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Improving Central Cancer Registry Surveillance through Interstate Data Exchange of Electronic Pathology Reports

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Abstract

When a cancer case is diagnosed or treated in one U.S. state, but the patient resides in another, the case report abstract is shared with the central cancer registry in the state of residence through interstate data exchange. However, the records shared may not include pathology reports. Cases diagnosed in another state that would be ascertained only from pathology reports thus may be missed. Utah Cancer Registry received many electronic pathology (e-path) records for non-resident cases that were not being shared. In 2019, Utah Cancer Registry implemented workflow changes and created a novel data extract process to share e-path in a North American Association of Central Cancer Registries (NAACCR) HL7 format. Utah Cancer Registry shared e-path records for an estimated 2,773 cases with other states for the diagnosis year 2018. Of these cases, both an e-path record and NAACCR-format abstract were shared for 1,709 (61.6%), whereas e-path only was shared for 1,064 (38.4%). The largest number of e-path went to two adjacent states, Idaho (n=1,084) and Wyoming (n=621). Receiving registries reported success importing the files. The e-path data stream resulted in ascertainment of 96 new cases for Idaho and 89 for Wyoming for diagnosis year 2018. Whereas most shared e-path represented cases already known to the receiving registry, registry staff provided feedback that it was beneficial to obtain

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the additional documentation. Linking and reviewing the shared e-path did represent additional workload. Central cancer registries can adopt this process for sharing e-path via interstate data exchange to support complete case ascertainment in collaborating states.

Keywords

Cancer Registries; Cancer Surveillance; Pathology; Data Sharing; Interstate Data Exchange

Introduction

Central cancer registries should capture all incident cancers occurring in their catchment area to assure high-quality data and to provide complete population-based estimates of cancer incidence.[1] In the United States (U.S.), many cancer patients are diagnosed or treated outside of their state of residence. Therefore, achieving ascertainment completeness is reliant on exchange of data among the network of central cancer registries across the U.S.[2]

Regulations in each state direct providers to report cancer cases to the central cancer registry (e.g., Utah Cancer Reporting Rule)[3] and do not limit that reporting to patients who are residents of the state. The program standards for the Centers for Disease Control and Prevention's National Program of Cancer Registries also state that central cancer registries should collect data on patients who were diagnosed or who received the first course of treatment in the registry's state or territory, regardless of the patient's state of residence.[4] Through the interstate data exchange process, the central cancer registry of the state where the case is reported (sending registry) shares information with the central cancer registry in the state of residence (receiving registry). A National Interstate Data Exchange Agreement establishes the terms of this data exchange, and the majority of registries in the United States, including Utah, have signed the agreement.[5, 6]

Typically, sending registries share the case report received from a hospital or other provider in an abstract format specified by the North American Association of Central Cancer Registries (NAACCR).[7] However, this interstate data sharing often does not include pathology reports. This is a potentially significant gap in cancer surveillance because some cancer cases are ascertained by a central registry based on only a pathology report and no abstract, i.e., "pathology-only" cases. Pathology-only cancers include cases diagnosed in non-hospital settings, as is often the case for melanomas and early-stage prostate cancers, and are challenging to capture.[8–11] This problem of ascertainment is compounded when the cancer is not diagnosed in the patient's state of residence. Thus under commonly-used interstate data exchange data practices, pathology-only cases will be missed if the pathology report is sent to the central registry for the state in which the case was diagnosed or treated but not to the state of residence. We hypothesized that sharing of pathology reports through interstate data exchange could help registries in the ascertainment of hard-to-capture pathology-only cases. Additionally, even for a case for which a NAACCR abstract is available, sharing of full-text pathology reports through interstate data exchange may provide needed additional documentation about the case to the receiving registry.

Cancer specialty hospitals located in Salt Lake City, Utah are the closest tertiary care facilities for residents of substantial areas of the intermountain west, including rural and frontier regions of Idaho, Nevada, Wyoming, and Montana. Many patients who reside in other states in the region travel to receive cancer care in Utah. The Utah Cancer Registry receives electronic pathology reports (e-path) for potentially reportable diagnoses from laboratories located in Utah, including large regional labs affiliated with the cancer specialty hospitals. The e-path records received by Utah Cancer Registry include many reports of cancer in patients diagnosed and/or treated at Utah facilities but are not Utah residents, but we had no standard process of sharing e-path between central cancer registries.

We initiated sharing of e-path reports from Utah through cancer registry interstate data exchange and evaluated the process. We sought to determine whether there were regulatory barriers to this additional data sharing, what workflow changes were needed to accommodate the exchange of e-path reports, and how many new cases would be ascertained by receiving registries. We present the results of the sharing of pathology reports from Utah Cancer Registry to central cancer registries in several states in the region for diagnosis year 2018 through interstate data exchange. We discuss the potential of this process for supporting central cancer registries' data quality and completeness.

Methods

Utah Cancer Registry staff examined legal and regulatory issues that might affect our disclosure of identifiable e-path reports. We reviewed the NAACCR Interstate Data Exchange Agreement[6] and Utah state regulations and agreements governing the central cancer registry. We discussed the issues with our Utah Cancer Registry Advisory Committee.

We evaluated our workflow to develop a strategy for exporting e-path for non-residents for exchange. The data management system used by Utah Cancer Registry, SEER*DMS,[12] has a function to extract NAACCR-format abstracts for interstate data exchange, but there was no extract function built-in for e-path. We discussed options for creating NAACCR HL7 e-path files with the software vendor, IMS Inc. We communicated with staff of central cancer registries in adjacent states to determine whether they could process this file format. Utah Cancer Registry staff then developed a custom extract to retrieve e-path data items from SEER*DMS and wrote SAS[13] code to format the files once outside of SEER*DMS. This two-step process resulted in e-path reports in a NAACCR HL7 format. The HL7 records were validated using the HL7 Messaging Workbench application and NAACCR Standards for Cancer Registries Volume V profiles to verify conformance with the NAACCR HL7 guidelines.[14, 15] Utah Cancer Registry staff used standard secure exchange methods including National Interstate Data Exchange Application System (N-IDEAS),[16] secure file transfer protocol (SFTP), and encrypted email to transfer the HL7 e-path reports to the central registry in the state of residence for each case. We tracked the number of reportable e-path records that Utah Cancer Registry shared with event dates in calendar year 2018. We summarized records sent by Utah Cancer Registry to receiving registries and the type of records shared (abstract only, pathology report only, both abstract and pathology report).

Receiving registries incorporated these records into their data management systems and reviewed them to determine how many represented a new case.

Results

For the question of whether there were regulatory barriers to sharing e-path, we noted that the NAACCR Interstate Data Exchange Agreement describes data to be exchanged as “resident cancer case information” and “all cancer registry records and information concerning cases.”[6] The agreement also includes the language “the data shall be formatted to follow the most current NAACCR data exchange record layout.” In practice, the records exchanged between central cancer registries have often been limited to NAACCR-format abstracts received from providers, but the agreement language “all cancer registry records and information” can be interpreted to extend to cover e-path records. After review of the Utah rules and agreements governing the central cancer registry, and discussion with our Utah Cancer Registry Advisory Committee, it was determined that sharing of identifiable e-path records describing reportable cancer cases is appropriate. However, under data privacy rules in Utah, a pathology report with findings that do not describe a reportable cancer diagnosis should not be disclosed.

Prior to this project, during Utah Cancer Registry’s initial screening of incoming pathology reports, a record could be categorized as non-reportable in Utah because either (a) the patient was a resident of another state, or (b) the record described a Utah resident with a non-reportable diagnosis, using the same “non-reportable” code for either criterion. In order to share reports representing reportable diagnoses in residents of other states, it was necessary to change our pathology screening workflow to one in which the staff member first coded every e-path report as a reportable or non-reportable diagnosis, regardless of state of residence, and then used another field to code for out-of-state residents. We also began coding the site, histology, behavior, and laterality for reportable diagnoses for non-Utah residents.

After this new workflow was applied to all e-path for event year 2018, we identified 4,476 e-path records describing reportable diagnoses for residents of other states. These accounted for 13.0% of pathology reports received by the Utah Cancer Registry for 2018. Ninety-seven percent of the e-path records for non-residents were submitted by laboratories affiliated with large cancer specialty hospitals in Utah. Based on auto-consolidation by the SEER*DMS system, the 4,476 e-path for non-residents represented 2,773 cases. For 1,709 (61.6%) of these cases, the SEER*DMS system matched the case to a NAACCR-format abstract received from a Utah hospital (Table 1). There were 1,064 (38.4%) out-of-state cases for whom an e-path record was the only information received by Utah Cancer Registry. Melanoma of the skin comprised 17.9% of the shared e-path only-cases. Utah Cancer Registry also shared 667 NAACCR-format abstracts without e-path (not shown in the table) for the 2018 diagnosis year.

The largest number of e-path records shared were for residents of adjacent states Idaho, Wyoming, and Nevada (Table 1). Among potential “e-path only” records, the largest number were for melanoma, followed by breast and prostate cancers.

Staff from receiving registries in neighboring states Idaho, Wyoming, Montana, and Colorado provided feedback about this process. They reported that they were able to incorporate the NAACCR HL7-format e-path from Utah into their data management systems. This included successful import into two commonly-used registry software programs, SEER*DMS and the Centers for Disease Control and Prevention (CDC)'s Electronic Mapping, Reporting, and Coding (eMaRC) Plus.[17] Receiving registries' staff reported that some e-path received from Utah Cancer Registry matched cases for whom they had already received a NAACCR-format abstract but had not obtained a pathology report. Some e-path records from Utah Cancer Registry proved to be duplicates, i.e., the same e-path report had been received directly by receiving registry. There were also e-path that the receiving registry determined to be a recurrence or, for some other reason, to be not a reportable incident case.

Receiving registries reported identifying new, previously unknown cases based on the shared e-path (Table 2). The Cancer Data Registry of Idaho created 96 new cases for which the only source of information was e-path from the Utah Cancer Registry (Table 2). The Wyoming Cancer Surveillance Program reported 89 new cases, the Montana Central Tumor Registry identified 26 new cases, and the Colorado Central Cancer Registry identified 30 new cases. Melanoma was the most frequent cancer site among the new cases from e-path, with melanoma representing 80.0% of Colorado's newly identified cases and 44.8% of Idaho's new cases, but smaller proportions for Wyoming and Montana (13.5% and 3.8%, respectively). Prostate cancer was the second-most frequent site among new cases from e-path.

Discussion

Utah Cancer Registry successfully implemented workflow changes and data extraction 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. Feedback from receiving registries was favorable, indicating that the e-path provided new and needed information. The e-path records shared included pathology-only cases that Utah Cancer Registry would not have sent under standard exchange practices.

Four adjacent states ascertained a total of 241 new cancer cases based on e-path records received from the Utah Cancer Registry via interstate data exchange. Melanoma of the skin, a cancer site for which central cancer registries face a challenge of ascertaining many non-hospital cases from pathology,[8, 9] proved to be a site for which e-path exchange was particularly beneficial for case-finding. Results from receiving registries in four adjacent states confirm that e-path sharing is valuable for identifying melanoma cases. There was apparent variation in the importance of shared e-path for identifying new melanoma cases across receiving registries. This variation may be the result of differences in practice patterns in referral of patients to specialty care in Utah. Prostate cancer was the second-most frequent cancer site for new cases ascertained from shared e-path.

Our report represents the experience of only one state as a sending registry. States differ in their overall proportions of records sent and received in interstate data exchange, and

practice and reporting patterns will influence the likelihood of ascertaining new cases through exchange of e-path. For the most recent complete reporting year, 2017, Idaho, Montana, and Wyoming had reportable incident cancer case counts of 8,624, 6,426, and 2,875 respectively,[18] and so new cases ascertained from shared e-path as documented in this report represent approximately 1% of incident cases in those states. In the context of states where crossing state lines for specialty health care is common, e-path reported to a central registry in an adjacent state are a data source that should not be ignored.

Utah Cancer Registry intends to continue the practice of providing e-path records through interstate data exchange. It is feasible for other registries to implement similar processes. Utah Cancer Registry's extract and SAS code will be shared and can be applied in other central cancer registries, not limited to those that use SEER*DMS. An HL7 export for e-path has recently been implemented in SEER*DMS. Users of CDC's data management software system eMaRC can create a NAACCR-format abstract from an e-path record. If central cancer registries using eMaRC follow this process for e-path describing non-residents, it should then be possible to export these records from eMaRC for interstate data exchange. This is already a practice for some states as sending registries in interstate data exchange, for example, Montana and Colorado. Central cancer registries that use other data management systems would need to evaluate possible technical barriers for extracting e-path records from their system.

The Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) is developing a cloud-based platform to standardize sharing of electronic reporting from laboratories that have nationwide client bases to central cancer registries.[19] However, current applications for this platform do not include hospital laboratories and regional laboratories, the types of labs that supplied most of the e-path reports that the Utah Cancer Registry shared with other states.

The largest obstacle that we anticipate to broader implementation of e-path sharing by central cancer registries in other states is the additional workload. Our experience was that the sending registry incurs additional workload of screening each e-path record for an out-of-state resident to assess reportability and workload of setting up a mechanism to export the records. Volume of interstate data exchange is recognized to affect costs of operations of central cancer registries.[20] Because some states send larger numbers of cases than they receive, the burden will be unequal across sending registries. The receiving registries will incur workload of incorporating the new data stream into their data management systems and reviewing the records. Based on our experience reported here, receiving registries will invest staff time in resolving a proportion of records that do not result in new information, such as duplicates or pathology reports describing recurrences. The amount of staff effort required for these processes will differ among receiving registries according to the capabilities of their data management systems. We anticipate that after the first year of experience with including e-path in interstate data exchange, familiarity with the process should reduce the workload.

This paper demonstrates the value of sharing pathology reports through interstate data exchange for improving central cancer registries' ascertainment of hard-to-capture

pathology-only cases. Sharing of full-text pathology reports through interstate data exchange also provided additional detailed documentation for some cases for which a NAACCR abstract was available, also supporting data quality.

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Table 1.

Estimated cancer cases with e-path records shared from Utah Cancer Registry to other state of residence, by receiving state, cancer site, and type of record shared, event year 2018

	Total cases with e-path shared		Type of Record Shared			
			Abstract and e-path		e-path only	
	n	%	n	%	n	%
Total	2,773		1,709		1,064	
State of Residence						
Idaho	1,084	39.1	624	36.5	460	43.2
Wyoming	621	22.4	443	25.9	178	16.7
Nevada	560	20.2	402	23.5	158	14.8
Montana	160	5.8	99	5.8	61	5.7
Colorado	121	4.4	38	2.2	83	7.8
Arizona	61	2.2	42	2.5	19	1.8
Other states	166	6.0	61	3.6	105	9.9
Site						
Breast	394	14.2	247	14.5	147	13.8
Skin Melanoma	292	10.5	102	6.0	190	17.9
Prostate	273	9.8	209	12.2	64	6.0
Colorectal	175	6.3	110	6.4	65	6.1
Lung	138	5.0	97	5.7	41	3.9
Non-Hodgkin Lymphoma	129	4.7	84	4.9	45	4.2
Brain and Nervous System	111	4.0	82	4.8	29	2.7
Leukemia	111	4.0	87	5.1	24	2.3
Oral Cavity and Pharynx	109	3.9	53	3.1	56	5.3
Bladder	109	3.9	76	4.4	33	3.1
Other	932	33.6	562	32.9	370	34.8

Table 2.

Number of new cases ascertained by receiving states based on Utah Cancer Registry interstate data exchange e-path only, diagnosis year 2018

	Receiving registry							
	Idaho		Wyoming		Montana		Colorado	
	n	%	n	%	n	%	n	%
Total new cases	96		89		26		30	
Melanoma	43	44.8	12	13.5	1	3.8	24	80
Prostate	7	7.3	10	11.2	6	23.1	0	0.0
Breast	5	5.2	7	7.9	3	11.5	1	0.3
Colorectal	3	3.1	5	5.6	0	0.0	0	0.0
Other	38	39.6	55	61.8	16	61.5	5	16.7