2021 NPCR COLORADO SUCCESS STORY

Colorado Central Cancer Registry: John Arend, MPH

Linking the All-Payers Claims Database (APCD) to the Colorado Central Cancer Registry: An Evaluation

National Program of Cancer Registries
SUCCESS STORY

SUMMARY

All-Payer Claims Databases (APCD) serve as a valuable repository for public and private claims data for health care services provided to insured individuals within a state. Linked with Cancer Registry data, the APCD data can potentially provide longitudinal data to study cancer care and outcomes across multiple payers. The Colorado Central Cancer Registry (CCCR) linked cancer registry data with APCD data from the Center for Improving Value in Health Care (CIVHC), a non-profit organization authorized by the state of Colorado to collect claims data. Research partners from the University of Colorado Anschutz Medical Campus (CU) evaluated the quality and completeness of the linked data. While the overall match rate was high, nearly one third of all matches did not have a plan in the APCD at the time of cancer diagnosis.

CHALLENGE

Cancer registry data contains a vast wealth of information on patient and tumor-level diagnosis and staging data but may not adequately capture treatment information beyond the first course of treatment. Claims data contain patient-level longitudinal information on cancer screening, treatment, and payment information but lack the precise diagnosis date, cancer stage, tumor characteristics, and vital status found in cancer registry data. Linking these two sources of information can significantly expand the capability of each source but can be time-consuming to perform and there may be limitations on data release due to privacy concerns.

SOLUTION

To minimize the release of personally identifiable information (PII) and Personal Health Information (PHI), CIVHC, CU, and the CCCR worked together to create a minimally identifiable linked dataset. CIVHC provided a patient finder file to the CCCR with patient identifiers (APCD member ID, Social Security Number (SSN), date of birth (DOB), last name, first name and sex) for all individuals 21 years of age and older that appeared at least once in the APCD from 2012 to 2017. The CCCR linked the patient finder file with the CCCR database using Match*Pro software and returned only the list of matching APCD member IDs to CIVHC. CIVHC extracted all claims data for linked individuals and provided them to the CU researchers. The CCCR provided minimally identifiable information for both linked and non-linked patients, along with the APCD member ID for the matches. CU combined the two data files by APCD member ID. Initial analyses include an evaluation of linkage quality and a subsequent evaluation of insurance validity, comparing the value of Primary Payer at DX to the enrolled insurance plan within the APCD.

RESULTS

Of the 146,884 patients first diagnosed with cancer between 2012 and 2017, 136,613 (93%) were linked to the APCD finder file. Of the matches, two-thirds were exact matches on the five identifiers, another quarter were missing SSN but matched on all other identifiers, and the remaining individuals included partial matches identified through manual review. The overall match rate for the six-year period was high, though when the analysis was restricted to a time window around diagnosis, nearly one third of all matches did not have a health plan in the APCD, resulting in a lower linkage rate at the time of cancer diagnosis. However, with baseline information available from the registry, claims made after diagnosis could still be used for research. As the linkage covered multiple years, it is likely that these individuals were covered by plans that did not submit claims data or were uninsured at the time of diagnosis. According to the Primary Payer at DX field from the registry, most of these individuals had a private insurance plan (58%), were uninsured (3%), or had other health insurance plans (17%). The APCD does not include all private insurance plans, and does not include claims data for the uninsured, highlighting some of the limitations of the dataset.

When comparing Primary Payer at DX to health plan enrollment from the APCD for those that linked, there was a high positive predictive value of the registry classification for Medicaid (97%) and private insurance (86%) for those under age 65, meaning that if the registry coded that insurance type, it was usually correct. There was also a high positive predictive value of Traditional Medicare (74%) and Medicare Advantage (81%) for those over 65. However, the sensitivity – the probability that the registry correctly identifies the type of health plan for those who have the plan – for each of those categories was considerably lower than the positive predictive value. Additionally, the registry did not accurately capture dual patients (those enrolled in both Medicaid and Medicare) with more than two-thirds of those classified as dually insured being enrolled in either Medicaid or Medicare, but not both, according to the APCD data.

SUSTAINING SUCCESS

Many manuscripts regarding the linkage and initial analyses are awaiting publication. Researchers at CU also continue to pursue other proposed research questions using the linked APCD/CCCR dataset. Supplementing this research with additional states that can link APCD data to cancer registry data would facilitate comparisons and help to evaluate data quality. For the CCCR, with fewer than one in ten matches requiring manual review, future linkages with the APCD dataset are feasible. The biggest barriers to linkage are related to administrative and/or privacy concerns. Additionally, the CCCR is currently in the process of negotiating expanded access to the CIVHC APCD dataset to improve data quality and completeness of data within the registry. Based on the results of the insurance validity analysis, the CCCR will be providing additional instruction and coding clarification to facility abstractors to further improve the quality of the Primary Payer at DX field.

REGISTRY CONTACT INFORMATION

303-692-2540
https://www.colorado.gov/pacific/cdphe/cancerregistry