2020 NPCR NORTH DAKOTA STATEWIDE CANCER REGISTRY SUCCESS STORY

STORY TOPIC/FOCI: Data Linkage, collaborative partnerships/projects

STORY CATEGORY: Registry Operations

STORY TITLE: Data Linkages in the North Dakota Statewide Cancer Registry

STORY AUTHOR(S): Yun Zeng, Xudong Zhou, Cristina Oancea, and Mary Ann Sens

SUMMARY

Data linkage is a process of joining records from one data source with another that describes the same entity. Bringing information from different sources together about the same entity enriches the dataset and produces valuable information that can be used for research and statistical purposes.

In addition to performing various data linkages to meet the requirements of the Centers for Disease Control and Prevention/National Program of Cancer Registry (CDC/NPCR), the North Dakota Statewide Cancer Registry (NDSCR) has performed data linkages for specific research projects, as various clinicians and researchers are showing increased interest in linking their clinical/research data with the Central Cancer Registry (CCR) data to support measurement of clinical performance, patient health outcomes and policy making. A good example is the data linkages the NDSCR performed using the Virtual Pooled Registry Cancer Linkage System (VPR-CLS).

CHALLENGE

The VPR-CLS was implemented by IMS, Inc about 3 years ago and coordinated by the North American Association of Cancer Registries (NAACCR) with funding from the National Cancer Institute (NCI). It is a web-based, one-stop-shop designed to connect researchers performing minimal risk cohort linkage with CCRs across the United States Cancer registries participating in the VPR-CLS perform a standard linkage using Match*Pro software, and upload aggregate match count reports (no patient records) to the VPR-CLS. The researchers then can select which registries to approach with requests for release of individual-level data on matched cases.

In order to participate in the data linkage through VPR-CLS to provide ND cancer data for research, the NDSCR staff needs to spend extra hours working on the projects on top of already busy work, and learn how to use the VPR-CLS system and Match*Pro software.

SOLUTION

To be well prepared for conducting the collaborative research projects, the NDSCR staff participated in the NAACCR webinars, learned how to use the VPR-CLS and Match*Pro software to perform the data linkages. Finally, the staff worked extra hours to get the job done.

RESULTS

Besides performing various data linkages, meeting CDC/NPCR requirements, receiving NPCR and NAACCR awards, the NDSCR staff performed data linkages for 6 collaborative projects

through the VPR-CLS in the past 2-3 years. All the projects have completed phase I activities which is for initial data linkage and case counts, and 2 of projects have entered into phase II for signing up Data Use Agreement (DUA), performing data linkage, and manually reviewing the linkage results.

Through participating in these projects, the NDSCR has helped to streamline the data request application and approval process for controlled release of individual-level data for appropriately approved studies, which extended the public health mission and value of the registry.

SUSTAINING SUCCESS

The NDSCR will continue to perform the data linkages required by the CDC/NPCR; The NDSCR will also continue to participate in this kind of collaborative projects and to provide ND cancer data for the research – pending on time availability.

REGISTRY CONTACT INFORMATION

North Dakota Statewide Cancer Registry
Pathology Department, UND School of Medicine and Health Sciences
 (701) 777 0791 (X2868)
https://ndcancer.org/index.html