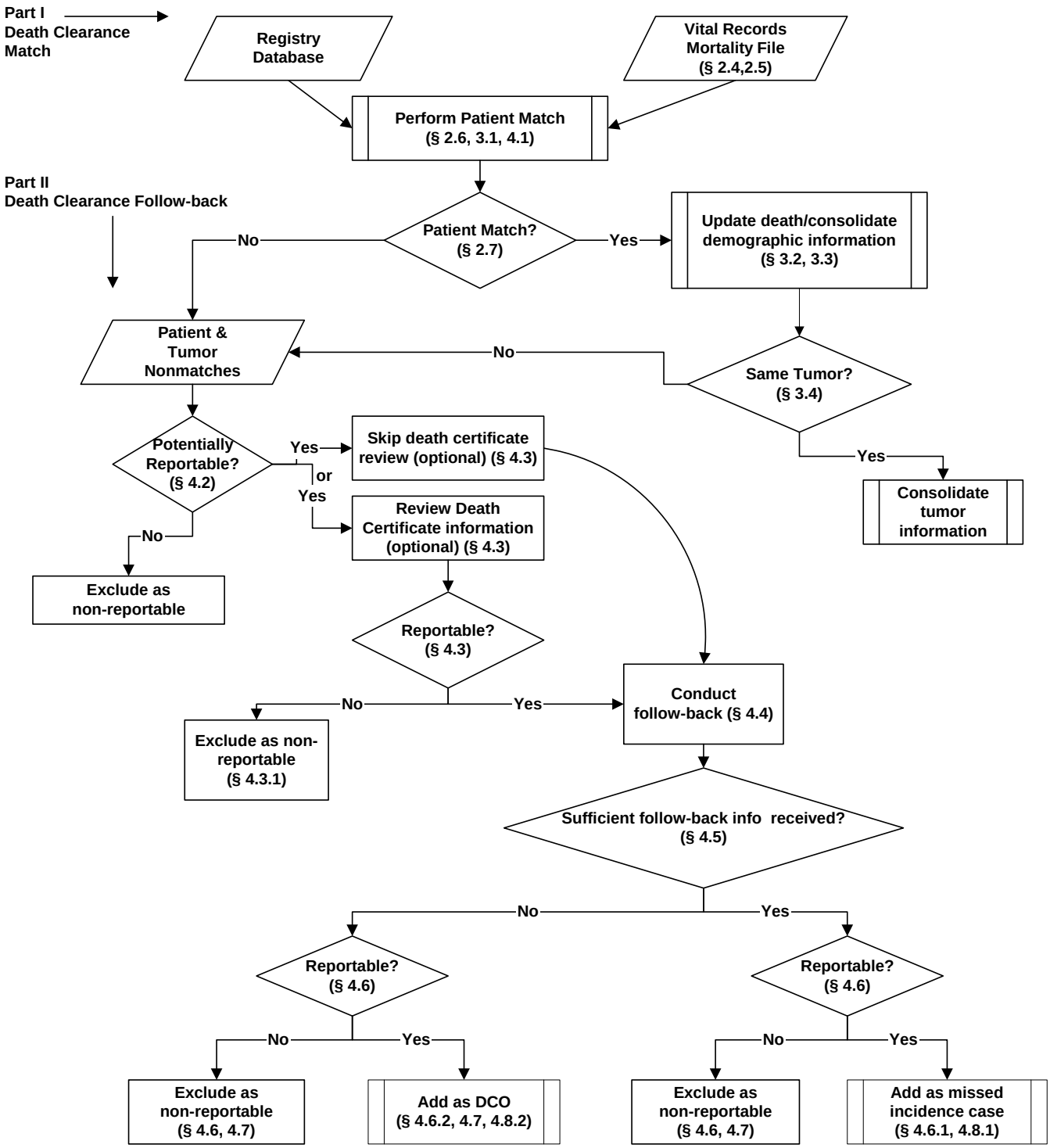
Tumor Match: A death certificate with a potentially reportable condition that matches to a patient and the patient's tumor in the registry database.

Tumor Non-Match: A death certificate with a potentially reportable condition that matches to a patient in the registry database, but not the patient's reported tumor in the registry database.

Underlying Cause of Death: The disease or injury that initiated the chain of morbid events that led directly to death or the circumstance of the accident or violence that produced the fatal injury. The underlying cause is coded and tabulated in official publications of mortality.

Underlying Cause of Death File: The official state, territorial, or provincial mortality file that contains only the disease or injury that initiated the train of morbid events leading directly to death. It does not contain any of the contributing causes of death.

Appendix C: Flow Diagram of Death Clearance Process



Appendix D: ICD-10 Casefinding Codes for Death Clearance

ICD-10 codes in the following table must be used to identify reportable conditions on death certificates for inclusion in the death clearance follow-back process. Additional codes may be used by the registry to identify reportable conditions.

C Codes	Code Categories	Description
C000-C979		**Malignant neoplasms**
	C000 - C759	Malignant neoplasms (stated or presumed to be primary) of specific sites, except lymphoid, hematopoietic, or related tissue
	C760 - C80	Malignant neoplasms of ill-defined, secondary, and unspecified sites
	C810 - C969	Malignant neoplasms (stated or presumed to be primary) of lymphoid, hematopoietic, and related tissue
	C97	Malignant neoplasms of independent (primary) multiple sites
D Codes	**Code Categories**	**Description**
D000-D039		***In situ* neoplasms**
	D000-D009	Carcinoma *in situ* of oral cavity, esophagus, and stomach
	D010-D019	Carcinoma *in situ* of other and unspecified organs
	D020-D029	Carcinoma *in situ* of middle ear and respiratory system
	D030-D039	Melanoma *in situ*
D050-D059	D050-D059	Carcinoma *in situ* of breast
D070-D099		**Other *in situ***
	D070-D079	Carcinoma *in situ* of other and unspecified genital organs
	D090-D099	Carcinoma *in situ* of other and unspecified sites
D320-D339		**Benign neoplasm of Brain/CNS**
	D32.0	Benign neoplasm of cerebral meninges
	D32.1	Benign neoplasm of spinal meninges
	D32.9	Benign neoplasm of meninges, unspecified
	D33.0	Benign neoplasm of brain, supratentorial
	D33.1	Benign neoplasm of brain, infratentorial
	D33.2	Benign neoplasm of brain, unspecified
	D33.3	Benign neoplasm of cranial nerves
	D33.4	Benign neoplasm of spinal cord
	D33.7	Benign neoplasm of other specified parts of central nervous system
	D33.9	Benign neoplasm of central nervous system, part unspecified
D352-D354		**Other reportable benign neoplasms**
	D35.2	Benign neoplasm of pituitary gland
	D35.3	Benign neoplasm of craniopharyngeal duct
	D35.4	Benign neoplasm of pineal gland

D Codes	Code Categories	Description
D420-D439		**Brain/CNS neoplasms of uncertain or unknown behavior**
	D42.0	Neoplasm of uncertain or unknown behavior of cerebral meninges
	D42.1	Neoplasm of uncertain or unknown behavior of spinal meninges
	D42.9	Neoplasm of uncertain or unknown behavior of meninges, unspecified
	D43.0	Neoplasm of uncertain or unknown behavior of brain, supratentorial
	D43.1	Neoplasm of uncertain or unknown behavior of brain, infratentorial
	D43.2	Neoplasm of uncertain or unknown behavior of brain, unspecified
	D43.3	Neoplasm of uncertain or unknown behavior of cranial nerves
	D43.4	Neoplasm of uncertain or unknown behavior of spinal cord
	D43.7	Neoplasm of uncertain or unknown behavior of other parts of central nervous system
	D43.9	Neoplasm of uncertain or unknown behavior of central nervous system, unspecified
D443-D445		**Other reportable neoplasms of uncertain or unknown behavior**
	D44.3	Neoplasm of uncertain or unknown behavior of pituitary gland
	D44.4	Neoplasm of uncertain or unknown behavior of craniopharyngeal duct
	D44.5	Neoplasm of uncertain or unknown behavior of pineal gland
D45		Polycythemia vera (diagnosed 01/01/2001 or later)
D460-D469		Myelodysplastic syndromes (diagnosed 01/01/2001 or later)
D471		Chronic myeloproliferative disease
D473		Essential (hemorrhagic) thrombocythemia
D721		Eosinophilia [Hypereosinophilic (idiopathic) syndrome 9964/3]
D758		Other specified diseases of blood and blood-forming organs [Refractory cytopenia with multilineage dysplasia 9985/3]
D760		Langerhans' cell histiocytosis, not elsewhere classified [Langerhans cell histiocytosis, disseminated 9754/3]