

2019 NPCR UTAH SUCCESS STORY

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Improving Interstate Data Exchange by Sharing Electronic Pathology Reports

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: Utah Cancer Registry implemented workflow changes and a novel data extract process to share electronic pathology (e-path) reports through Interstate Data Exchange. When a cancer case is diagnosed or treated in one state but resides in another state, the abstract is shared with the home state through Interstate Data Exchange. Utah Cancer Registry recognized that we receive many e-path records for non-resident cases, but the e-path was not being shared. In 2019, we implemented workflow changes and created a novel data extract strategy to share e-path records. Receiving states reported success importing the files and commented favorably about the value of this new data stream.

CHALLENGE: When a reportable cancer case is diagnosed and/or treated in one state but resides in another state, the central cancer registry of the state where the case is reported shares information with the state of residence through Interstate Data Exchange. The central registry sends the North American Association of Central Cancer Registries (NAACCR)-format abstract received from a provider to the case's state of residence. However, this data sharing does not usually include the pathology report for the case. This is a potentially significant gap in cancer surveillance for two reasons. First, there are a proportion of cancer cases who are initially ascertained by a central registry based on a pathology report but no abstract, i.e. "pathology-only" cases. The pathology-only case will be missed if the pathology report is sent to the central registry for the state where the case was diagnosed or treated but not to the state of residence. Second, for a case with a NAACCR abstract, the full-text pathology report provides additional detailed documentation for the case to the central registry.

Cancer specialty hospitals located in Utah are the closest tertiary care facilities for cancer for residents of substantial areas of the intermountain west, including rural and frontier regions of Idaho, Wyoming, Nevada, and Montana. Therefore, Utah Cancer Registry receives many reports of cancer in patients who are diagnosed and/or treated at Utah facilities but are not Utah residents. For example, 12.5% of pathology reports received by Utah Cancer Registry for diagnosis year 2017 were for patients who reside in other states. This issue was raised in discussion with CDC NPCR staff. Utah Cancer Registry and CDC agreed that sending these reports to the states of residence would be beneficial to the receiving central registries. However, we had no established mechanism to extract or share e-path records.

SOLUTION: Utah Cancer Registry worked with partners including our Advisory Committee, central cancer registries for adjacent states, and our data management software vendor IMS Inc. to modify our workflow and to develop a novel extract process to share e-path records.

Prior to this project, Utah Cancer Registry's work flow for initial screening of incoming pathology reports had been to use a single "non-reportable" code for in-state patients with a non-reportable diagnosis and for cases not reportable in Utah because the patient was a resident of another state. Based on review of our state cancer reporting rule and discussion with our Advisory Committee, it was determined that pathology reports describing a non-reportable diagnosis should not be shared with another state. In order to share only reports representing reportable diagnoses, it was necessary to change our pathology screening workflow. Utah Cancer Registry changed our process so that staff code the diagnosis for every e-path report as reportable vs. non-reportable regardless of state of residence. Further, for reportable diagnoses for non-Utah residents, Utah Cancer Registry also added coding of site, histology, behavior, and laterality to our work flow.

We sought to share an electronic record that would include standard e-path fields including patient and provider identifiers and pathology report text, as well as site, histology, behavior, and laterality as coded by Utah Cancer Registry staff, for Interstate Data Exchange. The data management system used by Utah Cancer Registry, SEER*DMS, has a function to extract NAACCR-format abstracts for Interstate Data Exchange, but there was no extract function for e-path built into SEER*DMS. We communicated with software vendor IMS Inc. and with central registry staff for adjacent states to decide on an extract format that we expected could be imported by the receiving state registries. Utah Cancer Registry staff then developed a custom extract for SEER*DMS and wrote SAS code to be applied outside of SEER*DMS to format the files. This two-step process resulted in e-path reports in a NAACCR HL7 format. The HL7 records were validated using the HL7 Messaging Workbench and NAACCR Volume V profile to verify conformance with the NAACCR HL7 guidelines. Utah used standard methods including N-IDEAS, SFTP, and secure encrypted email to transfer the HL7 e-path reports to the state of residence. After files were sent, we communicated with some receiving registries to learn whether the records had been successfully imported to their data management systems and to obtain their assessment of the value of the new data stream.

RESULTS: Utah Cancer Registry shared a new data stream of e-path reports in a NAACCR HL7 format to other states through Interstate Data Exchange. Utah sent 4,502 e-path records, representing an estimated 2,562 cases, with event date or diagnosis date in calendar year 2017. The largest number of e-path records were for residents of adjacent states Idaho, Nevada, and Wyoming (Table 1).

Table 1. Cancer cases with e-path records received by Utah Cancer Registry and shared with state of residence, by type of record shared, diagnosis or event year 2017

State of Residence	Total cases with e-path shared	Type of Record Shared	
		Abstract and e-path	e-path only
Idaho	1,044	680	364
Nevada	511	401	110
Wyoming	486	384	102
Montana	140	98	42
Colorado	119	39	80
Arizona	75	50	25
California	41	17	24
Florida	21	12	9
Other states*	125	65	60
TOTAL	2,562	1,746	816

*States with fewer than 20 cases grouped as "other"

For approximately two-thirds of the cases with e-path, 1,746 or 68%, Utah Cancer Registry had also received a NAACCR-format abstract from a provider and shared both type of records with the receiving registry. The other 32% or 816 cases had e-path as the only type of record sent from Utah Cancer Registry. This latter group were potentially pathology-only cases, but some of the cases may have been reported with a NAACCR-format abstract to the home state registry. Among the apparent pathology-only cases, over three hundred were melanoma of the skin. Many melanomas are treated in non-hospital settings and therefore it is important for registries to obtain pathology records for this site.

Among the receiving registries that provided feedback about this process, most reported that they were able to incorporate the NAACCR HL7-format e-path that Utah shared into their data management systems. This included successful import into SEER*DMS and into eMaRC Plus. The estimate of the number of new cases for a registry based on e-path received from Utah ranged from none to "about 60-80". Some registries reported that the e-path received from Utah all matched cases for whom they had already received a NAACCR-format abstract, but for some they were missing the pathology report and welcomed the e-path from Utah to complete their documentation.

A potential obstacle to implementing the sharing of e-path in other states is that the sending registry will incur an additional burden of work for staff to screen each e-path record for a resident of another state for reportability and optionally to code basic pathology information. Because some states send larger numbers of cases via Interstate Data Exchange than they receive, this burden will be unequal across registries. Utah's extract and SAS code can be applied in other central registries that use SEER*DMS. Registries that use other data management systems would need to evaluate possible technical barriers for extracting e-path from their system. The benefits of sharing e-path are both case ascertainment for "pathology only" cases and completion of documentation for other cases.

SUSTAINING SUCCESS: Utah Cancer Registry successfully implemented workflow changes and data extract techniques to share a new data stream, e-path reports, through Interstate Data Exchange. Receiving states were able to incorporate the e-path into their data management systems. We believe that some of the e-path represent pathology-only cases that will be important for case completeness in the receiving state. This approach will be sustained in Utah and can be applied in other states. Utah Cancer Registry will share methods and codes for extracting e-path. We anticipate that in future, vendors of cancer data management systems will incorporate functions to extract e-path.

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