Data Analysis for Cancer Control Programs

Cancer registries do not exist in a vacuum. It is recommended that registries work very closely with cancer control programs in their state. Cancer control programs are designed to create, implement, and promote cancer prevention and control initiatives. These programs use the central cancer registry data to create and evaluate data-driven policies and recommendations. Therefore, it is important to have a strong partnership with these programs.

It is considered a best practice to provide data and analytic support to state cancer control programs.

As the data analyst for the registry, you are the data expert. Many times, requests from partners at cancer control programs can be vague as they are unfamiliar with the data and how to interpret it. It falls on the analyst to determine and clarify what is needed from each request and how to best support the program.

To support the objectives of cancer control, these programs are looking for standard statistics, incidence and mortality rates, 5-year survival, or stage distribution. This information assists the cancer control programs in designing and implementing public health policies and priorities. The programs will use this information to target populations or geographic areas for implementation of interventions. For example: increase breast screening opportunities in an area that has a high proportion of late-stage diagnoses and high mortality rates. Many health departments have Breast and Cervical Cancer Programs that can work with community partners to schedule mammography buses to provide screenings in that area.

Another thing to keep in mind, because these programs are often housed within the same department as the registry and also have a state or provincial public health mandate, data provided to these programs might be data your registry would not release publicly. For example, you may provide small area estimates for communities (by zip code/postal code or census tract) or non-suppressed small cell counts. Therefore, it is critical that cancer control programs only use the data internally and do not re-release any data without specific, documented approval by the cancer registry.

Overall, the data requested will depend on the program and their priorities. Initially, the most important thing is to communicate with these partners to ascertain how the data can best be utilized. Once data are provided, it is crucial to provide context and interpretation of the results to best inform cancer control and prevention activities.

It is considered a best practice to provide both data and technical consultation to support cancer center-based cancer control programs.

In addition to state cancer control programs, there are cancer control programs located in cancer centers—many of them attached to academic institutions. Cancer registry data are a great resource for these programs, and researchers in these centers are generally very enthusiastic about using registry data. The work of these cancer center programs is often research in nature, so, rather than curated statistics, they generally require a research dataset. Unlike the work of state-based cancer control programs, these cancer prevention and control activities do not fall under a public health mandate, therefore, data release may be more limited than what is provided to state cancer control programs.

As the cancer registry analyst, your role is to provide the data, as appropriate, and to engage with the research team to ensure that the limitations of the cancer registry data are accounted for in the project methodology. Central registry analysts ideally would provide technical consultation during methods development and interpretation. Note: not all hypotheses can be tested using cancer registry data. As a condition of data release, all researchers must apply research questions and methodology that are appropriate for our data. As cancer registry data are collected with surveillance as the primary use, our

data are not suitable to answer every important research question. It is the role of the analyst to engage with the researcher to ensure that the data are only released for research that is applicable for our data.

Analysts may find data release resources on the NAACCR *Data Security and Confidentiality Issues* webpage useful (available here: https://www.naaccr.org/data-security-confidentiality-issues/).