2022 NPCR COLORADO SUCCESS STORY

Colorado Central Cancer Registry; John Arend

Implementation of New and Emerging Biomarker Data Collection: The Colorado Experience

National Program of Cancer Registries
SUCCESS STORY

SUMMARY

The Colorado Central Cancer Registry (CCCR) embarked on a multi-phase effort to examine the availability of select biomarker and prognostic factor (BPF) data and establish statewide requirements for their collection. Eleven BPFs were selected for collection. New biomarker coding standards were incorporated into central cancer registry software and CCCR staff trained and provided data collection procedures, code sets, quality control procedures and edits to all Colorado registrars and facilities to incorporate into their electronic data collection systems. Three biomarkers collected by Colorado were adopted by national standard setters and are now required nationwide. The collection of three other biomarkers were discontinued in 2022. The remaining biomarkers will continue to be collected and evaluated regularly.

CHALLENGE

In an era of personalized medicine and targeted therapy, there is rising interest in using BPF data to provide the best treatment for cancer. National, statewide, and local cancer registry leaders have suggested the inclusion of biomarkers and prognostic factors to the standard transmission files. With support from the Centers for Disease Control and Prevention (CDC), the CCCR embarked on a multi-phase effort to examine the availability of select BPFs and establish statewide requirements for their collection.

SOLUTION

Using medical records from cancers diagnosed in 2017, the CCCR reviewed hospital-documented biomarker data to determine what data were available for coding and analysis. The CCCR aligned facility coding with the College of American Pathologists (CAP), Site Specific Data Items (SSDI), American Joint Committee on Cancer (AJCC), and National Comprehensive Cancer Network (NCCN) guidelines to create a standardized code set for each biomarker to align with clinical practice guidelines. New biomarker coding standards were incorporated into central cancer registry software and CCCR staff trained and provided data collection procedures, code sets, quality control procedures and edits to all Colorado registrars and facilities to incorporate into their electronic data collection systems. Starting with diagnosis year 2018, facilities were required to document select biomarkers in text fields. This allowed hospitals time to modify software, implement existing electronic pathology reporting protocols, and update infrastructure so that the biomarker data for cancers diagnosed in 2019 and later could be directly coded by facility registrars.

To evaluate the implementation, the CCCR distributed a survey to hospital registrars and their managers to get insight into the technical pieces of biomarker data collection. The survey quantified feedback from hospitals regarding the data collection process, the availability of biomarker and prognostic factors, and data quality at the facility level to garner registrar views on the project's strengths and weaknesses.

RESULTS

For the collection of the new fields, the stepwise implementation of the project allowed reporting facilities time to develop and adopt a new data collection protocol, which facilitated the collection of BPF data. Data completeness improved and the percentage of eligible cases coded to blank or unknown fell each year between the 2018 and 2020 diagnosis years. For example, for colorectal cancers diagnosed in 2018, 43% of eligible cases had microsatellite instability coded as "indeterminate" or blank. That percentage dropped to 38% for 2019 diagnoses, and further to only 30% for cancers diagnosed in 2020. Obtaining the biomarker data was more time-consuming than originally anticipated, however much of the data was readily available.

One biomarker that was not readily coded was Thyroid BRAF. Tests were not performed, or were not documented in the medical record, for more than 90% of eligible cancers. Based on feedback from registrars and physicians, thyroid BRAF was typically only collected if patients failed treatment and had a recurrence even though about 87% of all papillary thyroid cancers are BRAF positive. The difficulties encountered by the central registry staff's initial collection of data proved invaluable in training registrars for what to look for and how to interpret results.

The time spent reviewing the charts and records also guided our code sets to take advantage of the data that was available. In 2020, three biomarkers collected by Colorado were adopted by national standard setters and are now required SSDIs nationwide. The SSDI coding definitions align almost exactly to those developed by Colorado, which will allow for seamless comparisons of data across years.

Responses to the Colorado biomarker survey were extremely helpful in identifying the biomarker collection burden and areas for improvement. The survey was distributed to 75 registrars across the state, with 49 registrars responding. Of the respondents, 44 had at least 5 years of registry experience. The respondents overwhelmingly felt that the process implemented by the registry was "very good" or "excellent", with almost 90% responding that they received adequate training from the state registry. Most respondents reported that it took less than five minutes to code any biomarker; however, the thyroid biomarkers took longer and were the most challenging to find and collect. Respondents felt that most of the Colorado-specific biomarkers could be collected nationally.

SUSTAINING SUCCESS

As we move forward, the CCCR plans to use a blended approach to biomarker data collection. As stated previously, three Colorado BPFs have already been adopted by national standard setters. Colorado registrars will transition to collecting those SSDIs and the matching Colorado fields will be phased out. Colorado also will no longer require the collection of thyroid BRAF, Thyroid Mutant Allele Frequency, or Melanoma BRAF Assay Sensitivity. The lack of available data, as well as the time and effort required to code those fields, outweighed the potential value of continued collection. The remaining biomarker fields will continue to be collected and evaluated at regular intervals to ensure that registrars' time and energy are well-spent. We also plan to leverage existing relationships with labs to implement electronic feeds, where possible. Our goal is to reduce the time and effort required to collect these important fields while continuing to receive high-quality data.

STORY QUOTE

"I was at CCCR when biomarkers were being explored and the team did much research and discussion on what to implement and how to do it. They completely did their homework." – Survey Respondent

REGISTRY CONTACT INFORMATION

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