Data Reports: They Can Always Get What They Want
(But do they get what they need?)
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Background
Central cancer registries have been criticized for not providing timely data to address cancer control efforts. The Massachusetts Cancer Registry (MCR) is experimenting with releasing preliminary data.

Purpose
To provide preliminary 2013 cancer incidence data as well as trend data, incidence (2003-2013) and mortality (2003-2014) for four major cancers in Massachusetts. The trend report was a collaborative effort between the Massachusetts Cancer Registry (MCR), the Behavioral Risk Factor Surveillance System (BRFSS), the Massachusetts Comprehensive Cancer Prevention and Control Network (MCCPCN), the Women’s Health Network Care Coordination Program (WHNCCP) and the Massachusetts Tobacco Cessation and Prevention Program (MTCPP) to provide within a single source the most recent available data on trends and program information for the following four major types of cancer: prostate, female breast, bronchus and lung, and colorectal.

Example of Report Contents


- The incidence rate for invasive breast cancer for all women did not change significantly from 2003 to 2013. The mortality rate for all women dropped significantly by 2.9% per year from 24.3 per 100,000 in 2003 to 18.7 per 100,000 in 2014.

- Self-Reported Mammogram During the Previous Two Years Among Massachusetts Females Age 50+, 2000-2012*

- Massachusetts Department of Public Health Program Initiatives

Selected Initiatives for Breast Cancer

- The Women’s Health Network Care Coordination Program:
  - Funded 11 clinical sites in community health centers to provide education and patient navigation for screening of breast, cervical and colorectal cancers.
  - Developed and promoted the Can We Talk? materials to help empower women to feel more comfortable discussing breast and cervical cancer screening with their healthcare providers.
  - Implemented the Community Based Organization Outreach, Education and Linkage project to link those most in need to a medical home and screening services.

Questions

1. Was early release of 2013 incidence rates misleading?
2. Did we gain anything by releasing preliminary rates?

Comparison of Preliminary vs. Final Incidence Rates for Males and Females - 2013

- In general, preliminary model overstated the magnitude, but not the direction of trends.
- Use of ‘final’ rates changed the underlying model for all but female breast and female colorectal cancer.

Did they get what they needed?

- Massachusetts Executive Office of Health and Human Services liked the report; the result was an interview with Boston Public Radio WBUR.
- Between December 2015 – April 2016 there were 297 MCR web page hits on this report.
- MCCPCN used this report for the following: updating cancer burden in Massachusetts; preparing for the updated Cancer Control Plan; Performance Measures Tracking; program evaluation and design.
- Release of preliminary data contributes to a favorable public perception.

For the Future

- Include Delay Adjustment Factors to more accurately access current trends.
- Include additional cancer sites.

*Statistically significant trend (p<.05)

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