2020 NPCR UTAH CANCER REGISTRY SUCCESS STORY

STORY TOPIC/FOCI: Collaborative partnerships/projects, electronic reporting

STORY CATEGORY: Registry Operations

STORY TITLE: Implementing Standardized, Timely Death Certificate Reporting to a Central Cancer Registry through Collaboration with the State Office of Vital Records and Statistics

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SUMMARY

Utah Cancer Registry collaborated with the Utah Department of Health in a CDC-sponsored project to establish timely reporting of death certificates to our registry in a standard electronic format. This enabled the registry to receive records sooner and to incorporate them with high integrity and fewer manual steps. This standardization and improved interoperability of electronic death certificates supports the registry death clearance process, reduces reporting delays for cases identified from death certificates, and enables staff to know the accurate vital status of any case who is selected to be contacted for research.

CHALLENGE

Timely receipt of death certificates is important for central cancer registries. Death records are essential for a cancer registry process known as death clearance, which includes 1) matching death certificates to cancer registry records to obtain cause and date of death information for cases known to the registry and 2) finding potential unreported cancer cases based on death records that indicate cancer as a cause of death. In addition, for central registries that contact cases for research studies, up-to-date death records are important to avoid the situation in which the registry staff may inadvertently mail research recruitment information addressed to an individual who is deceased. The Utah Cancer Registry previously received electronic death certificates from the Utah Department of Health Office of Vital Records and Statistics as an initial incomplete record followed by a final version of the same record. The process required that a health department programmer periodically download, compile, and transmit batches of records. The death records were received in a non-standard fixed-width format that also required manual processing steps at the cancer registry before import into the cancer registry data management system. The cancer registry experienced delays in some cases of more than six months from the time a death certificate was finalized until it was linked to a cancer case. This meant that vital status and survival information for some cancer cases was not up-to-date in the registry. For cancer cases not otherwise reported to the registry but identified through death records with cancer as cause of death, the process of follow-back to obtain diagnosis information from health care facilities and offices was more difficult if receipt of the death record was delayed and more time had elapsed since the cancer diagnosis.

SOLUTION

With support from CDC under the award "Improving the Timeliness and Quality of Drug Mortality Data and the Interoperability of State Electronic Death Registration Systems", Utah Cancer Registry collaborated with the Utah Department of Health Office of Vital Records and Statistics and the Health Informatics Office to establish reporting of death certificates to the registry in a standardized electronic format. The Health Informatics Office developed the informatics capability to export death records in a standardized HL7 format and to transmit these in almost-real time. Cancer registry and vital statistics staff collaborated to determine which variables from the HL7 Implementation Guide for Vital Records Death Reporting should be included in the death records created for a cancer registry. Variables were chosen based on availability and on the registry's information needs. Specifically, the cancer registry requires individual identifiers to match death records to cancer cases, and cause of death and date of death for individuals who link. For the situation in which a death record indicates cancer as a cause of death but does not link to a case previously reported to the cancer registry, the registry requires information about the health care provider and/or facility so that registry staff can follow back and obtain cancer diagnosis information to complete the death clearance process. The health department first submitted test files for the cancer registry to validate, and then began to transmit death records automatically as they were finalized. Utah Cancer Registry worked with its database management system vendor to create a process and rules for how these records are imported and matched in the database.

RESULTS

Following implementation of the project to share standardized, interoperable, and timely electronic death records, Utah Cancer Registry now receives death records via SFTP every forty-eight hours and registry staff have implemented script to automatically import them with high integrity into our database management system.

Utah Cancer Registry noted two significant differences in variables available from death records in the original, non-standard fixed-width format to those in the standardized HL7 format. First, HL7 files did not include identifiers for an informant, and second, the HL7 files include a variable describing time from onset of the primary cause of death. The informant, usually a next-of-kin, is sometimes contacted by a central registry to follow-back cases not otherwise reported. However, this is not a preferred approach and Utah Cancer Registry has found that this process required considerable staff time, often without yielding information that could not be obtained from other sources. The time-from-onset variable has proven to be useful in death clearance because it provides an approximate date of diagnosis, a data item that was not previously included in the death certificate files. When the only source of information is the death certificate, the registry may be forced to use the date of death as the date of diagnosis. The time from onset variable provides the registry with a better estimate of the diagnosis date.

Another advantage to the new process for sharing death certificates is that this process provides just one, finalized record so that the registry no longer has to manage or reconcile both an initial and final death record for the same case. Additionally, since implementing the new death certificate process, we have identified 22 cases selected to be contacted for a research study who were recently deceased. The timely death certificate information saved staff time checking other sources to attempt to confirm that the case was alive and prevented any potential distress to a family member from receiving mail addressed to a decedent. Utah Cancer Registry has begun to evaluate our death clearance process to assess whether other changes to workflow can be implemented to take advantage of the faster receipt of death records.

SUSTAINING SUCCESS

The new process has proven more efficient for both Utah Cancer Registry and Utah Department of Health Office of Vital Records and Statistics and addresses several challenges that we experienced under the old process. The Utah Cancer Registry will continue with this new process and will evaluate and improve the death clearance processes to best utilize the timely death records. The use of standardized, interoperable, HL7-format death certificates should be generalizable to all states.

REGISTRY CONTACT INFORMATION

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