

Using Registry Data to Help Investigate a Possible Kidney Cancer Cluster

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SUMMARY

The public was concerned about environmental pollution and a possible excess of kidney cancer cases in the Merrimack area of New Hampshire. The state legislature funded a feasibility study to understand the need for, and feasibility of, conducting a definitive study. As part of this effort, the team analyzed 27 years of cancer registry data, first conducting quality checks and harmonizing the data to permit a rigorous analysis.

CHALLENGE

- Changes in cancer data classifications have occurred over time, as scientists' and clinicians' understanding of cancer behavior has advanced through research. Intensive evaluation and data harmonization was needed to ensure that data collected over 27 years could be rigorously analyzed.
- Presenting the findings to the public with appropriate interpretations and explanations will require additional work, together with state partners.

SOLUTION

- Advisors with pathology, registry, and epidemiology expertise guided data harmonization to address changes in the coding of histology subtypes for 1995 to 2021. It was particularly useful to understand the history underlying changes in cancer histology classification over time.
- This effort was supported by clinical, research, and public health experts on the study team, external scientific advisors, and a steering committee.
- Data were analyzed using a pre-specified data analysis plan to produce standardized incidence ratios for cancer subtypes and geographic sub-regions.

RESULTS

- Because cancer data were collected systematically over almost three decades, the study team could harmonize the data, taking into account changes in clinical and pathology practice over time.
- The team reviewed the data in detail to ensure cases were coded consistently over time.
- The harmonized dataset was used to identify possible excesses of specific cancer subtypes and in specific geographic locations.
- Changes in national coding standards over time required considerable effort to review and harmonize the data. However, without decades of registry data, it would not be possible to explore in detail the possible excess of kidney cancer in Merrimack Town, New Hampshire, and the surrounding area, and respond to community concerns about cancer and environmental pollution.
- In this way, registry data are being used to support cancer statistical analysis for messages to the public in New Hampshire.

CONCLUDING REMARKS

Cancer registry data are critical to the state effort to respond to public concern about kidney cancer in a community. Working with health department colleagues, the team is finalizing its analysis of the cleaned dataset. The team will explore options for a future definitive study and develop a report using plain language to explain the findings. The next steps are for the study team to determine whether a Phase IV study is warranted and feasible.