

2021 NPCR CALIFORNIA SUCCESS STORY

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Collection of Genomic Biomarkers by the California Cancer Registry: A Collaborative Pilot to Enrich Cancer Registry Data

National Program of Cancer Registries SUCCESS STORY

SUMMARY

Funded by the Centers for Disease Control and Prevention (CDC), the California Cancer Registry (CCR) worked with multiple partners to conduct a pilot project collecting and processing genomic biomarker data that was not yet part of the registry data warehouse or national data standards (novel data items). Two approaches were implemented: (1) electronic pathology data collection utilizing standards defined by the College of American Pathologists (CAP) and (2) manual data collection based on federal standards developed by the North American Association of Central Cancer Registries (NAACCR). The pilot found that the collection of novel prognostic factors is possible but not efficient at the population level. However, lessons learned from the pilot may be useful in designing systems to acquire novel data items for targeted research studies.

CHALLENGE

Two critical challenges were encountered in this pilot:

1. Data mapping: Translation of electronic data in the CAP electronic cancer checklist format to NAACCR standard formats was a challenge due to the specialized technical nature of the task and the time required.
2. Data Use: It is well known that data use drives data quality. Identification of potential partners to use the resulting genomic data for research purposes was a challenge.

SOLUTION

To overcome the mapping challenge, California collaborated with the CDC to procure resources to complete the translation effort. This required planning and tracking on the parts of both partners. California has not identified a solution to the data use challenge. This contributed to our recommendation to focus on and facilitate targeted collection of novel prognostic factor data based on targeted requests by researchers with a pre-defined use case and sub-population foci.

RESULTS

The pilot process successfully collected both electronic and manual biomarker data. Collaboration with the CDC, the Cancer Registry of Greater California, and the College of American Pathologist was integral to this success. California captured structured biomarker data from 42 unique facilities through electronic data streams after working extensively with CDC to ensure data integrity as it flowed from the reporting source (electronic message) through eMaRC to the CCR interface engine. In addition, California manually captured biomarker data from six reporting entities. Though data capture was successful, the workload involved in maintaining this data capture through either route is not practical on an ongoing, population-based level unless a clear and cogent need is expressed by the research community.

SUSTAINING SUCCESS

Though this pilot did not find population-based collection of novel prognostic factor data to be a practical approach, findings point to the value of learning from the pilot to develop operational models to procure novel data for targeted data collection initiatives. In collaboration with CDC partners, California will publish findings from the pilot to encourage development and implementation of these operational processes. If supported by the state, California could create research grants to promote application of this model to a variety of cancer prognostic factors including genomic information, imaging, and treatment data.

REGISTRY CONTACT INFORMATION

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