2020 NPCR RHODE ISLAND CANCER REGISTRY SUCCESS STORY

STORY TOPIC: Completeness in cancer data collection and reporting

STORY CATEGORY: Registry Operations

STORY TITLE: A Cancer Surveillance Gap Was Filled by Resumption of Veterans Affairs Data Release

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SUMMARY

Rhode Island Cancer Registry (RICR) established Data User Agreement (DUA) with Providence Veterans Affairs Medical Center (PVAMC) in April 2018 to resume PVAMC's data release to RICR. RICR and PVAMC Registry took two and half years to troubleshoot persistent data transmission barriers. Starting from November 2019, RICR could receive and merge more than 1,800 PVAMC abstracts into the RICR database. RICR now includes, in statewide surveillance reporting, cancer incidence among Rhode Island veteran population, and narrows a reporting gap of many years. Timely capturing of VA cases is also critical to collect complete and quality information.

CHALLENGE

The Providence Veterans Affairs Medical Center (PVAMC), the only inpatient care VA facility in the state, serves more than 62,000 veterans in Rhode Island.[1] Veterans make up 6% of Rhode Island population. Like national statistics, most veterans in Rhode Island are men (92%) and age 55 years and older (68%).

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[1] Living Veterans By State, Age Group, and Gender, 2018-2048. U.S. Department of Veterans Affairs. National Center for Veterans Analysis and Statistics. Extracted October 6, 2020. https://www.va.gov/vetdata/Veteran_Population.asp

Until 2007, cancer reports from PVAMC were transmitted to RICR as required by state law. In 2007, the U.S. Department of Veterans Affairs issued a policy change and required a DUA between state central cancer registries and VA facilities. Thereafter, PVAMC did not release its data to RICR. As rates of aging and risk of cancer development among aging veteran population were progressing rapidly, a growing concern was under-reporting of cancer burden attributed to missing PVAMC reports. To fill a gap in data collection and reporting since 2007, RICR set an objective in DP17-1701 to establish an agreement between PVAMC and RICR, and resume PVAMC's data release to RICR.

SOLUTION

In April 2018, DUA was successfully developed between Rhode Island Department of Health (RIDOH) and PVAMC, with authorizations from RIDOH Director and PVAMC Director. However, DUA

establishment did not automatically allow RICR to obtain PVAMC's data. For 2 and ½ years until November 2019, staff in RICR and PVAMC Registry met numerous times to troubleshoot persistent data transmission barriers, attributed to PVAMC's internet firewall and restrictive encryption protocol. Staff also consulted many VA facilities across the nation. Supported by PVAMC Information Technology (IT) Department, PVAMC data were eventually transferred and opened, via encrypted messaging (Nov 2019). From Nov 2019-Oct 2020, RICR could receive, review, process, and merge more than 1,800 PVAMC abstracts (diagnosis years: 2001-2017) into the RICR database.

Following milestone activities demonstrate how RICR and PVAMC endeavored toward the common goal – overcoming the IT barriers and challenges.

- April – May 2018: RICR and PVAMC Registry staff reviewed Rhode Island Regulations on cancer reporting; discussed required data items/format by central registry standards, and assured secured data transfer policies/measures, and confidentiality.
- October 2018: PVAMC applied for firewall waiver. However, PVAMC IT Department/ISO received a pushback for data transfer using ShareFile® – secured data transfer website used by all Rhode Island reporting facilities for monthly electronic data submissions to RICR. This was an unexpectedly surprising issue for RICR, because security measures and protocols were thoroughly reviewed and cleared by PVAMC IT/ISO before DUA was signed.
- February – September 2019: With no progress in IT clearance, PVAMC suggested data transfer, using alternative media, CD-ROM or USB thumb drive. PVAMC IT applied for waiver to have ability to copy and save VA Registry data to CD-ROM or USB. PVAMC CTR physically carried the disc to RICR office and tried to open the file at central registry computer. However, the file was corrupted and unable to be viewed. Despite multiple attempts and visits each other's office, PVAMC CTR failed to save and transfer its data in NAACCR format.
- October – November 2019: A possibility of RICR receiving encrypted emails from PVAMC was explored. Azure Rights Management Services (RMS) was set up on PVAMC and RICR computers, for email encryptions. PVAMC file was first time successfully transmitted to RICR and opened!

RESULTS

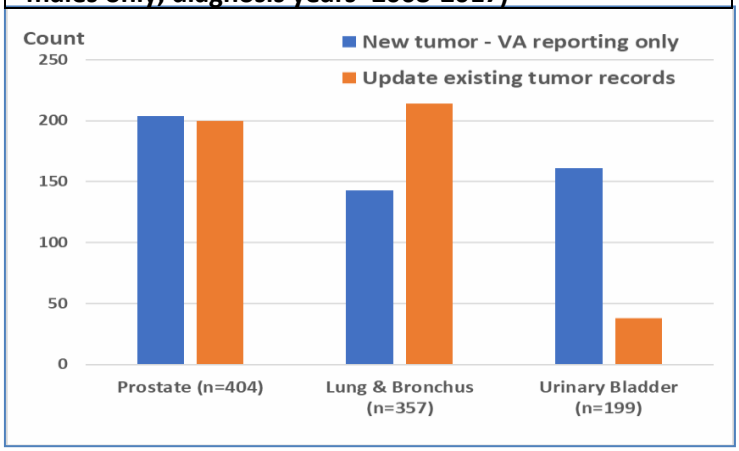
From November 2019 to October 2020, RICR received a total of 1,840 *unduplicated* records from PVAMC (not including pending records, as of October 2020). Of these, majority (98%) were tumor records diagnosed in 2007-2017 among male adults (age 20 years and older). Common cancers in the prostate, lung/bronchus and bladder consisted of approximately 60% of the reports (Table 1). Therefore, further analyses were restricted to these three (3) common cancers of males age 20 years and older.

To measure effects of PVAMC data inclusion in statewide cancer incidence reporting, PVAMC *abstract* records were categorized as (1) "*update*" when records were related with pre-existing tumors in RICR database, and PVAMC records updated/modified pre-existing reports (created from non-VA sources: hospitals, labs, radiation treatment facilities, and death certificates), and (2) "new" when tumors were reported by PVAMC only, and had not been reported by other facilities/sources, prior to PVAMC's submissions. Of 960 common male cancers diagnosed in 2008-2017, more than 500 were identified as

"new" cases; higher percentage of bladder cancers were newly added to RICR database, than prostate and lung cancers (Figure 1).

Table 1. PVAMC abstract records by primary cancer site (diagnosis years=2001-2017, submitted from Nov 2019-Oct 2020)	
Primary Cancer Site	**Count**
Prostate	447
Lung & bronchus	399
Urinary bladder (incl. in-situ)	218
Colon & rectum	102
Oral cavity & pharynx	70
Liver & Bile Duct	56
Skin Melanoma (excl. Basal & SCC)	54
Esophagus	45
Kidney & renal pelvis	45
Larynx	43
Stomach	40
Non-Hodgkin Lymphoma	35
Pancreas	31
Thyroid	31
Leukemia	29
Total*	1,803*

Figure 1. "New" PVAMC-only reporting cases *vs.* "Update" pre-existing cases (3 common cancers among males only, diagnosis years=2008-2017)



* Sites counted with less than 6 are not listed in the table;

Cell values do not add up to the total due to suppressed numbers.

Finally, age-adjusted rates for three (3) common cancers of the prostate, lung/bronchus, and bladder were calculated, using (1) all *consolidated* tumors *without VA-only reporting*, and (2) all *consolidated* tumors, as of October 2020. With this method, we could measure cancer incidence changes prior to and after PVAMC case inclusion, and an extent of RICR would have under-reported without VA data. Although incidence changes varied by year of diagnosis and cancer site, all 3 common cancers studied showed rate increases by 3-6% (all diagnosis years combined), attributed to PVAMC data inclusion in the RICR database (Table 2).

Table 2. Cancer Incidence of Male Common Cancers, RICR 2008-2017							
Cancer Site	Diagnosis Year	Cancer Incidence *without* PVAMC-only reporting NEW cases*		Cancer Incidence, *including* PVAMC-only reporting NEW		Change after PVAMC- only	
Prostate	2008	912	231.7	942	239.3	+30	1.03
	2009	805	201.4	833	208.3	+28	1.03
	2010	728	179.7	739	182.1	+11	1.01
	2011	779	189.5	807	196.0	+28	1.03
	2012	669	156.0	683	159.1	+14	1.02
	2013	585	134.1	604	138.0	+19	1.03
	2014	606	135.7	626	139.8	+20	1.03
	2015	627	138.3	644	141.9	+17	1.03
	2016	643	139.7	658	142.7	+15	1.02
	2017	691	146.2	713	150.7	+22	1.03
	2008-2017	7,04	163.6	7,24	168.	+204	1.03
Lung & Bronchus	2008	446	120.8	466	126.7	+20	1.05
	2009	448	119.3	460	122.2	+12	1.02
	2010	395	104.3	403	106.4	+8	1.02
	2011	428	111.7	434	113.2	+6	1.01
	2012	455	113.8	464	115.8	+9	1.02
	2013	448	110.9	458	113.3	+10	1.02
	2014	456	112.2	470	115.5	+14	1.03
	2015	458	109.3	472	112.7	+14	1.03
	2016	470	108.5	493	113.6	+23	1.05
	2017	396	89.8	421	95.3	+25	1.06
	2008-2017	4,40	110.0	4,54	113.	+141	1.03
Urinary Bladder	2008	257	71.0	268	73.8	+11	1.04
	2009	270	73.2	284	76.7	+14	1.05
	2010	220	58.4	233	61.9	+13	1.06
	2011	264	68.8	283	73.8	+19	1.07
	2012	274	69.6	285	72.3	+11	1.04
	2013	261	66.1	273	69.3	+12	1.05
	2014	257	63.1	272	66.4	+15	1.05
	2015	240	59.2	255	62.7	+15	1.06
	2016	237	56.6	264	62.4	+27	1.10
	2017	233	55.4	256	60.9	+23	1.10
	2008-2017	2,51	63.8	2,67	67.8	+160	1.06

* Case counts and rates were among male adults ages 20 years and older, as of October 2020.

SUSTAINING SUCCESS

RICR reached an agreement with PVAMC, and then identified a secure method that permitted PVAMC to overcome IT barriers and transfer its cancer data to RICR electronically. RICR now includes, in statewide surveillance reporting, cancer incidence among Rhode Island veteran population and narrows a reporting gap of many years. Our results demonstrate that additional cases attributed to VA reporting significantly change cancer statistics, particularly among males.

Finally, timely capturing of VA cases is critical to collect quality data, but also save central registry's resources. If PVAMC data submission had not been interrupted for many years since 2007, RICR would have saved time and labors that spent for addressing incomplete, inaccurate and often delayed information from non-hospital sources. Hundreds of PVAMC's tumor records submitted during 2009- 2010 were effectively used to correct and revise uncertain data fields, such as site code, diagnosis date, patient's demographics and more, in pre-existing reports that were generated from pathology reports, out of state registry data, or death certificates.

REGISTRY CONTACT INFORMATION

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