NORTH CAROLINA CANCER RESEARCH ADVISORY PANEL RECOMMENDATIONS

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BACKGROUND

In 2016, cancer was the leading cause of death in North Carolina (NC DHSS, 2016). While for many cancers, the causes are unknown, scientists have identified a small number of chemicals, lifestyle factors, and genes involved in causing cancer and promoting its development. In NC, public health officials took on the difficult task of attempting to determine the possible cause(s) of two recent potential cancer clusters, thyroid cancer in Iredell County and ocular melanoma in Huntersville. The US Centers for Disease Control and Prevention (CDC) defines a cancer cluster as a “greater than expected number of cancer cases that occurs within a group of people in a geographic area over a defined period of time” (CDC, 2013).

Investigating cancer clusters can be challenging because studies tend to be small, either in terms of covering a small geographic area or including a small number of people. This makes analyzing patterns of cancer in a specific area and over time difficult in these situations, especially for rare cancers. Other challenges in investigating cancer clusters include:

- difficulty applying statistical methods to a small number of cases;
- movement of people leading to changing demographics of a study; and
- changes in medical practice and cancer screening guidelines may also cause a change in cancer rates.

Cancer can also take decades to develop after exposure to a cancer-causing agent (carcinogen). This means that community exposure at the time of diagnosis may not reflect an important exposure period.

Because of these difficulties, cancer cluster investigations are often unsuccessful in determining the causes of suspected clusters. For this reason, it is important that policy-makers and other community stakeholders understand the processes used in cancer cluster investigations and their limitations. It is also important that groups conducting or contributing to such investigations actively educate residents and manage expectations.

In 2019, the NC General Assembly passed Senate bill 297 (Session Law 2019-145) directing the Collaboratory to convene an advisory panel on cancer research, with the purpose of identifying strategies for assessing NC cancer incidence and mortality rates and patterns over time and geography.

POLICY RECOMMENDATIONS

The Cancer Research Advisory Panel proposed five recommendations that address strategies to assess NC cancer incidence and mortality. These recommendations encompass specific research, methodology, and funding recommendations:

- **Improve Communication Process by Identifying One Single-Point-of-Contact Person for Health Departments, Community Members and Other Stakeholders**
  - Designate a single point-of-contact-person, through the NC Department of Health and Human Services, for cancer cluster investigations
  - Identification of a single point-of-contact person allows for early and consistent communication with residents and is critical to effective cancer cluster investigations

- **Invest in More Robust Infrastructure to Strengthen Coordination and Implementation of Cancer Cluster Investigations Across North Carolina**
  - Strengthen the NC DHHS team that coordinates cancer cluster inquiries and investigations, through the creation of a cancer epidemiologist position dedicated to cancer cluster investigations
  - Develop an enhanced NC Cancer Cluster protocol for cancer cluster investigations that would improve efficiency of investigations and ensure the quality of science conclusions were based upon
  - Create a risk communication position with the OEEB to support communication between local health departments and residents
  - Enhance the existing NC Carolina Central Cancer Registry (CCR) website to increase cancer rate information available for citizens

- **Enhance Cancer Data Resources and Analytical Capabilities for Cancer Cluster Surveillance**
  - Improve thoroughness of cancer case reporting across the state, through improved statistical methods and software tools
  - Enhance surveillance and analysis of cancer patterns in North Carolina
  - Incorporate carefully examined new tools and solutions into the NC cancer cluster protocol
o Develop a statewide training program on cancer case reporting for physicians, and hire two new CCR Certified Tumor Registrars (CTRs)

- **Develop a NC Environmental Public Health Tracking Web-Portal**
  o Convey environmental hazard information via an online web-portal, known as Environmental Public Health Tracking, allowing residents to view comprehensive environmental and health data by time, geography, cancer type, age group, year, and other factors

- **Convene a Cancer Cluster Advisory Committee**
  o Assemble an advisory committee to provide prompt input on issues related to suspected cancer clusters
  o Committee can ensure that the development of best practices for cancer cluster investigation and responses are addressed
  o The committee would be composed of experts including, cancer epidemiologists, environmental health scientists, and statistics, NC DHSS staff, at least one Local Health Director, community member, and others as required.

A list of all of the recommendations can be found in the full North Carolina Cancer Research Advisory Panel Recommendations found at: [https://collaboratory.unc.edu/files/2020/04/cancer-research-advisory-panel-recommendations.pdf](https://collaboratory.unc.edu/files/2020/04/cancer-research-advisory-panel-recommendations.pdf)

**FUTURE ACTION**

During the 2020 legislative session bills were introduced in the North Carolina General Assembly related to the Advisory Panel’s recommendations.

Senate Bill 746, and an identical companion bill H 1138, proposed implementing many of the substantive and funding recommendations found in the Advisory Panel’s report. The bills were referred to the Committee on Rules and Operations of the Senate and House Appropriations Committee respectively.

More information about Senate Bill 746 can be found at the North Carolina General Assembly website: [https://www.ncleg.gov/BillLookup/2019/S746](https://www.ncleg.gov/BillLookup/2019/S746)