

2021 NPCR MAINE SUCCESS STORY

Maine Cancer Registry: Carolyn Bancroft, Kim Haggan, Kathy Boris, Jessica Cross, Sara Huston, and Denise Yob

Responding to Constituent Cancer Concerns: The Maine Cancer Registry's Cancer Inquiry Group

National Program of Cancer Registries SUCCESS STORY

SUMMARY

The Maine Cancer Registry (MCR) receives, on average, ten to twelve constituent inquiries per year related to concerns about specific cancer diagnoses in a neighborhood or place of work and connections with environmental factors or other hypothesized causes. In April 2021, the MCR established a Cancer Inquiry Group to develop a standard process for reviewing and responding to cancer concerns from the public, based on guidance from the Centers for Disease Control and Prevention (CDC) and Council on State and Territorial Epidemiologists (CSTE). The registry also undertook a review of how MCR responded to constituent inquiries over the past 20 years to identify trends and lessons.

CHALLENGE

Maine's cancer incidence and mortality rates are higher than the United States, even after adjusting for age, and cancer is the leading cause of death in Maine.¹ There are a variety of potential factors that contribute to Maine's disproportionate cancer burden and mortality. These include higher prevalence of smoking and lower prevalence of physical activity (when compared with national averages)², environmental exposures like radon and arsenic, and occupational exposures in some industries in the area (e.g., shipbuilding and mills). In addition, social determinants of health (SDOH) -- such as people experiencing poverty and people who are medically underserved (and may lack in adequate screening and treatment due to the state's rurality) -- may contribute to the disparity.³

While the MCR made some progress on drafting a cancer concern inquiry protocol several years back and proposed creating a Cancer Inquiry Group to review concerns, that work was not finalized due to leadership changes and other staffing issues. The MCR continued to respond to cancer concern inquiries as they were received during this time, but the MCR desired to have a more standardized process and a designated group with different areas of expertise to guide responses and to promote a timely and consistent approach.

SOLUTION

In early 2021, the MCR established an internal Cancer Inquiry Group with the goal to develop and pilot a standardized process for responding to cancer concern inquiries based on internal draft procedures from 2015 and 2013 guidance from the CDC and CSTE.⁴ The MCR Program Manager recruited seven members to serve on the Cancer Inquiry Group: the state Lead Environmental Epidemiologist, the state Lead Chronic Disease Epidemiologist, two MCR Epidemiologists, the Director of Data, Research and Vital Statistics (where MCR is housed), the MCR Program Manager, the MCR Data Quality Manager (who is a Certified Tumor Registrar) and an Epidemic Intelligence Service officer assigned to Maine CDC (ME CDC) with extensive background in cancer epidemiology. The group met for the first time in April 2021 and meets on a quarterly basis if there are inquiries to review.

MCR epidemiologists developed an established workflow and several templates and tools to guide this work. First, a structured questionnaire intake form outlines the information that the MCR epidemiologist gathers from the concerned constituent. Next, a standardized incidence ratio calculator tool and background data review template guide the preliminary analysis completed prior to the Cancer Inquiry Group meeting. The data review template includes relevant information about the cancer(s), the town(s) or geographic area, and environmental exposures of concern. It includes a section for registry data such as a case listing and

analysis of local, county, and state rates to compare trends and present standardized incidence ratios (SIR). Based on the first two Cancer Inquiry Group meetings, the group revised a list of eight decision criteria to help summarize the level of concern, next steps, and recommendations.

RESULTS

In the first nine months of 2021, the Maine Cancer Registry received ten cancer inquiries. Three inquiries were addressed via telephone conversations and email without review by the committee, and the remaining inquiries were reviewed by the Cancer Inquiry Group in quarterly meetings held in April and August 2021. The inquiries provided an opportunity to revise the intake form, update the background data review template, and test the SIR calculator tool.

At the same time, MCR reviewed inquiries received over the last two decades and created a reference table that can be used to identify inquiries by location or specific cancer site. This provides an overview of how the MCR responded previously to different types of concerns which may guide responses to inquiries in the future (e.g., groups of cancer among teachers in a school). In addition, it documents whether MCR previously investigated cancer in a certain area. The MCR regularly

receive requests from internal partners such as environmental health or from external constituents asking "Has MCR investigated cancer in ____ town?" The review provides a single point of reference rather than relying on staff memory or searching through archive files.

A few key lessons have emerged from this work thus far. First, having consistent protocol, tools, and templates for reviewing and responding to an inquiry allows the group to determine next steps in a timely manner. Second, a multi-disciplinary group with different areas of expertise from certified tumor registrar to environmental and chronic disease epidemiologists strengthens the Cancer Inquiry Group discussions and decision-making. Third, having an index of resources for constituents improves

our response, especially when in most cases the group does not pursue further epidemiologic investigation. Resources range from information about how the state supports testing well water and soil for contaminants to information about cancer prevention, screening, and diagnosis. Fourth, clear communication and follow-up with all relevant parties (both the constituent as well as local elected officials and others, as appropriate) helps to ensure that all concerned parties are aware of the MCR review and response. This is especially relevant in situations where the same concern is referred to MCR through multiple channels.

SUSTAINING SUCCESS

The MCR Cancer Inquiry Group will continue to work on establishing standards for analysis, communication, referral, and outreach in response to constituent cancer concerns. Furthermore, MCR will consider how to better connect and integrate with Maine CDC environmental health resources as well as Maine CDC cancer prevention and control colleagues to provide appropriate resources to concerned constituents. We will continue to document trends and consult with neighboring states when concerns are in border towns. Once updated cancer cluster guidance is available from CDC, those recommendations will be incorporated into existing protocols and procedures.

REGISTRY CONTACT INFORMATION

207-287-5272

<http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/>



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention

1. THE MAINE 2020 ANNUAL REPORT OF CANCER. Augusta, ME: Maine Center for Disease Control and Prevention; 2021.
2. BRFSS Prevalence & Trends Data: Home | DPH | CDC. Accessed August 26, 2021.
3. Pizzonia C, Lichter EL, Teach F, Birkhimer N, Morian-Lozano E. The Way Health Should Be: Social Determinants of Health in Maine 2019. Augusta, Maine: Maine Center for Disease Control and Prevention.
4. Centers for Disease Control and Prevention. Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists. MMWR 2013;62(No. 8).