

# *Cancer Research Advisory Panel Recommendations*

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## Abbreviations

<b>ACCCC</b>	North Carolina Advisory Committee on Cancer Coordination & Control
<b>CCR</b>	North Carolina Central Cancer Registry (NC DHHS)
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CTR</b>	Certified Tumor Registrars
<b>LHDs</b>	Local Health Departments
<b>NC DHHS</b>	North Carolina Department of Health and Human Services
<b>NCI</b>	National Cancer Institute
<b>OEEB</b>	North Carolina Occupational and Environmental Epidemiology Branch (NC DHHS)

## Cancer Research Advisory Panel

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## Executive Summary

In 2016, cancer was the leading cause of death in North Carolina (NC) (NCDHHS, 2016). Although cancer is often referred to as a single disease, there are many different types of cancer. Scientists have identified a small number of chemicals, lifestyle factors, and genes involved in causing cancer and promoting its development. Yet for many cancers, the causes are unknown.

When cancer is diagnosed among multiple people in a community, questions often arise about the potential role of exposure to pollution and other hazards in the environment (referred to as **environmental exposures**) in causing cancer. While it's appropriate to consider potential environmental exposures as an explanation for diagnoses of cancer among multiple people in a community, cancer can also develop because of non-environmental characteristics of that community (such as the age-structure of community, cancer screening in the community, or access to health care).

When the number of cancer cases in a community is perceived as unusually high, community residents (including physicians and the media) may refer to **cancer clusters**. 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). Public health officials in NC 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.

A challenging aspect of investigating cancer clusters is that studies tend to be small, either in terms of covering a small geographic area or including a small number of people. Analyzing patterns of cancer in a specific area and over time is difficult in these situations, especially for rare cancers. Investigators use statistical methods to figure out how multiple factors that may cause cancer contribute to the occurrence of cancer in an area. Those methods do not necessarily work well with small numbers of cases. Additionally, as people move, demographics of a study area can change, making it harder to interpret cancer rates over time. Finally, changes in medical practice and cancer screening guidelines may also cause a change in cancer rates.

Another challenge is that even when dealing with one type of cancer, different characteristics and causes may be involved, including associations with genetics, lifestyle, and environmental factors, some of which may work together to increase cancer occurrence. Cancer also can take decades to develop following exposure to a cancer-causing agent (or **carcinogen**). This means that community exposure at the time of diagnosis may not reflect an important exposure period, which may have occurred years earlier or possibly at another geographic location.

Because of these barriers, cancer cluster investigations often are unsuccessful in determining the causes of suspected clusters (Goodman, 2012). 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 essential that groups conducting or contributing to such investigations actively educate residents and other stakeholders and manage expectations.

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In NC, two programs within the North Carolina Department of Health and Human Services (NC DHHS) work with local health departments and communities on cancer cluster investigations: the **Central Cancer Registry (CCR)**, which is the legislatively mandated, population-based cancer surveillance program to identify new diagnoses of cancer in individuals residing in North Carolina, and the **Occupational and Environmental Epidemiology Branch (OEEB)**. In these investigations, the CCR analyzes newly identified cases of cancer (or cancer **incidence**) and prepares a report. The OEEB provides expertise on environmental exposures and cancer. OEEB and CCR also consult with academic researchers to better understand gaps in scientific knowledge and with local health departments on communication strategies.

State law requires that all NC health care providers that diagnose or treat cancer (such as hospitals, physician offices, radiation oncology centers, and diagnostic laboratories) report detailed information about all cancer cases to the CCR. Their quality control process ensures that the registry has complete and accurate information (for example, about stage of cancer diagnosis and treatment) for as many cases as possible. Although health care providers must submit initial data within six months of patient diagnosis, they must then complete the diagnostic work-up and develop a treatment plan. For this reason, complete registry information is usually not available until 12 to 24 months after diagnosis.

The CCR routinely monitors data at the county level to identify significantly elevated rates of the most common cancers, which include lung/bronchus, female breast, prostate, and colorectal cancers. For less common types of cancer, including thyroid cancer, the CCR conducts routine analysis at the state level. Currently, due to a lack of resources and large variations in cancer rates, the CCR does not actively look for trends in smaller geographic areas. When such concerns are identified, NC DHHS and Local Health Departments (LHDs) partner with community residents and researchers to investigate concerns further.

The OEEB assists the CCR when investigations involve environmental concerns. OEEB staff have expertise in epidemiology, toxicology, industrial hygiene, and health communications. OEEB identifies and quantifies environmental concerns for public health surveillance, provides medical consultation for exposures of concern at work or in communities, conducts risk assessments, and provides scientifically based guidance on acceptable levels of exposure to environmental contaminants. Together, CCR and OEEB work with LHDs to share information with the community and also share CCR's results with residents or agencies who request the data.

In 2020, the NC General Assembly convened 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. The panel proposed five recommendations. Cost estimates for each recommendation are included in the full report.

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### Recommendations

#### **Recommendation 1. Improve communication process by identifying a single point-of-contact for local health departments (LHDs), community residents, and other stakeholders**

Given the potential for heightened community concern, **early and consistent communication with residents and other stakeholders is critical to an effective investigation.** Questions about potential cancer clusters are often communicated to LHDs and DHHS. LHDs typically do not have the resources or capacity to address these issues. As a result, LHDs and others who are contacted may spend considerable time and effort responding to the public, policy makers, and the media.

The panel recommends that **NC DHHS designate a single point-of-contact (POC) for cancer cluster investigations.** This POC should be identified on NC DHHS web pages referencing cancer cluster investigations and should lead the investigation process, coordinating among NC DHHS units that typically are involved (CCR, OEEB).

#### **Recommendation 2. Invest in more robust infrastructure to strengthen coordination and implementation of cancer cluster investigations across NC**

##### ***2a. Strengthen the NC DHHS team that coordinates statewide cancer cluster inquiries and investigations and enhance the NC Statewide Cancer Cluster Protocol***

The CCR receives approximately eight (8) requests for suspected cancer cluster investigations each year. These **investigations can take many months to resolve.** Often data from multiple sources must be processed and analyzed, and multiple NC DHHS units are involved. Keeping up with the media and other public communications can further complicate these investigations.

The panel recommends **creating a cancer epidemiologist position dedicated to cancer cluster investigations within NC DHHS.** This professional would conduct routine surveillance activities, proactively monitor cancer rates statewide, and communicate with other units in NC DHHS and external partners. Monitoring would include analyzing patterns of cancer incidence over geographic areas and time. Access to geospatial data, visualization tools, and statistical methods for cluster analyses would be essential, and this epidemiologist could serve as the designated point-of-contact for all cancer cluster investigations (as mentioned in Recommendation 1).

The panel also recommends that **an enhanced NC Cancer Cluster protocol be developed.** A state-of-the-art protocol for cancer cluster investigation would improve efficiency and ensure that conclusions were based on the best available science. Currently, the CCR and OEEB follow a protocol based on CDC guidelines (CDC, 2013). This protocol could be enhanced by addressing state / local infrastructure and needs, incorporating new analytic approaches, and addressing communication strategies.

This protocol could be based on new CDC guidelines (expected in 2020-2021) and those from other states (New Jersey, 2017; Texas, 2016; Utah, 2016). Incorporation of recommendations

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from the CDC's Subcounty analysis and the National Cancer Institute (NCI) Zone project also should be considered. This protocol should periodically be updated as new approaches are developed. Communication—within NC DHHS and with external stakeholders—should be explicitly addressed within the protocol to ensure efficiency and objectivity in responding to public concerns. The development and ongoing review of this protocol would be led by the cancer epidemiologist.

### *2b. Improve communication capabilities within NC DHHS to better support LHDs in communicating with residents*

Often community residents are alarmed when they perceive cancer rates to be elevated, making clear and open communication a key aspect of effective response (CDC, 2013). **Communication can be challenging** due to residents' concerns for family and friends, media engagement, the complicated scientific concepts involved (such as latency, statistical significance, etc.), and limited information about the causes of cancer. Further, LHDs have an established infrastructure for responding to infectious disease outbreaks, but not for cancer cluster investigations.

The panel recommends **creation of a risk communication position within NC DHHS** to support LHDs in communicating with residents. This professional would serve as a liaison between NC DHHS, other state and local health departments, and environmental agencies. The position would facilitate communication during investigations, working with LHDs to provide timely information in communities and respond to media and public requests. The professional also could represent NC DHHS at public health and cancer surveillance meetings and enhance and maintain updated information on cancer risk and prevention on the NC DHHS and CCR websites.

### *2c. Enhance cancer rate information available for citizens*

With an expanded surveillance and analysis protocol, the panel recommends **updating the CCR website with an interactive dashboard**, to make cancer information more accessible by residents. Providing the public with current, online information on cancer rates for each county would increase transparency and may reduce cancer cluster inquiries and reduce the associated burden on LHDs. An enhanced web site would require regular updating and maintenance.

## **Recommendation 3. Enhance cancer data and analytical capabilities**

### *3a. Improve completeness of cancer case reporting across state*

**Accurate and timely data is foundational to cancer surveillance and cancer cluster investigations.** With incomplete data, cancer patterns and distribution of cases across the state cannot be assessed. For example, a lack of reporting by all physician practices across the state hindered analysis of rates of ocular melanoma in Huntersville, NC. When the CCR was first established, hospitals and cancer centers oversaw a majority of cancer diagnoses and care, but now many cases are diagnosed or treated in outpatient physician practices. In these settings, there is less knowledge of and willingness to comply with reporting requirements. This leads to a lack of reporting and incomplete identification of all cancer cases. For example, in 2018, 6,000 cases

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were reported to the CCR by 680 physician practices, yet an additional 600 cases were identified by CCR's pathology records as not included in data reported by these practices.

The CCR has a coordinator that ensures compliance with the reporting mandate by physician practices, but **one FTE is insufficient to reach all physician practices across the state**. Complete case identification is further complicated by staff turnover at physician practices and a lack of awareness of reporting requirements. Additional CCR staff are needed to coordinate outreach and improve the capacity of outpatient practices to report cancer cases.

The panel recommends that **two new CCR Certified Tumor Registrars (CTRs) be hired**. These CTRs will be responsible for monitoring and supporting compliance by physician practices. These positions could train staff in physician practices on case entry into a web-based application developed by CDC. Along these lines, the panel recommends that CCR develop a **comprehensive statewide training program about cancer case reporting**.

Further, because cancer registration is required by state law, the NC legislature and the NC State Medical Board must be engaged in a coordinated effort with the CCR to strengthen the communication to physician practices regarding their legal responsibility to report.

### *3b. Enhanced surveillance and analysis of cancer patterns in North Carolina*

Confirmation of cancer clusters is complicated by multiple critical challenges, all of which limit the CCR's ability to accurately estimate cancer rates and patterns. **Current cancer incidence rates usually reflect cancer that began developing anywhere from one year to decades earlier** and sharing these rates without communicating their limitations may amplify public concerns about cancer surveillance. Although CCR routinely examines cancer incidence and mortality patterns of common cancers in NC and produces publicly available reports, **these reports often do not include rare cancers and sub-county geographic units**.

**Because different statistical methods have different strengths in terms of identifying increased cancer rates**, a rigorous approach is needed to select appropriate analytical methods. As a result of these challenges to analyzing and interpreting results of cancer data, important patterns may be missed or inappropriately interpreted, and potential risk factors may not be identified. Limited resources in the CCR further constrain expanded geographic analyses using innovative methods and tools, underscoring the need for **an ongoing, systematic approach that is routinely implemented**.

The panel recommends that the cancer epidemiologist collaborate with an advisory committee and outside experts to **evaluate and incorporate improved statistical methods and software tools** now available for analyzing cancer rates and cluster detection. We recommend that new applications be carefully considered and solutions incorporated into the NC cancer cluster protocol as needed.

We further recommend that the enhanced state cancer cluster protocol be used to **monitor patterns on an ongoing basis** with the methods described above. This would enable analysis of

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patterns at a greater resolution by cancer type, geography, and/or time to detect a “signal,” which may suggest changes in cancer incidence or mortality at a larger population level.

### Recommendation 4. Develop a NC Environmental Public Health Tracking Web Portal

To examine the relationship between environmental exposures and cancer occurrence, researchers often need access to specially combined (or aggregated) data. Currently, **there is not an easily accessible way to view information related to environmental exposures across NC.** Relevant information is available from multiple sources, yet it is neither integrated nor easily accessible. Several US states have developed online data visualization tools that provide access to cancer incidence rates and associated information. Providing this information via an online portal would enable viewing of aggregated environmental and health data by time, geographic location, cancer type, age, or other factors.

The panel recommends that **NC DHHS develop a pilot Environmental Public Health Tracking Web Portal** to inform the assessment of and communication about cancer clusters in NC and the potential role of environmental exposures. This would better position NC DHHS to apply for CDC funding to sustain the program. A web portal could have multiple benefits: broad, public access to data; improved ability for LHDs to respond to local community health / environmental concerns; and improved competitiveness of NC DHHS in pursuing CDC funding to support continued environmental public health tracking.

### Recommendation 5. Convene a cancer cluster advisory committee

**An advisory committee could provide timely input** on a range of issues related to suspected cancer clusters. The advisory committee could: assist with updating the cancer cluster protocol, suggest and evaluate analytical methods, and consult on current investigations. An advisory committee also could foster communication and collaboration across stakeholders, helping to ensure best practices for cancer cluster investigations and communication with residents.

The panel recommends that **NC DHHS convene a cancer cluster advisory committee**, either as a free-standing group or as a subcommittee of the legislatively appointed NC Advisory Committee on Cancer Coordination & Control (ACCCC). This committee would advise the cancer epidemiologist in reviewing current protocols and any cancer cluster investigations around the state. Its members would include cancer epidemiologists, environmental health scientists, statisticians, NC DHHS staff, local health directors (or designee), and community representatives.

## Cancer Research Advisory Panel Recommendations

### Introduction

A cancer cluster is defined by the Centers for Disease Control and Prevention (CDC, 2013) 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.” Cancer clusters pose a unique public health concern to the community, public health officials, policymakers, and research scientists. The occurrence of cancer among family members, friends, co-workers, neighbors, or in the broader community can understandably raise concerns and fears, often centering on possible environmental factors or hazards in the workplace. It’s often the case that suspected clusters are reported by community members, physicians, the media and others in circumstances where the number of cases or a specific cancer or multiple types of cancer are perceived as unusually high.

As shown in the recent cancer cluster investigations of ocular melanoma in Huntersville and thyroid cancer in Iredell County, North Carolina (NC), public health officials charged with investigating suspected cancer clusters face a daunting task in attempting to investigate these occurrences and determine a cause. Cancer can occur in specific patterns over space and time for a variety of reasons. Although attention is often appropriately focused on the role of environmental exposures as an explanation for diagnoses of cancer among multiple people in a community, these patterns can also arise because of non-environmental characteristics of the population (such as the age-structure of the community, cancer screening in the community, or access to health care).

Separating these causative factors epidemiologically and statistically in small areas (geographically and in terms of number of cancer cases) is especially challenging. First, analyzing patterns of cancer cases in a defined area and over time is challenging for rare cancers because of the small number of cases. In addition, the demographics of the study area can change due to people moving in and out of an area over time. It can be problematic to use statistical methods to sort out the relative contributions of multiple causative factors when a small or modest number of cases occur in a community. These factors can make it harder to interpret cancer rates over time.

Second, the nature of cancer, as compared to other health outcome scenarios such as infectious disease outbreaks, poses several challenges. Cancer actually includes many different diseases. Even the same cancers can have differing characteristics and causes, including association with genetics, lifestyle, and environmental factors, some of which may appear in combination to increase cancer occurrence. Moreover, cancer can take decades to be detected after potential exposure to a cancer-causing agent. This means that assessing community exposure at the time of diagnosis may not reflect the important exposure period, which may have occurred years earlier or possibly at another geographic location. Finally, changes in medical practice and cancer screening guidelines may also cause a change in cancer rates.

These barriers typically result in the lack of determination of the cause of suspected clusters (Goodman, 2012). It is important that communities, policy makers, and other stakeholders understand the processes undertaken for these investigations and their limitations, and that groups conducting or contributing to these investigations provide education and manage expectations.

## **Cancer Research Advisory Panel Recommendations**

The North Carolina Department of Health and Human Services (NC DHHS) works with local health departments and communities; together they have a history of conducting cancer cluster investigations in North Carolina. The NC DHHS' Central Cancer Registry (CCR) is the statewide, mandated population-based cancer surveillance system. State statute requires that all health care providers that diagnose or treat cancer (i.e., hospitals, physician offices, radiation oncology centers and diagnostic laboratories) report detailed information to the NC CCR about all cancer cases. In NC, reporters must submit initial diagnostic data within six months of patient diagnosis. The CCR quality control process helps ensure that the registry has complete and accurate information (e.g., stage of cancer diagnosis, treatment) for as many cases as possible. Physicians must have time to complete the diagnostic work-up and develop a plan of action for treating the cancer. For this reason, complete registry information, especially treatment data, are usually not available until 12 to 24 months after diagnosis.

The NC CCR routinely monitors data at the county level to identify significantly elevated rates of the most common cancers (e.g., lung/bronchus, female breast, prostate, colorectal). For less common types of cancer, including thyroid cancer, the CCR conducts routine analysis at the state level, but due to a lack of resources they do not actively look for trends in smaller geographic areas. When concerns are identified, NC DHHS and local health departments partner with community members and researchers to provide available data and investigate concerns further. The CCR works with local health officials to share information with the community and shares its results with citizens or agencies who request the data.

Currently, the NC Occupational and Environmental Epidemiology Branch (OEEB) investigates workplace and environmental conditions that may pose a risk to human health. Staff expertise includes epidemiology, toxicology, industrial hygiene, and health communications. They identify and quantify environmental concerns for public health surveillance, provide medical consultation for exposures of concern at work or in communities, conduct risk assessments, and provide scientifically based guidance on acceptable levels of exposure to environmental contaminants.

For cancer cluster investigations, the CCR performs the analysis of incidence rates and prepares a report. The OEEB offers its expertise in environmental conditions that pose a risk to human health and provides literature reviews when there are concerns about possible environmental contributors to cancer. As needed, both CCR and OEEB consult with academic investigators for gaps in scientific knowledge and with local health departments on communication strategies and provide content for public communication.

## Cancer Research Advisory Panel Recommendations

### Panel Charge

The Panel was constituted on the basis of Senate Bill 297 ([Appendix A](#)). The panel subsequently determined the following working charge:

*The Panel will primarily focus on recommendations regarding strategies to assess NC cancer incidence and mortality rates with regard to patterns over time and geography. The Panel will consider methodologies applied to the analysis of cancer rate data, underlying assumptions such as data quality, the scope of geographic area under investigation, statistical inference, and appropriate interpretation of patterns. The Panel will review methods to investigate cancer patterns, including case data review and epidemiologic studies to evaluate demographic, behavioral, occupational, genetic, environmental and other possible risk factors. Finally, the panel will make recommendations regarding strategies to communicate cancer rate patterns and interpretations with community members, local and state governmental organizations, media, and other stakeholders.*

## Cancer Research Advisory Panel Recommendations

### Panel Recommendations

The panel proposed five recommendations as detailed below (see [Appendix B](#) for a recommendation cross-mapping table).

#### **Recommendation 1. Improve communication process by identifying one single point-of-contact person for local health departments, community members, and other stakeholders**

**Rationale:** Potential cancer clusters may be brought to the attention of Local Health Departments (LHDs) and the NC DHHS by concerned residents, community organizations, clinicians, and others. Given a potential context of heightened community concern, **early and consistent communication with residents and other stakeholders is critical** to an effective investigation process. Questions and concerns about potential cancer clusters are often communicated to local public health officials. LHDs are often not equipped, nor have the resources or capacity to address cancer cluster concerns reported by the public. LHDs and other officials who are contacted to answer cancer cluster questions often spend considerable amounts of time and effort responding to the public, policy makers and the media. For these reasons, LHDs, the public, and others would greatly benefit by identifying a single point-of-contact person within NC DHHS to respond to cancer cluster investigations under a clearly defined standard set of procedures and processes (protocol). This action would achieve more effective and efficient investigations, providing for a quicker response and clearer channel for communication.

**Key elements:** The central element to this recommendation includes the designation of a primary single point-of-contact person within NC DHHS. We recommend that the single point-of-contact would be the new cancer epidemiologist and housed within CCR ([Recommendation 2a](#)). The single point-of-contact would have knowledge, training and experience in cancer epidemiology including cluster investigations. The single point-of-contact will be clearly identified on any NC DHHS web pages referencing cancer investigations as the designated point-of-contact. The single point-of-contact will be a central part of an overarching cancer cluster protocol process among NC DHHS units that typically are engaged in cluster evaluation and investigation (e.g., CCR, OEEB, NC Department of Environmental Quality).

**Cost:** The formal designation of a cancer epidemiologist serving as a single point-of-contact does not require additional funding to implement Recommendation 1. The focus of Recommendation 1 is designating a key professional who will lead investigations in collaboration with colleagues across NC DHHS divisions and provide a hub for communication with the community and other organizations.

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### Recommendation 2. Invest in more robust infrastructure to strengthen coordination and implementation of cancer cluster investigations across NC

#### *2a. Strengthen the NC DHHS team that coordinates state-wide cancer cluster inquiries and investigations; Enhance the NC Statewide Cancer Cluster Protocol*

**Rationale:** Suspected cancer cluster inquiries come from a variety of sources, including residents, LHDs, elected representatives, and the media. LHDs often have neither the resources nor the capacity to address reported cancer cluster concerns, necessitating the involvement of NC DHHS. Since 2000, the CCR has been primarily responsible for responding to cancer cluster inquiries, in collaboration with the OEEB (see [Appendix C](#), NC DHHS organizational chart). CCR staff carry out the data management and basic analysis of rates during cancer cluster inquiries, per a standard cancer cluster protocol based on the CDC 2013 Guidelines (CDC, 2013). OEEB assists in these inquiries by offering environmental and occupational epidemiologic consultation and literature review for possible environmental contributions to elevated cancer rates. **Currently, neither CCR nor OEEB have a cancer epidemiologist on staff.** As mentioned previously, there is not a single person and point-of-contact in NC DHHS whose primary responsibility is to coordinate and communicate cancer cluster activities. Such activities include serving as the primary point-of-contact, overseeing analyses (whether in response to community concerns or as part of an ongoing monitoring program), and developing and disseminating reports.

A suspected cancer cluster inquiry should be addressed using a cancer cluster protocol that includes best practices for all phases of cancer cluster assessment, including surveillance (identifying new cancer cases and monitoring trends), inquiries, detection and investigation, and a comprehensive communication plan. Current CDC guidelines (CDC, 2013) offer a basic framework for state and local health departments to assess cancer clusters and conduct investigations. However, additional opportunities to enhance the basic CDC protocol should account for local and state infrastructure and needs, as well as the development of new analytic approaches and related methods. In addition, enhancements to the communication components of the protocol may be desired.

An **enhanced and updated NC Cancer Cluster protocol should be developed** based on the existing CDC (2013) guidelines and those from other states (Utah, 2016; Texas, 2016; New Jersey, 2017). The protocol should reflect the new CDC cancer cluster guidelines, when they are available (expected to be released in 2020-2021), and periodically be updated as new approaches are developed. An essential component in the protocol should relate to communication within NC DHHS, and externally with the community, local health department, the media, and other stakeholders.

Currently, the CCR receives approximately eight (8) requests for suspected cancer cluster investigations each year. Some of these **investigations can take many months to resolve.** Often data from multiple sources must be processed and analyzed, and other NC DHHS groups, such as OEEB, need to be involved in the investigation. Potential misinformation in the public space can further complicate these investigations and require careful management of external communications. Maintaining a state-of-the-art protocol with a focus on effective communication improves investigation efficiency and ensures that conclusions are based on the best available science.

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Many states across the US have developed their own tailored cancer cluster protocols. An enhanced, updated NC cancer cluster protocol would lead to improved efficiency and objectivity in responding to public concerns and investigating potential clusters. This is a relatively low-cost venture that could build on the work of the CDC, National Cancer Institute (NCI), and other states.

**Key elements:** The key element would be **hiring a dedicated cancer epidemiologist**. This professional, located in CCR, would conduct routine surveillance activities, communicate with DHHS colleagues and external partners, and proactively monitor cancer rates statewide. Such proactive monitoring of cancer rates would include analyzing geographic and time trend patterns in cancer incidence across the state using geographic (geospatial) data and visualization tools and statistical methods for cluster analyses ([Recommendation 3b](#)). This epidemiologist could be the point-of-contact for all cancer cluster investigations ([Recommendation 1](#)).

Another key element is **enhancing the NC Statewide Cancer Cluster Protocol**. The development and ongoing review of the cancer cluster protocol would be led by the cancer epidemiologist and assisted by outside advisors/experts from a new advisory group ([Recommendation 5](#)). The protocol development and review would also include communications experts from NC DHHS, LHDs, and academic institutions to help tailor health communication messaging to the local level.

**Cost:** One cancer epidemiologist FTE position for the CCR at DHHS (see [Appendix D](#), budget justification).

### ***2b. Improve communication capabilities within NC DHHS to better support LHDs in communicating with residents***

**Rationale:** A key part of responding to cancer cluster concerns is communication. The CDC (CDC, 2013) has underscored the importance of developing clear two-way communication with communities during cancer cluster investigations. Residents may be alarmed when they perceive cancer rates to be elevated in their communities. **Communication can be challenging** due to concerns about affected family and friends, scientific concepts involved (such as latency, statistical significance, etc.) and frequent lack of information about specific contributing factors. LHDs have an established infrastructure for responding to infectious disease outbreaks, but not for cancer cluster investigations. For these reasons, **the panel recommends the creation of a risk communication position within NC OEEB** to better support LHDs in communicating with residents.

**Key elements:** The risk communication professional would serve as a liaison between DHHS, other state/local health departments, and environmental agencies. The professional would facilitate communication during investigations and as results are made available to local health departments, media and the general public. Specific tasks could include developing talking points for agency staff, assisting NC DHHS Communications with media reports, developing written and electronic materials (such as fact sheets and web sites), attending community meetings or other public events where information is shared with residents and others, and

## Cancer Research Advisory Panel Recommendations

otherwise supporting LHDs as needed. This professional would also work with the new cancer epidemiologist on communication issues ([Recommendation 2a](#)).

When there are not active cancer cluster investigations, this professional could serve to enhance and maintain updated information on cancer risk and prevention on the NC DHHS website, help represent NC DHHS at public health and cancer surveillance meetings as appropriate, and create and update content on the CCR website ([Recommendation 2c](#)). In addition, this person could support the development and use of the Environmental Public Health Tracking Network ([Recommendation 4](#)). Using this tool, the risk communicator could help communities across the state better understand possible connections between environmental factors and health, increase transparency of available data for the public, and build trust with communities.

**Cost:** 1 FTE risk communication professional (Public Health Educator II) within the Occupational and Environmental Epidemiology Branch. This professional requires expertise in science and risk communication, and health education or other relevant background (see [Appendix D](#), budget justification).

### *2c. Enhance cancer rate information available for citizens*

**Rationale:** There is the need to **enhance the existing CCR website** to make additional information available for residents, including an interactive dashboard. Providing the general public with up-to-date and easy-to-access web-based information on cancer rates for each county may provide benefits, including: a) help to reduce cancer cluster inquiries, b) provide transparency and ease public health concerns, and c) reduce burden on local health departments. Moreover, the proposed expanded surveillance and analysis protocol ([Recommendation 3b](#)) will require the updating of the CCR website. This enhancement will be supported by the risk communication and cancer epidemiologist professionals who would provide advice and specific content for the display and interpretation of statistical data ([Recommendation 2](#)).

**Key Elements:** The enhanced CCR website would be expanded and updated on a regular basis. Note that this enhanced CCR website would link to the Environmental Public Health Tracking Web-Portal ([Recommendation 4](#)). However, that Tracking Portal would be a separate infrastructure and set of enhancements that would also include environmental data.

## Cancer Research Advisory Panel Recommendations

**Cost:** The development of the additional data processing for use in an enhanced CCR website and website maintenance will require the following CCR positions (see [Appendix D](#), budget justification). In addition, the cancer epidemiologist and risk communicator would be involved ([Recommendation 2](#)).

- 1 FTE **web developer/manager** to develop and manage the additional work of the CCR website. This position would be responsible for updating data, postings and design for the CCR website and ensuring accessibility to meet NC DHHS guidelines.
- 1 FTE **Geographic Information Systems analyst position** to assist with geocoding and create/manage the online maps/portal/dashboard. This person would also assist with the analyses described in [Recommendation 3b](#).
- **Software licenses** (ESRI's ArcPro) and **cloud storage** for map services (credit usage for ESRI's ArcOnline) would also be needed.

### Recommendation 3. Enhance cancer data and analytical capabilities for cancer cluster surveillance

#### *3a. Improve completeness of cancer case reporting across state*

**Rationale:** Accurate and timely state cancer data is foundational to cancer surveillance and investigation of cancer patterns and trends, including potential clusters. Without complete data we cannot properly understand cancer patterns and burden across the state. For example, the analysis of rates of ocular melanoma in Huntersville was inhibited by gaps in reporting of melanoma cases by some practices across the state. In the CCR's early years, hospitals and cancer centers oversaw the majority of cancer diagnoses and care. A substantial number of cases are now diagnosed or treated in the outpatient physician practice. In this outpatient setting, there is less knowledge and readiness to comply with state-mandated reporting requirements,<sup>1</sup> which has led to a lack of routine reporting and thus incomplete ascertainment of all cancer cases in the state. For example, in the 2018 diagnosis year, the CCR received 6,000 cases from physician practices. However, an additional 600 cases were identified through the CCR's pathology records reporting as being missed from approximately 680 outpatient physician practices that currently report.

The CCR currently has a single coordinator to help ensure physician offices comply with the state mandate to report cancer cases across all practices and regions of the state. However, **one CCR FTE provides very limited resources to reach all practices across the state**. This is further complicated by staff turnover at the physician practices, the need for re-training, and a low level of engagement by practices to ensure complete case identification. Awareness of the state law in the absence of CCR staff availability to support and train practice staff has not provided sufficient incentive to comply.

<sup>1</sup> The Central Cancer Registry is established by [North Carolina General Statute Chapter 130A - Article 7](#). Effective October 1, 2014, [legislation](#) mandates electronic reporting to the Central Cancer Registry. Its administrative rules are codified as [North Carolina Administrative Code Title 10A - Chapter 47 SubChapter B](#)

## Cancer Research Advisory Panel Recommendations

**Key elements:** NC CCR should develop a **comprehensive statewide training program about cancer case reporting** for physicians practicing in stand-alone outpatient settings. This program would include expanding awareness, recruitment, and training of physician offices on cancer case reporting requirements. To accomplish this goal, additional CCR staff are needed to coordinate outreach and other activities to improve the capacity for outpatient coordination and identification of cancer cases.

The comprehensive training program would including the following: identify eligible practices and staff contacts, communicate and justify the requirement to report; onboard and train staff in the reporting requirements, use of software and case submission; and monitor each case submission to ensure accurate reporting, a process that can take several months for each practice to implement.

Because cancer case reporting is required by state law, the NC legislature and the NC State Medical Board must also be engaged in an impactful and coordinated effort with the NC CCR to strengthen the communication to physician practices regarding their legal responsibility to report to the CCR. This includes actions such as requiring self-identification of eligibility; documenting compliance of reporting and supplying key contact personnel as part of the annual physician license renewal; and reinforcing compliance through clinical/medical conferences and other communication outlets.

**We recommend that two new CCR Certified Tumor Registrars (CTRs) be hired.** These CTRs will be responsible for designing and implementing an onboarding and training program that will support higher compliance of physician practice reporting achieved through external collaboration. They will also provide training (and re-training when necessary) to designated physician practice staff, including case entry into a web-based application developed by CDC and maintained by the CCR IT staff, as well as monitoring compliance of reporting.

**Cost:** Hire two full-time NC CCR professionals who are Certified Tumor Registrars (CTRs) to coordinate outreach, communication and onboarding with the physician practices to improve case identification (see [Appendix D](#), budget justification) across the state. Two FTE professionals are needed to cover the entire state and address the sheer volume which leads to a very labor-intensive process. CTRs have a specialized skill set and play an important role in capturing complete history, diagnosis, treatment and health status for every cancer patient.

### ***3b. Enhanced surveillance and analysis of cancer patterns in North Carolina***

**Rationale:** Potential cancer clusters or unusual cancer patterns over time or by geographic location are often brought to the attention of local health directors, NC DHHS, or other groups (e.g., media). The identification of possibly unusual cancer patterns requires examining time trends in cancer rates. To appropriately understand the proper assessment of cancer rates, several factors need to be taken into account.

In general, a confirmed cancer cluster is defined through data and statistical analysis based on the number of new cancer cases for a given type of cancer in a specific location during a specific period of time. Arriving at a conclusion in this context is often met with several critical

## Cancer Research Advisory Panel Recommendations

challenges. First, **current cancer incidence rates may reflect the initiation of the cancer process, from one year to even decades earlier.** In addition, the nature of the cancer reporting and verification causes delay in public access to “real-time” cancer incidence rates. Sometimes providing data that are not current, without appropriately communicating the caveats, can lead to an inappropriate magnification of public concerns, poor communication, and questions raised about how well the NC DHHS performs surveillance of cancer in the state ([Recommendation 2b](#)).

Second, the CCR routinely examines cancer incidence and mortality patterns of most common cancers that are preventable and have screening guidelines (lung/bronchus, prostate, colorectal, and female breast) in North Carolina and produces publicly available reports. These reports focus on cancers with the highest burden to population health. **The existing reports often do not include rarer cancers, or cancer rates at the sub-county geographic units and other factors.** This is due to issues such as the small number of cancer cases for standard statistical analyses and privacy rules.

Third, **epidemiologists face challenges when computing cancer rates of small population size at various geographic levels** (e.g., county, census tracts, zip codes) ([Recommendation 2](#)). The CDC and the NCI have been examining various approaches to the important problem of properly defining the study area for rate analysis. The final CDC subcounty recommendations released in March 2020 should be considered by the CCR, which participated in the CDC pilot project. The NCI Zone project methodology should also be considered in an enhanced NC protocol. Also, changing demographics with people moving in and out of an area (e.g., county) may impact the validity of cancer rates because the population “at risk” for cancer may not be reflected in the population estimates used from census reports. Additionally, improved data and methods need to be used to better estimate and examine cancer rates by important subgroups (e.g., by sex, race/ethnicity, healthcare access, etc.) that may reflect different cancer risk factors and outcomes.

Fourth, it has been shown that **different statistical methods have different strengths in terms of identifying the presence or absence of an unusual geographic cancer pattern.** This highlights the need for a careful and rigorous approach to selecting methods and tools. Moreover, datasets to provide these additional variables need to be maintained in a timely fashion, and at the geographical level necessary to inform the analyses of potential cancer clusters.

All of these elements have important consequences that limit the ability of the CCR to accurately estimate cancer rates and patterns. That is, important cancer patterns or trends may be missed or inappropriately interpreted, or potential risk factors may not be identified. It is critical that these analyses stand up to scientific peer review and have the highest public confidence. The CCR has limited resources for expanded geographic analyses using innovative methods and tools. It would be beneficial for communities, NC DHHS, researchers, and other stakeholders to **have an ongoing and systematic approach that is routinely implemented** to examine cancer patterns across the state in a more detailed and complex manner.

**Key elements:** We propose that the cancer epidemiologist ([Recommendation 2a](#)), the advisory committee ([Recommendation 5](#)), and outside experts **evaluate and incorporate improved statistical methods and software tools** that are now available for analyzing cancer rates and cluster detection. We recommend that new tools be carefully examined, and solutions be incorporated into the NC cancer cluster protocol as needed ([Recommendation 2a](#)). The data and

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analytic modifications to the protocol have implications for communication aspects and should also integrate with the web-based resources ([Recommendation 4](#)).

We further recommend that the **enhanced state cancer cluster protocol includes monitoring patterns on an ongoing basis with the methods described above**. This would allow for examining patterns at a greater resolution by cancer type, geography, and/or time to detect a “signal,” which may suggest change in cancer incidence or mortality at a larger population level. This approach will require careful consideration of statistical thresholds to prevent unnecessary time and effort devoted to investigating “false positives.” Because the finalization of state cancer data requires up to two years to assimilate (for any state cancer data, not just in North Carolina), the inability to perform “real time” analyses needs to be recognized.

**Cost:** No additional costs beyond those outlined in [Recommendation 2a](#).

### Recommendation 4. Develop a NC Environmental Public Health Tracking Web-Portal

**Rationale:** The public, state and local decision makers, and other interested parties **currently do not have an easily accessible way to view information related to environmental hazard concerns** across the state. Some relevant information is available across multiple sources and platforms, but this is not integrated or accessible in a broadly informative manner. In addition, researchers planning studies to address the relationship between environmental factors and cancer occurrence often need access to specially combined (aggregated) data for planning cancer research. Conveying this information via an online web-portal, commonly known as *Environmental Public Health Tracking*, would allow residents and others to view aggregated environmental and health data by time (e.g., year), geography (e.g., county), cancer type, age group, year, and other factors.

This online web-portal would serve as an important resource that would provide transparency between government agencies and the public. It would improve efficiency to county health departments by reducing public inquiries. It would increase responsiveness to local community health and environment concerns and build trust with policy makers. It would also make NC more competitive with other states that are receiving CDC funding to fully implement and maintain such a web-portal.

**Key elements:** Several states in the US have developed online, data visualization tools that provide the public easy access to view data on environmental exposures and related information (see [Appendix E](#) for examples of data visualization tools). We **recommend that NC DHHS develop a pilot Environmental Public Health Tracking Web-Portal** to better inform the assessment and communication of cancer and environmental patterns in NC, and better position NC DHHS to apply for CDC funding to sustain the program. The staff from OEEB and CCR would work collaboratively with the new cancer epidemiologist ([Recommendation 2a](#)) to develop and implement a pilot portal system. Note that this proposed system, which emphasizes environmental factors, is distinct from the proposed enhancement of the CCR website ([Recommendation 2c](#)).

## Cancer Research Advisory Panel Recommendations

**Cost:** Funds are required to support developing the pilot phase of this program. NC DHHS has existing infrastructure to support development of this tool using Tableau software. The budget would consist of software and storage costs (see [Appendix D](#), budget justification).

### Recommendation 5. Convene a cancer cluster advisory committee

**Rationale:** As described in previous recommendations, it would be valuable to **assemble a standing advisory panel to provide timely input** on a range of issues related to suspected cancer clusters. The advisory committee can provide essential guidance to NC DHHS staff by assisting with the review and updating of the cancer cluster protocol, suggesting and evaluating methods, and providing consultation on ongoing cancer cluster investigations. Creating an advisory committee can help foster communication and collaboration across stakeholders, utilize the considerable scientific expertise in our state, and assure transparency in government. This committee can also ensure that development of best practices for cancer cluster investigations and responses for NC communities are properly addressed.

**Key elements:** We recommend that a cancer cluster advisory committee be formed. At the discretion of NC DHHS, the committee can either be a new free-standing group or a new subcommittee of the legislatively appointed NC Advisory Committee on Cancer Coordination & Control (ACCCC).<sup>2</sup> The panel should meet quarterly to review current protocols and any cancer cluster investigations around the state. The panel members would be comprised of experts including cancer epidemiologists, environmental health scientists, statisticians, and NC DHHS staff, plus at least one Local Health Director (or designee), community member, and others as required.

**Cost:** There may be a request for funds to support meeting costs, including staff and travel funds, depending upon the organizational nature of the committee.

<sup>2</sup> The Advisory Committee on Cancer Coordination & Control is established by [North Carolina General Statute Chapter 130A - Article 33.50](#).

## Cancer Research Advisory Panel Recommendations

### Acknowledgements

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North Carolina Department of Health and Human Services Division of Public Health, State Center for Health Statistics. Vital Statistics, 2016—Volume 2, Leading Causes of Death. October 2017.

National Center for Environmental Health, CDC, Atlanta, Georgia. Investigating suspected cancer clusters and responding to community concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists. *MMWR Recomm Rep*. 2013;62(RR-08):1-24.

Goodman M, Naiman JS, Goodman D, LaKind JS. Cancer clusters in the USA: What do the last twenty years of state and federal investigations tell us? *Critical Reviews in Toxicology*. 2012;42(6):474-490.

Utah Department of Health Division of Disease Control and Prevention Bureau of Epidemiology Environmental Epidemiology Program Protocol for Investigating Cancer Cluster Concerns in Utah. May 2, 2016.

Texas Department of State Health Services Environmental & Injury Epidemiology and Toxicology Unit. Protocol for Responding to Community Cancer Cluster Concerns. January 15, 2016.

New Jersey Department of Health. Environmental and Occupational Health Surveillance Program Cancer Surveillance Unit. Cancer Cluster Response Protocol. January 6, 2017.



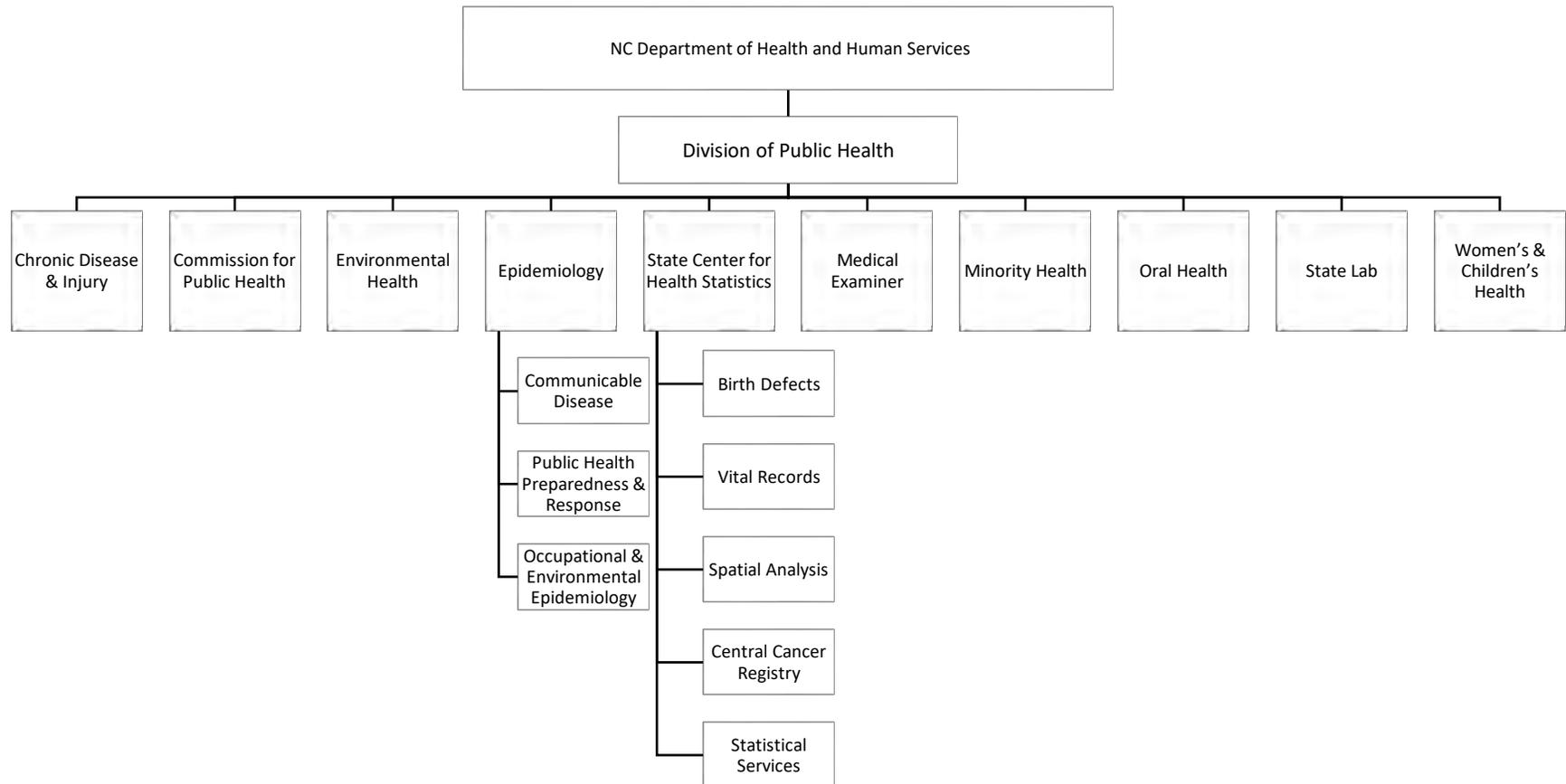
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### Appendix B. Recommendations Cross-Mapping Table

Issue / Gap Addressed, by Recommendation	1. Single Point-of-Contact	2a. Cancer Epidemiologist	2a. Protocol	2b. Risk Communication position	2c. Web developer/manager	3a. 2 Certified Tumor Registrars	3b. Stat/ Analytical Methods	3c. GIS analyst position	4. EPH Tracking Web Portal	5. Cancer cluster advisory committee
Early and consistent communication with residents, LHDs and other stakeholders	✓	✓	✓	✓	✓				✓	
Facilitated communications during investigations: talking points, media reports, written & electronic materials, website content, attendance at community meetings		✓		✓	✓					
Routine surveillance activities of cancer rates statewide		✓					✓	✓	✓	✓
Protocol developed based on existing CDC (2013) guidelines		✓	✓	✓						
Accurate and timely state cancer case reporting from all physician practices					✓					
Comprehensive statewide training program with physician practices re: reporting					✓					
Proactive identification of possible unusual cancer patterns		✓				✓	✓	✓	✓	✓

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### Appendix C. NC Department of Health and Human Services Organizational Chart



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### Appendix D. Budget for Recommended Positions

Position Title	FTE	Budgeted Salary	3% L.I.	Months	Total Salary (Account 531212)	Soc Sec 7.65% (Account 531512)	Retirement 21.44% (Account 531522)	Medical \$6,647 (Account 531562)	Total Fringes	Total Salary & Fringes
<b>Business &amp; Technology Applications Analyst (GIS Analyst)</b>	1.00	\$75,714	\$2,271	12	\$77,986	\$5,966	\$16,721	\$6,647	\$29,334	\$107,320
This position will be responsible for GIS activities including geo-enabling the CCR database, support of cancer cluster investigations, and geographic analysis of cancer patterns.										
<b>Business &amp; Technology Application Specialist (Website Developer)</b>	1.00	\$91,503	\$2,745	12	\$94,249	\$7,211	\$20,207	\$6,647	\$34,065	\$128,314
This position will enhance and support the complex SCHS website to include data visualization tools to identify cancer rates by geographic regions. This position will maintain the website environments to operational standards for performance, security, availability and integrity. This position will ensure 6-day x 24-hour online system availability requirements.										
<b>Public Health Epidemiologist</b>	1.00	\$68,637	\$2,059	12	\$70,697	\$5,409	\$15,158	\$6,647	\$27,214	\$97,911
This position provides a leadership role as project supervisor. This position plans, develops and conducts investigations into the causes of possible increases in cancer throughout the state. They will collect, analyze and interpret statistical data, and prepare epidemiologic reports for consultation and will assist in the development and coordination of plans to reduce the risk of negative health outcomes from cancer. Work includes assisting county health departments in formulating strategies to manage cancer cluster inquiries. Employee may specialize in a number of areas including cancer epidemiology.										
<b>Oncology Data Analyst (Physician Office Coordinator #1)</b>	1.00	\$44,629	\$1,339	12	\$45,968	\$3,517	\$9,856	\$6,647	\$20,020	\$65,988
<b>Oncology Data Analyst (Physician Office Coordinator #2)</b>	1.00	\$44,629	\$1,339	12	\$45,968	\$3,517	\$9,856	\$6,647	\$20,020	\$65,988

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Position Title	FTE	Budgeted Salary	3% L.I.	Months	Total Salary (Account 531212)	Soc Sec 7.65% (Account 531512)	Retirement 21.44% (Account 531522)	Medical \$6,647 (Account 531562)	Total Fringes	Total Salary & Fringes
<p>These positions are responsible for working with physician practices and other non-hospital reporting sources to establish, implement and monitor cancer reporting according to NPCR grant deliverables. These positions will perform technical and professional cancer registrar work to ensure the overall accuracy, timeliness and completeness of cancer data meets national standards. They will work as team members of the CCR. The people in this position must be CTR (Certified Tumor Registrar) eligible and obtain the CTR credential once the required work experience has been met.</p>										
<b>Public Health Educator II</b>	1.00	\$58,845	\$1,765	12	\$60,611	\$4,637	\$12,995	\$6,647	\$24,279	\$84,890
<p>This position provides consultative and administrative work that directs a program of health education for a large geographical area of the state. Work will focus on educating the public about cancer prevention. Work is performed under administrative supervision and is evaluated through conferences and written reports.</p>										
<b>Annual Position Totals for CCR + OEEB</b>	6.00	\$383,957	\$11,518		\$395,479	\$30,257	\$84,793	\$39,882	\$154,932	\$550,411

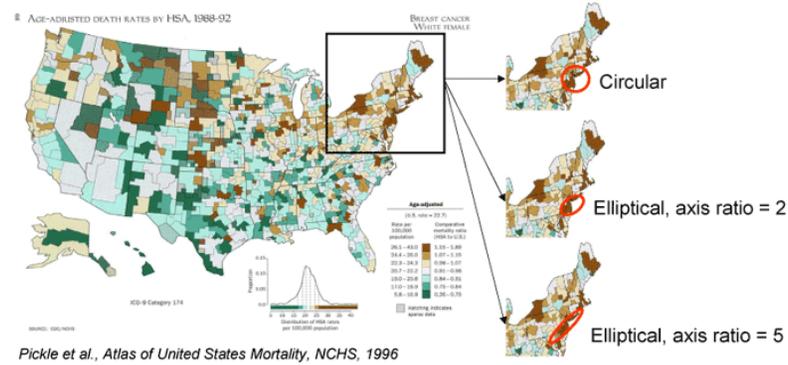
<b>Software and Storage Costs</b>	
<b>CCR GIS Software</b>	(annual costs)
Esri ArcPro Advanced	\$7,369
GIS data Storage/Online Credits	\$600
<b>OEEB Tracking Software</b>	
Creator, Explorer, Viewer	\$3,896
Storage space	\$4,200
<b>Totals for CCR &amp; OEEB</b>	<b>\$16,065</b>

<b>TOTAL ANNUAL BUDGET REQUEST</b>	
Personnel	\$550,411
Software and storage	\$16,065
<b>TOTAL</b>	<b>\$566,476</b>

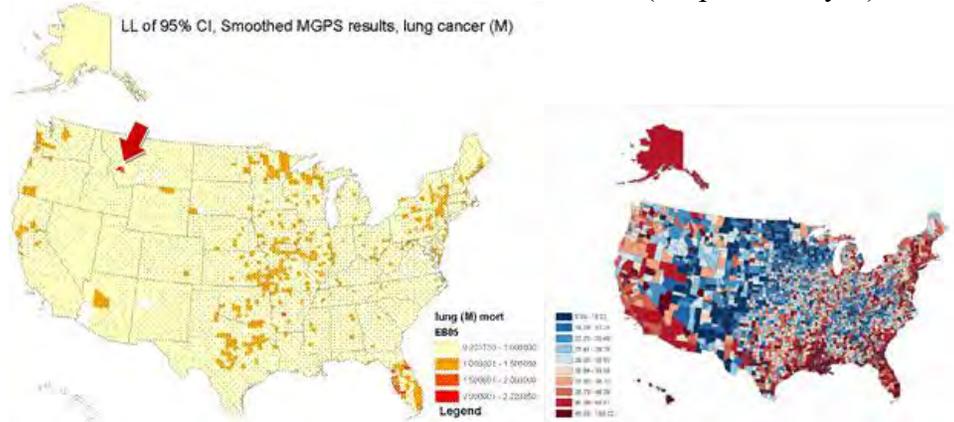
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## Appendix E. Examples of Geospatial Data Visualization & Analysis Tools

Cluster Detection (spatial scan statistic for Bernoulli or Poisson event data)  
(SaTScan Software)

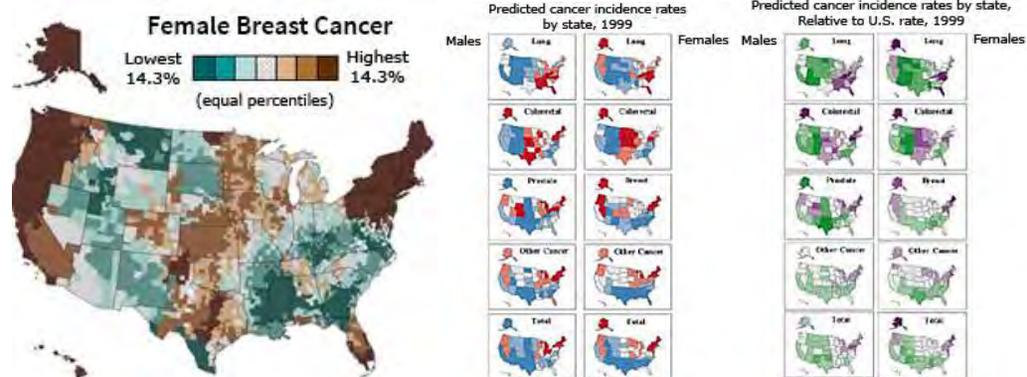


Outlier Detection for Cancer Surveillance (Empirical Bayes)

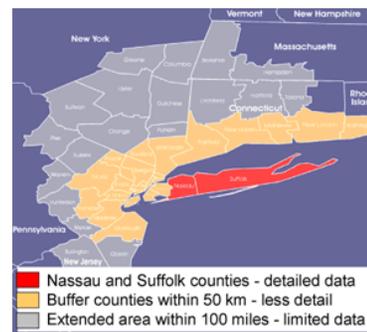
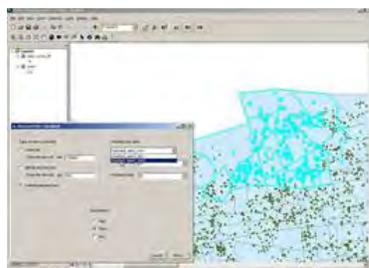


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### Statistical Modeling (hierarchical Poisson regression): Predicted Incidence Rates



Environmental Exposure Assessment  
(ESRI, Geographical Information System)



SaTScan

<https://www.satscan.org/>

GeoDA

<https://spatial.uchicago.edu/geoda>

## Example of California Cancer Registry Web Portal

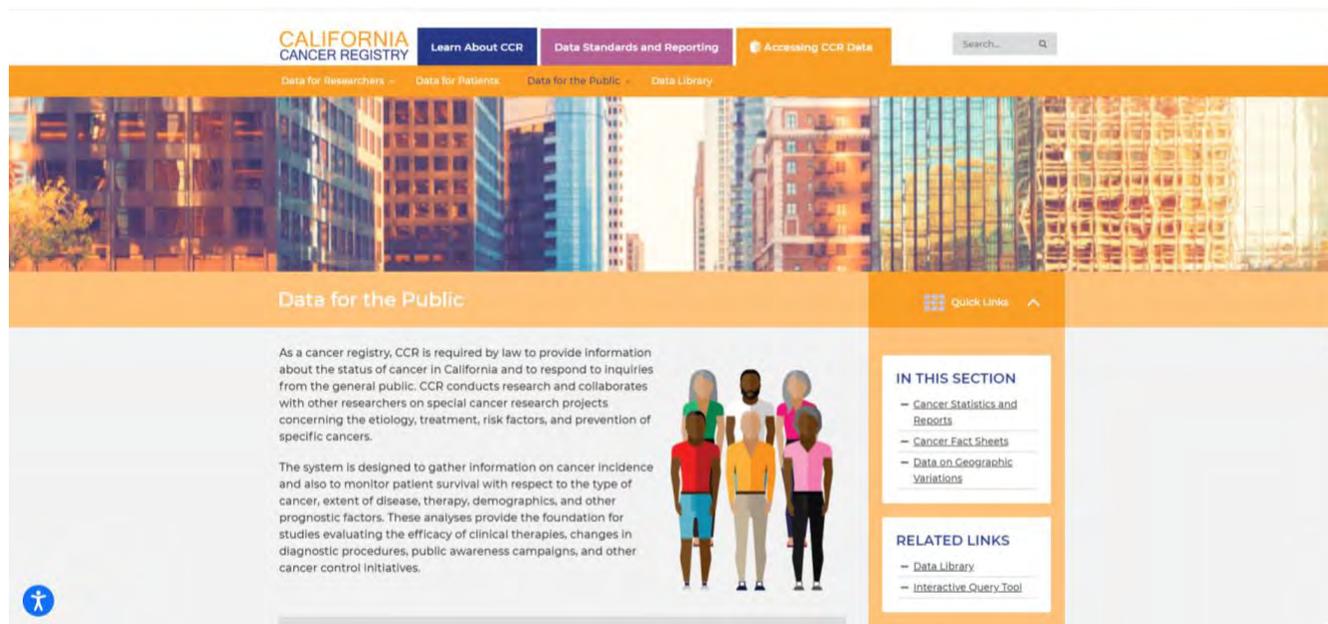


Figure 1. Landing page for the Public to view data statistics on California Cancer Registry Web Portal

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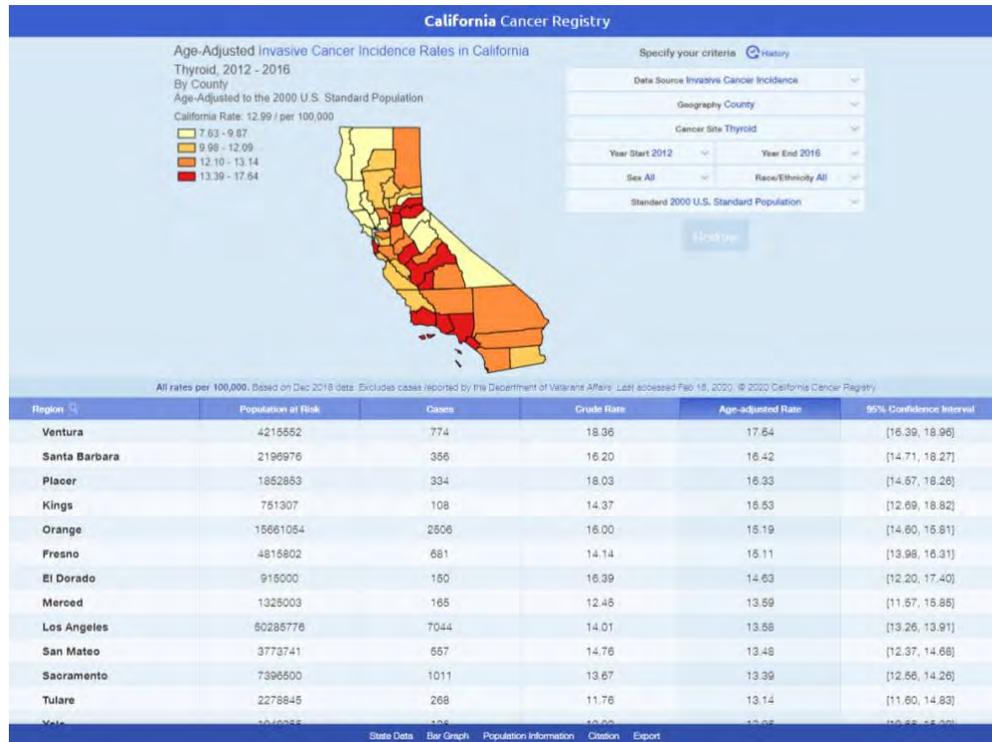


Figure 2. View of crude and age-adjusted Thyroid Cancer rates by county

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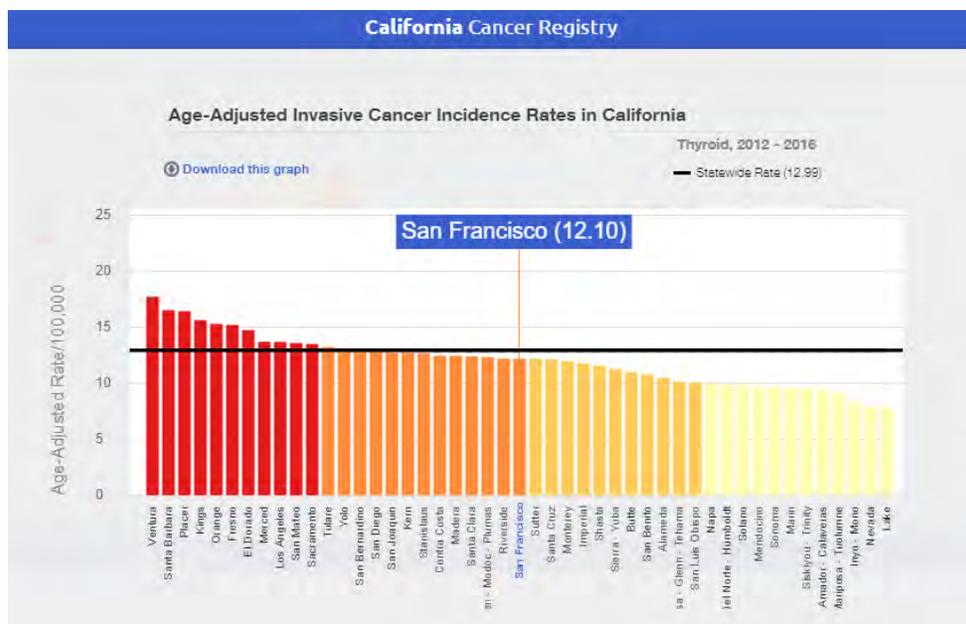


Figure 3. Figure of age-adjusted invasive cancer incidence rate in California (mouse over shows San Francisco at 12.10 per 100,000)

### *Available Geospatial Tools*

#### *National Cancer Institute*

[https://gis.cancer.gov/gis-nci/spatial\\_data\\_analysis.html#detection](https://gis.cancer.gov/gis-nci/spatial_data_analysis.html#detection)

#### *SaTScan*

<https://www.satscan.org/>

#### *GeoDA*

<https://spatial.uchicago.edu/geoda>

*Examples of national and state cancer registries and health mapping in the US with Interactive Web Portals for Displaying Cancer Data, Statistics and Mapping*

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North American Association of Central Cancer Registries – Analysis and Data Improvement Tools

<https://www.naaccr.org/analysis-and-data-improvement-tools/>

National Cancer Institute – Geospatial Tools

[https://gis.cancer.gov/tools/geospatial\\_tools.html](https://gis.cancer.gov/tools/geospatial_tools.html)

Washington State Cancer Registry

<https://fortress.wa.gov/doh/wscr/Query.mvc/Query>

North Carolina Central Cancer Registry

<https://schs.dph.ncdhhs.gov/data/hsa/cancer.htm>

California Health Maps

<https://www.californiahealthmaps.org/>

### ***Examples of national and state health departments in the US with Interactive Web Portals for Displaying Cancer and Environment Data, Statistics and Mapping***

National Environmental Public Health Tracking Web Portal

<https://www.cdc.gov/nceh/tracking/default.htm>

California Tracking Program

<https://trackingcalifornia.org/cancer/query>

New Jersey Tracking Program

<https://www.cancer-rates.info/nj/>

Massachusetts Tracking Program

<https://matracking.ehs.state.ma.us/Health-Data/Cancer/index.html>

Florida Department of Health Tracking Program

<https://www.floridatracking.com/healthtracking/topic.htm?i=22>

## Appendices

### *Examples of national and state protocols for investigating cancer clusters*

*CDC- Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and CSTE (note that new guidelines are being developed and will be released in 2021).*

<https://www.cdc.gov/nceh/clusters/default.htm>

Maryland Department of Health and Mental Hygiene

Guidelines for the Management of Inquiries Related to Cancer Concerns or Suspected Cancer Clusters

[https://phpa.health.maryland.gov/cancer/SiteAssets/SitePages/Cancer%20Clusters/Maryland%20State%20Guidelines%20on%20Cancer%20Clusters\\_10.26.2015.pdf](https://phpa.health.maryland.gov/cancer/SiteAssets/SitePages/Cancer%20Clusters/Maryland%20State%20Guidelines%20on%20Cancer%20Clusters_10.26.2015.pdf)

Texas Department of State Health Services

<https://dshs.texas.gov/epitox/CancerClusters.shtm>

### *Communication Tools for Cancer Clusters*

NPHIC: Cancer Clusters: A toolkit for Communicators

<https://www.nphic.org/toolkits/cancer-cluster>

### *Additional supporting documents on Cancer Clusters*

*Answering cluster investigations requests: the value of simple simulations and statistical tools.*

<https://www.ncbi.nlm.nih.gov/pubmed/16151879?dopt=Abstract>

*Cancer clusters: Findings vs. Feelings*

<https://www.ncbi.nlm.nih.gov/pubmed/12817212>

*Understanding cancer clusters*

<https://www.cancer.org/cancer/cancer-causes/general-info/cancer-clusters.html>