Objectives

- Briefly cover the background of this lengthy process (ROC DCWG est. 2004)
- Discuss the evolution of the minimum requirements with the goal being consistency among states re: Death Clearance procedures
- Review the proposed minimum requirements
- Receive your comments
- Discuss steps to finalize the manual
Why is it taking SO long??

● One universal truth:
  ● No audience approached to discuss Death Clearance will agree: technical staff, managers, or standards setters
  ● Each person is very passionate about what he/she believes about the topic

● Everyone in this room will not totally agree on these minimum requirements
  ● We want you to understand how these requirements and guidelines have evolved over the years they have been addressed
In 2009, the Death Clearance Manual was released with new minimum requirements. They were met with difficulty from some states.

The DCWG volunteered to continue working on a plan to evaluate the impact of the new minimum requirements through a survey to all states assessing several criteria:

- Death match – include Multiple/contributing Cause File?
- Link at patient and tumor level, following back on both?
- “History of” cases – eliminate or include?
- Several new members joined the group
Survey results received were sparse.
Not enough information was gleaned to make meaningful assessment of impact of new requirements.
Developed a new plan - establish minimum requirements that all states could accomplish.
3 additional projects were set up to further develop guidelines:
  - Tumor Linkage
  - DCO Values
  - EDITS for DCOs
Consistency through Minimum Requirements

- Least common denominator – registries should be able to complete with files and staffing resources available

- Scaled down from 2009 version of the Manual

- If central registries choose to do more, or standards setters require more, that is up to them.

- Establish a separate measure(code) from which the impact of ‘doing more than the minimum could be determined
4.1 Minimum Requirements for Performing Death Clearance Follow-back

- Identify the least the registry must do to perform death clearance follow-back
- Additional requirements may be added by standard setting organizations or registries
Minimum Requirement 4.1.1

Death Clearance Follow-back must be conducted at least annually.

- Registries may find it beneficial to conduct death clearance follow-back more often to distribute the follow-back workload over a longer period.

- Standards setters will determine timeline for completion
Minimum Requirement 4.1.2:

The official mortality file from the state, territorial, or provincial vital records office containing deaths for the specified year must be used to match against the registry database.

- Must include residents in registry catchment area who die in catchment area
- Residents who die in another catchment area should be included whenever possible (issue: re-release restrictions)
- Deaths of residents of another catchment area who die in the registry catchment area may be included for follow-back if standard-setter requires or registry chooses to include
Minimum Requirement 4.1.3:

Death Certificates with a reportable condition coded in at least the underlying cause of death field on the mortality file must be included in the death clearance follow-back process.

- Multiple/contributing cause files may be used, but not required unless required by standard setter, or registry chooses to include
Minimum Requirement 4.1.4:

Non-matches, at least at the patient level, must be reconciled through the death clearance process.

- Non-matches at the patient level must be included in the death clearance process – occur when death certificate contains a reportable condition as COD and patient is not in registry database.

- Non-matches at the tumor level occur when the death certificate contains a reportable condition as COD, patient is in registry but for a different reportable condition. Registries are strongly encouraged to identify and reconcile tumor non-matches, but tumor level matching is required only when standard setting organizations require or registries choose to include it.
Appendix E: Tumor Comparison Guidelines

- Provides multiple primary determinations guidance for comparing a COD coded in mortality file with a primary site/histology coded case in registry database.
- May be used to perform tumor comparison manually but were designed to be used to automate the process to increase efficiency of task.
CDC NPCR Feedback

- NPCR ORTAT Position: Tumor Linkage is important for completeness, especially for multiple primaries and secondary cancers; however, after considering the cost, and NPCR grantees’ decrease in resources, the group ‘strongly recommends’ tumor linkage and follow-back, but does not require it.

- Consider a future NPCR project to work with a few states to determine the cost/benefit of tumor linkage.
Minimum Requirement 4.1.5:

Follow-back information must be obtained from a medical record or clinical source to confirm the diagnosis and initiate abstracting a non-match as an incidence case.

- Includes info from hospital, physician, nursing home, or other health care practitioner and facility
- Sources, i.e., non-MD coroner, uniform billing hospital discharge data set may be used to ID clinical sources for follow-back.
  - This source alone cannot be used to remove a case from DCO status, but can be used in conjunction with clinical source
Minimum Requirement 4.1.6:

Follow-back information must provide at least confirmation of the diagnosis by a medical practitioner and date (or estimated date) of diagnosis to abstract a non-match as an incidence case.

- Goal of Follow-back process is to obtain as much clinical info as possible to create the most complete abstract or to determine the non-match is not reportable. When not sufficient to complete all required data items, the follow-back source must provide at least confirmation of the diagnosis and date of diagnosis (or estimated date) before case can be taken out of DCO status.
Minimum Requirement 4.1.6: contd.

- **Confirmation of Diagnosis**: The diagnosis was made by a recognized medical practitioner, is supported by information from a clinical source or medical record, and was obtained through follow-back. It may be from the MD who signed the death certificate or another MD identified through follow-back. It may **not** be provided by non-MD Coroner.

- **Date of Diagnosis**: An exact or estimated date must be obtained. The diagnosis date may be estimated from info provided by follow-back sources. If source confirms the diagnosis but cannot provide a date, and info on the death certificate can provide an estimated date, the death certificate info can be used to meet this requirement. (See Manual Appendix X: Estimating Diagnosis Date).
Minimum Requirement 4.1.6: contd.

- **Identifying non-reportable cases**: Copies of death certificates, paper or microfiche, and/or supermicar files may be reviewed to provide details on the COD as it is documented on death certificate.

- **No Follow-back**: Follow-back is not required to be conducted on all non-matches. A registry may choose not to conduct follow-back on some or any of the non-matches due to reasons such as past experience with a source, lack of info to contact a source, insufficient staffing or time to conduct follow-back. These non-matches must be entered as DCOs in the registry database because the only source of info is the death certificate.
The death certificate states breast cancer as COD with no diagnosis date listed. Place of death was skilled nursing facility that has never provided useful follow-back info in past.

Registry elects not to contact nursing facility for this or any other cases. Registry must enter these cases as DCOs if the CODs are reportable and no dates of diagnosis on certificate indicate diagnosis prior to registry reference date.
Minimum Requirement 4.1.7:

A non-match must be made a Death Certificate Only (DCO) when the only information available is from the death certificate.

- This is the ONE definition we must all agree on to have any consistency at all.

- If date of dx can be estimated by info on death certificate, signed by MD, that info may be used, but case is still considered a DCO for appropriate diagnosis year.

- Not a MDO case, otherwise we disguise a DCO as ‘something other than what it is’
Minimum Requirement 4.1.8:

Each non-match must be reconciled as one of the following types of cases to complete the death clearance process:

1) deleted as non-reportable;
2) added to the registry database as a missed incidence case from follow-back information; or
3) added to the registry database as a DCO.
1) **Non-Reportable Case**: A case first identified as a non-matched cancer death that after further investigation does not meet reporting criteria.

2) **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 clinical source(s) or medical record(s).

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

- **Minimum Requirement to be added:**
  - Data items required to be completed for a DCO case

- **Idea for consideration:** DCOs identified from performing activities beyond minimum requirements (doing more) should be identified by a special code.
  - Promote consistency among all states for minimum requirements
  - Provide additional information for further analysis and evaluation of minimum requirements
Steps to Finalize

- Incorporate all comments received
- DCWG-2 to review final document
- Request review by Standards Setting Orgs and incorporate their feedback
- Present final document to Steering Committee
- Obtain other approvals as needed
- Recommend Implementation in 2014 for 2012 deaths.
Comments/Questions???

- Now is the time to provide feedback to take back to DCWG-2.

It's QUESTION TIME!!