The New Death Clearance Manual

Susan Bolick, MSPH, CTR
Co-chair
NAACCR Death Clearance Workgroup
NAACCR Annual Conference
June 18, 2015
Objectives for Today

● Summarize in a few minutes the process that took 10 years to complete 😊
  ● See Background Section (pg. 1) in DC Manual for historical facts that led to the New DC Manual development and completion

● Provide insight to the thought process of (and guidance received by) the Workgroup

● Stimulate thought as to the ‘ultimate benefit’ achieved from performing death clearance
Definition of Death Clearance

- The process of matching registered deaths in a population against reportable conditions in the central cancer registry database in order to achieve:
  - Ascertainment of death information for cases in the registry
  - Identification of all deaths with a reportable condition mentioned as a cause of death that are not found in the registry database

- (Year of deaths corresponds to cancer incidence year being completed)
Polling Question

What do you consider the “ultimate benefit” to be achieved by conducting death clearance?

A. Calculation of DCO percentage
B. Addition of death information to cases already in the registry database
C. Overall improvement of casefinding and quality enhancement of the registry cases
Lessons Learned Through this Process

- Sometimes, no matter how hard (or how long) a group tries, consensus may not be achieved.
- Best outcome may be to identify and accept viable options.
- Thus, the approach of minimum requirements was taken.
  - i.e., the least common denominator that can be feasibly reached by all.
Goal of the New Death Clearance Manual:

“Consistency” through Minimum Requirements

- Restrict what “must be done” to achieve death clearance, taking into consideration limited staff and funding resources for these time-intensive tasks

- Provide methods that can be consistently applied to ensure comparability and (hopefully) fairness across registries
Purpose of the New DC Manual

- To be implemented with 2015 death clearance using 2013 deaths

- Provide a comprehensive, yet practical, resource under one cover for death clearance
  - So that registries find ‘all’ they need to complete the process successfully and consistently

- Provide clear, concise minimum requirements necessary for completion of the components of Death Clearance:
  - Death Match, Death Clearance Follow-back, Calculating the DCO percentage
Purpose of the New DC Manual

- Provide options to ‘do more’ than the minimum, but not to ‘do less’
  - If registry chooses or standard setter requires
  - Establish a separate measure (code) from which the impact of ‘doing more than the minimum’ could be determined

- Provide options for the degree of the registry’s effort toward accomplishing the death clearance processes
  - While assuring accountability for the outcomes of that process at the end of death clearance
Example: Death Clearance Follow-back Minimum Requirements

- Follow-back on non-matched deaths is required for Underlying Causes of Death only.
- Following back on non-matched deaths from the multiple or contributing causes of death is recommended but not required, unless by standard-setter, or registry chooses.
- Option: Death clearance follow-back on non-matched deaths can be limited or totally excluded... however,
  - Resolution of each non-matched death is required for process to be complete.
Example: Death Clearance Follow-back Minimum Requirements

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

- deleted as non-reportable
- added to the registry database as a missed incidence case from follow-back information
- added to the registry database as a DCO.
Example: Death Clearance Follow-back Minimum Requirements

- Non-matched deaths at the patient level must be reconciled through follow-back to clinical source to confirm the cancer and date of diagnosis.

- Reconciliation of deaths at the tumor level where the death matches a case in registry database but for a different cancer site is recommended but not required.
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.
A non-matched death 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’
Contents of the DC Manual

- **In addition to Minimum requirements:**
  - Best practices for each requirement
  - Guidelines for getting the most from the process
  - Scenarios with resolution for practical use
  - Glossary of terms for consistency in interpretation
There will be a NAACCR Webinar produced providing instruction on the details of each of the minimum requirements of the new DC Manual for those who conduct death clearance.

Watch for NAACCR announcement.

In the meantime, questions can be routed to the workgroup through the NAACCR office or directly to me.
Ultimate Goal of Death Clearance Process

- Look beyond the DCO percentage at what death clearance can tell you about your registry operations
  - Use the process to examine characteristics of cases identified from death certificates – both missed incidence cases & DCOs
  - Track and analyze those cases as to the reasons they were not reported as incidence cases from reporting facilities
  - Use those results to identify patterns and to improve and enhance casefinding procedures and casefinding sources
  - “In the future” - Utilize MU Stage 2 reporting sources to expand sources for clinical follow-back on non-matches
Finally….

- The DC Workgroup spent countless hours giving careful thought to the death clearance process and its many scenarios.
- Our hope is that this final product provides a reasonable, achievable set of requirements, best practices, and guidelines under one cover for all registries to accomplish this process.
- Even though DCO cases may not be ‘fit’ for use, the process can help improve registry completeness and overall quality over time.
Special thanks

- Robin Otto, Co-chair
  - For her outstanding leadership in this effort
- DC Workgroup members
  - For their dedication and stick-to-itiveness
    (Defined as ‘dogged perseverance’)
- Standard-setting organization leaders and NAACCR Board
  - Who provided guidance throughout the process
  - And endorsed the manual for release
Contact Info for questions

bolicks@dhec.sc.gov
(803) 898-3001