

2022 NPCR DELAWARE SUCCESS STORY

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Changes to Delaware Cancer Reporting

National Program of Cancer Registries SUCCESS STORY

SUMMARY

After healthcare facilities report to the Delaware Cancer Registry (DCR), these data are used in multiple ways. These include monitoring trends in cancer incidence and mortality, guiding cancer control program planning and evaluation, assisting in prioritizing health resource allocation, conducting clinical, epidemiological, and other research, and evaluating cancer clusters ^[1].

Delaware legislation mandates cancer data reporting within census tracts to be shared with the public and interested parties. The Cancer Prevention and Control (CPC) Bureau has found it increasingly difficult to provide meaningful cancer statistics to the public that are epidemiologically sound. In most instances, the statistics either are suppressed due to few cases at the census tract level, or the provided information can be misleading about cancer risk in a particular area due to unstable rate calculations with low case counts.

Thus, after a collaboration between CPC epidemiologists and other leadership within our health department, it was agreed upon to change the reporting style to the public at the census tract level to not include additional stratification analysis, but still report on overall (all-site) cancer incidence rates within Delaware census tracts.

CHALLENGE

Census tracts are "...geographic entities within counties (or the statistical equivalent of counties)." A county is fully covered by census tracts, comparable to the way a state is broken up into counties. Census tracts use 4-digit codes for identification, ranging between 0001-9999. They may also have an additional 2-digit suffix code that ranges between .01-.98. A census tract can be fully identified through its 11-digit code that specifies the state, the county, and the tract code ^[2].

Census tract reporting in a legal requirement in the state of Delaware, as presented below:

"...(b) The agency shall create a detailed map of each county in Delaware that graphically illustrates the overall incidence of cancer in each census track [sic]. The census tracks will be identified on the maps and shall be color-coded to designate the degree of cancer incidence in each track. These maps shall be created within 90 days of the agency receiving the cancer incidence data."

"...(c) The agency shall post the maps created under the subsection above on their website in a format that can be easily accessed and read by the public" ^[3].

Census tract data are subject to limitations. Certain census tracts can have small populations, and sometimes may contain rural areas. If the number of cancer cases is small in one area, this small sample size limits the power of the rate calculations. These small case numbers can also lead to seemingly large fluctuations in rates from year to year; confidence intervals added to these rates can help establish the confidence and statistical significance. Confidence intervals, along with how to interpret them, are provided annually to the public in cancer reports. However, interpretation of confidence intervals is a hard concept for the public to understand, therefore it was difficult for the public to note areas of concern.

The state of Delaware presents a challenge for county-specific reporting because Delaware only has three counties that are relatively large in population. Reporting at a county level may mask patterns in cancer rates particularly if the populations within the counties are very heterogeneous. Census tract reporting is a very dynamic type of reporting due to factors such as redistricting and population movement that affect fluctuations of the distribution of populations within the census tracts.

Sound sub-county analysis data are crucial to help drive cancer outreach initiatives by identifying areas disproportionately affected by cancer. These data impact the allocation of public health resources for Delawareans.

SOLUTION

One of the ways DCR addressed the census tract data reporting challenges is to no longer include additional stratification by gender and cancer type. The current reporting method reports on only all-site cancer incidence within census tracts. This allows for data to be released to the public that is more meaningful instead of misleading or unclear data. This change will remove previous limitations in the data by increasing the sample size used for calculations.

Research was conducted into census tract reporting methods that other states utilized, and comparisons were made to the state of Delaware's current reporting practices. A solution was proposed and subsequently approved by the Delaware Cancer Consortium (DCC). The DCC is made up of policymakers, medical providers, state officials, non-profit members, and others who have a stake in Delaware's cancer burden.

This change also came at the same time as a national interest in more sound sub-county analysis. Delaware responded in turn by adopting the National Cancer Institute (NCI)/North American Association of Central Cancer Registries (NAACCR) Zone Project to address this need. The project utilizes creating reporting zones, by aggregating census tracts, that are homogeneous in nature based on the percentage of urbanicity, minority, and poverty levels within each zone.

RESULTS

Because census tracts are small geographic areas and may not contain a large population of people or small case incidence counts, calculated cancer rates are evaluated carefully for statistical significance and confidence. As mentioned previously, census tract calculations are subject to limitations, and it is helpful to compare them to other data sources such as the state average. Thus, it was decided to no longer stratify this data by gender and cancer type at the census-tract level for the public since it was not epidemiologically sound and could have been misinterpreted. The goal of this change is to provide the most meaningful and effective data possible for public consumption.

As a first step, Delaware's Department of Public Health (DPH) began reporting only all-site cancer rates within census tracts, with no additional stratification analysis. According to the 2015-2019 Delaware Census Tract Analysis Compendium, 76% of Delaware's census tract all-site incidence rates were not significantly different from the state's rate from 2015-2019 or were unable to be calculated. Conversely, 14% of the census tract rates were statistically significantly higher than Delaware's average incidence rate, and 10% of the census tracts for this period had incidence rates that were statistically significantly lower than Delaware's average rate [4].

Delaware's DPH is also participating in the NCI/NAACCR Zone Project. The cancer epidemiologists within the Cancer Prevention and Control Bureau have partnered with other epidemiologists within the Delaware Division of Public Health to form the Epi Working Group. The Epi Working Group will help finalize the zones chosen for Delaware. These zones will be populated with data from the DCR. This project once implemented will address the national demand for better sub-county analysis methods and will help to better inform cancer programs for community outreach efforts.

SUSTAINING SUCCESS

The state of Delaware seeks to integrate the NCI/NAACCR Zone Design Project cancer reporting zones into their reporting infrastructure once the zones have been defined more clearly. These cancer reporting zones will consist of aggregated census tracts and will create sub-county areas for reporting that are all similar in population size and are homogenous in terms of percent of households with incomes below the federal poverty level, percent minority, and urbanicity. DCR plays an important role in this project by providing the data used to make up these zones.

This initiative will require some adaptation and investigation to implement-- especially regarding the utilization of the new reporting zones-- but ultimately will result in a new reporting methodology that should have benefits for the state's cancer reporting. The state of Delaware and the DCR will also remain abreast of any legislative changes that may occur that would impact mandated cancer reporting. Providing cancer information to interested parties remains a high priority and could be used to inform policymakers about any potential changes to cancer reporting, including sub-county data standards.

The DCR collaborates closely with the Delaware Comprehensive Cancer Control Program and Delaware Breast and Cervical (B&C) program. The latter two programs use data from the DCR to help guide cancer outreach initiatives within their programs. For example, the B&C program managers want to know which areas in Delaware are most affected by late-stage cancer diagnosis and high mortality from breast and cervical cancers. The program managers will utilize this information to ensure screening is made accessible in these areas. Similarly, the program managers for the Comprehensive Cancer program rely on the DCR to provide information on health disparities to help guide choices of community partnerships that will best address Delaware's cancer burden.

The reporting zones created through the NCI/NAACCR project will provide more sound insight into the areas and populations that disproportionately affected by cancer. The state of Delaware is committed in the advancement of health equity, so with the creation of the reporting zones, the DCR will continue to collaborate closely with the program managers within the Breast and Cervical program and the Comprehensive Cancer Control program to ensure services are targeting the Delawareans most in need.

REGISTRY CONTACT INFORMATION

855-386-6149
Delaware Cancer Registry Website

REFERENCES

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