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Reporting Practices and Challenges from Non-Hospital Facilities and Physicians for Death Follow Back of Death Clearance in Maryland

Westat

Abstract

Background: Death clearance is defined as the process of matching registered deaths in a population against reportable conditions in the central cancer registry database in efforts to reduce the Death Certificate Only (DCO), case for which the Death Certificate is the only source of information, rate within standards. One of the purposes on this process is to identify of all deaths with a reportable condition mentioned as a cause of death which are not found in the central cancer registry, called death follow back. NPCR requires state registries to conduct death clearance. By NAACCR Standard V.c.2, DCO cases must represent 3% or fewer of total cases in the registry database. To this end, the Maryland Cancer Registry (MCR) conducted an extensive follow back to hospital facilities and non-hospital facilities, including nursing homes, hospice, and physician offices.

Purpose: This study aims to assess the reporting practices of non-hospital reporters because they are less likely to have training in cancer registration.

Methods: Westat conducted the death clearance process in accordance to the NAACCR Death Clearance Manual. Patients and tumors of Maryland residents who died in 2009 were first matched to the MCR database of reported cancers by use of SAS programming. Facilities and physicians were followed back to identify the reportable tumors listed on the death certificate but not found in the MCR database. Hardcopy forms were mailed. Data received from reporters and met the minimum requirements to clear DCO status were inputted into the MCR database. All other reportable tumors were added to the system as DCO.

Results/ Conclusion: This presentation will describe the reporting practices of non-hospital facilities and physician reporters; compare the quality and completeness of non-hospital reporting with hospital reporting; and identify the most common reporting issues among non-hospital facilities and physician reporters. We will also discuss the challenges to following back non-hospital reporting facilities and physicians as well as lessons learned.

Introduction

Death clearance is defined as the process of matching registered deaths in a population against reportable conditions in the central cancer registry database in efforts to reduce the Death Certificate Only (DCO), case for which the Death Certificate is the only source of information, rate within standards. One of the purposes on this process is to identify of all deaths with a reportable condition mentioned as a cause of death which are not found in the central cancer registry, called death follow back. NPCR requires state registries to conduct death clearance. The Maryland Cancer Registry (MCR) conducted an extensive follow back to hospital facilities and non-hospital facilities, including nursing homes, hospice, and physician offices as a means of more complete reporting for Maryland.

Aim

This study aims to assess the reporting practices of non-hospital reporters because they are less likely to have training in cancer registration.

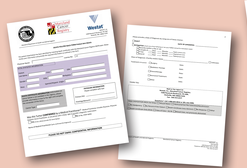
Methods

Westat conducted the death clearance process in accordance to the NAACCR Death Clearance Manual. Patients and tumors of Maryland residents who died in 2010 were first matched to the MCR database of reported cancers by use of SAS programming. Facilities and physicians were followed back to identify the reportable tumors listed on the death certificate but not found in the MCR database. Hardcopy forms were mailed. Data received from reporters and met the minimum requirements to clear DCO status were inputted into the MCR database. To clear DCO status cases should be have at least a date of diagnosis and be medically confirmed by a practitioner. All other reportable tumors were added to the system as DCO.

Data Collection Forms

Mailed to Hospitals, Nursing Homes, Hospice and Assisted Living Facilities

Facility Collection Form



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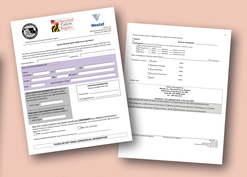
Tumor Collection Form



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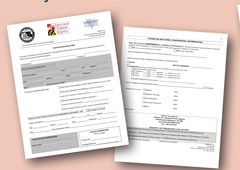
Mailed to Physicians

Physician Collection Form



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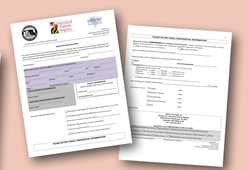
Tumor Collection Form



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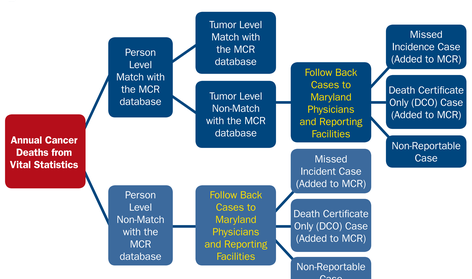
Death Clearance Process

Figure 1 – Death Clearance Process

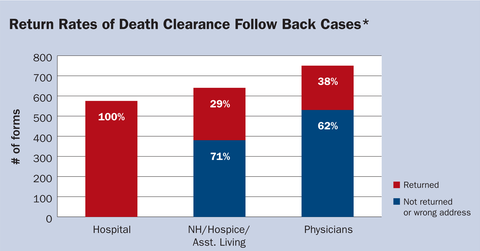


Results

Table 1 – Qualitative Summary of Reporting Commonalities for Followed Back Cases Regarding Death Clearance By Facility Type

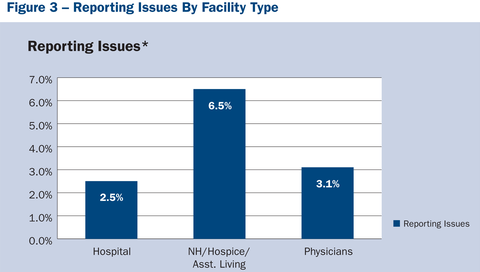
	Quality	Completeness	Challenges
Hospitals	■ Likely to provide needed information to clear a case from DCO status	■ Most likely to attach medical documentation	■ No consistent reporting issues
Nursing Homes/ Hospice/ Assisted Living	■ Provided codes for primary sites other than ICDO3 or ICD10 coding system ■ Misunderstanding of Class of Case	■ No diagnosis date given ■ No medical confirmation given ■ No information on histology	■ Most calls to the technical line regarding reporting requirements and form completion questions
Physicians	■ Provided accurate information	■ Most comprehensive information provided ■ Most likely to provide additional detailed information	■ Wrong address/returned mail ■ Completed information on the instructions ■ Most returned forms after submission deadline

Figure 2 – Return Rate for Death Clearance Follow Back Cases Per Facility Type



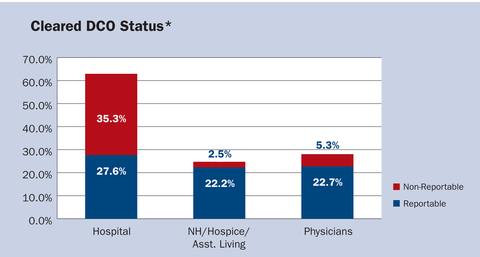
* = Hospitals were sent a total of 572 follow back cases. Nursing Homes/Hospice/Assisted Living facilities were sent a total of 635 follow back cases. Physicians were sent a total of 752 follow back cases.

Figure 3 – Reporting Issues By Facility Type



*= Reporting Issues includes instances where the facility or physician provided some information on the case yet did not provide either the date of diagnosis or medical confirmation.

Figure 4 – Percentage of Returned Followed Back Cases that Cleared DCO Status



*= Cleared DCO Status/Death Clearance Rate for this study is defined as cancer cases that were confirmed as reportable by a practitioner and included a date of diagnosis or cases that were confirmed as non-reportable.

Conclusion

Hospitals

Hospital registrars are trained and experienced in reporting cancer cases to the central registry. This proved true with the Death Clearance process. The return rate for hospital registrars was 100% of 572 cases with a DCO clearance rate of 63%. This rate was double the rate of non-hospital facilities and physicians. Although hospitals had a 2.5% reporting issues rate, no consistent issues were noted across the responses on the 572 data collection forms returned. Hospital registrars were most likely to attach medical documentation and respond with the necessary information to clear a case from DCO status. Hospitals were sent the least amount of Death Clearance follow back cases among which 35.5% were found to be non-reportable.

Nursing Homes/Hospice/Assisted Living

Nursing Home/Hospice/Assisted Living facilities in the state of Maryland received 635 Death Clearance follow back cases in the second year of follow back to these facility types. The return rate for Nursing Home/Hospice/Assisted Living facilities was 38% with a DCO clearance rate of 24.7% (22.2% reportable and 2.5% non-reportable). Personnel for these facilities were most likely to provide a medical code other than ICD-10 or ICD-O-3 to confirm the primary site of a tumor and were least likely to provide information on histology. Across many facilities, there was a misunderstanding of how to complete the Class of Case question listed on the data collection form. The Nursing Homes/ Hospice/Assisted Living personnel were most likely to provide insufficient information to clear a case from DCO status by either not providing the date of diagnosis or not providing information on medical confirmation. Personnel at these facilities were likely to call the technical phone line to inquire about completion of the data collection form and about becoming a reporting facility to the MCR prospectively.

Physicians

Physicians provided the most comprehensive information on cases returned and had the highest DCO clearance rate per returned cases when compared to Hospitals and Nursing Homes/Hospice/Assisted Living facilities by commonly providing commentaries which included accurate detailed information about the patient's cancer diagnosis. The return rate for physicians was 29% with a 28.1% DCO clearance rate of which 22.7% were reportable cancer cases. Therefore, if a case was returned to the MCR, it was most likely to be cleared from DCO status. However, the physician group had the highest amount of follow back cases at 752 forms and poorest response rate. Unique to the physicians reporting group was that they, in several cases, provided follow back information on the instruction packet versus the actual data collection form. This occurrence was not noted for other facility types. Two common issues to following back cases to physicians is returned unopened mail due to a incorrect address and responses received after the deadline.

Lessons Learned

Since there were interpretation issues among Nursing Homes/Hospice/ Assisted Living personnel, we will create a new form to be sent to these facilities. The new form will be more sensitive to persons not trained or experienced in cancer reporting. For example, *Class of Case* is a term particular to the cancer registry field. Therefore, we will revise the question for *Class of Case* to the following:

Table 2 – Revised Class of Case Question for future Data Collection form sent to Nursing Homes/Hospice/Assisted Living Facilities

Questions		
Does your facility have records on this patient?	*Yes*	*No*
	Your facility	Other facility – if so please provide the facility name
Where was patient diagnosed?		
Where was the patient treated?		
If no treatment, where was the decision not to treat made?		

To address the challenge of physicians completing follow back information on the instruction packet versus the data collection form, we will add a watermark stating "INSTRUCTIONS" to each instruction page.

The challenge of sending Death Clearance follow back cases to the correct address proves to be difficult. Central registry staff collects address information from the Maryland state physician license database. Therefore, these addresses should be correct and current. However, this is not the case. Since most of the Death Clearance follow back cases belong this group of reporters yet the wrong address/returned mail is highest for physicians as well, a cost/ benefit analysis should be conducted to explore the impact of following back Death Clearance cases to physicians.

Access to the technical phone line was helpful. The reporters who spoke to central registry staff at Westat completed the forms correctly in most instances. We will continue educating Maryland cancer reporters on the reporting requirements in Maryland and on how to complete death follow back forms with clear and concise instructions.

Overall, following back cases to both non-hospital and hospital reporters proved to be a successful and comprehensive process.

Funding

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