

2019 NPCR NEVADA SUCCESS STORY

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How Missing Data Can Build Partnerships

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: The Nevada Central Cancer Registry (NCCR) provides statistical data to assist epidemiologists, health researchers, and individuals in the medical and allied health professions. This data helps identify cancer risk, evaluate cancer patient care, and illustrate leading trends in cancer incidence, survival, and mortality in Nevada. NCCR has made great strides in data quality and completeness attributed to the process improvement and outreach activities and recognizes the need to work with non-hospital sources to improve cancer reporting. In 2016, NCCR began focusing on Medical Oncology practices and started working with Nevada’s largest cancer treatment center who were identified as non-reporters. This facility offers medical oncology, hematology, radiation oncology, breast surgery, pulmonary medicine, cancer genetic counseling and clinical research with 15 treatment centers and offices throughout Southern Nevada.

CHALLENGE: Nevada Central Cancer Registry contacted the facility in August of 2016 regarding complying to the requirements stated forth in Nevada Revised Statutes 457 and provided them with the reporting procedures and methods of submissions. The group initially did not agree that the facility was out of compliance with statutory and regulatory requirements.

SOLUTION: Over the next 12 months, facility administration and their legal team worked collaboratively with the Division of Public and Behavioral Health (DPBH) administration and the Nevada Attorney General’s office to understand NCCR’s intent for collection of cancer data and to develop a data use agreement which defined necessary data fields and responsibilities. During that time, this facility became an integral part of the work group to better define Nevada Administrative Code 457 which regulates the collection of NCCR data.

NCCR began work with the data team to seek a solution to extract and report the data since the data were collected across multiple data systems at multiple facilities. An extract needed to be created from their billing system to pull patients who were seen in a clinic during a specified period. Another extract was needed from their individual practices EHR software to pull treatment information. The facility stated the data may not be complete with all records without manual chart review which would require hiring third party staff at a significant expense to the individual medical oncology practices.

The solution was an Excel spreadsheet which included 5 tabs containing Patient Demographics, Diagnosis & Staging, Attending Physician, Medications, and Completed Treatment. Data was combined to create single patient records for processing. This initial process identified data quality problems and required many registry staff hours to perform data cleaning and transformation into a usable NAACCR format. Feedback and collaboration improved data submissions and reduced registry staff processing time.

RESULTS: While there were some initial challenges, the data received is a “win” for NCCR and the local, state and national cancer communities. Through demonstration of how cancer data is used and the benefits of more complete data, NCCR was able to help this facility understand the importance of accurate and complete information including the use of data to develop strategies for outreach and treatment. NCCR works collaboratively on data quality feedback and data submissions continue to improve with more complete data and better return on usable cases.

Data submissions from this facility began in July 2018 and the registry receives files on a quarterly basis. Submitted cases range from diagnosis years 1970 – 2019. The graph below demonstrates that a total of 6,577 new cancer cases for various data years were identified and 2,436 existing cancer cases were updated with additional demographic and treatment information.

YEAR	Total Cases Received	Cases with Valid Diagnosis & Staging Data	Cases after Linkage with Pathology	Cases after Linkage with Pathology	New Cases after Record Consolidation	New Cases by DX Year
2018	11,207 (4 Qtrs.)	7,039	5,286	2,436	2,850	2015 And Prior = 894 2016 = 161 2017 = 1,458 2018 = 382 Total = 2,850
2019	7,707 (3 Qtrs.)	4,572	3,727	0	3,727	2016 and Prior = 305 2017 = 1,382 2018 = 1,125 2019 = 915 Total = 3,727
TOTAL	18,914	11,611	9,013	2,436	6,577	

SUSTAINING SUCCESS: Continuous collaboration will build and support this partnership. Regular data feedback reports will improve data submissions and promote greater awareness and use of cancer registry data. As EHR systems improve, the registry hopes to transition to a fully automated data exchange.

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