Incorporating Genomics Into An Existing State Level Cancer Surveillance System

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Background

In 2003, the Michigan Department of Community Health (MDCH) received federal funding to **integrate genomics** into public health activities. One objective included examining existing surveillance systems to identify those with the potential to meaningfully integrate family history of disease data. The Michigan Cancer Surveillance Program (MCSP) was chosen as one of the larger surveillance systems with this type of potential.

Since 1984, the MCSP has operated under a statewide mandate to report new cases of cancer, and contains data on 910,000 incident cases. Over 90% of cases are reported by hospitals. The MCSP collects demographic, tumor and treatment information, but does not routinely collect information regarding family history of cancer. As a collaborative effort, program staff from the genomics unit and the MCSP at the MDCH created an audit tool that specifically addressed family history of cancer. This tool was included in the annual auditing activities used for maintaining data quality of the registry.

Objectives

- To assess the presence and availability of genomic elements in a state cancer surveillance system
- To evaluate the feasibility and utility of including family history of cancer as a required data element in the Michigan Cancer Surveillance Program

Methods

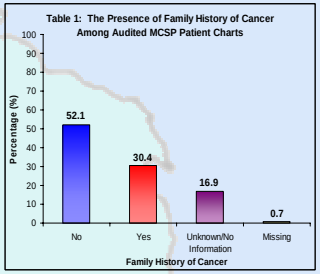
- N = 853 charts reviewed
- Chart abstraction period: December 2003 to October 2004
- Chart abstraction process:
  - Facilities were chosen based upon the normal audit cycle (each facility is audited every three years) and notified of the audit
  - Cases at each facility were randomly selected based upon the minimum number of primary cancer sites that must be audited:

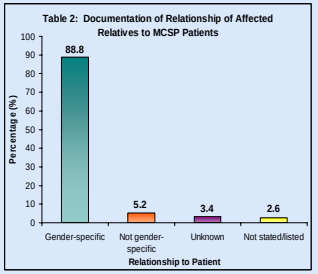
Primary cancer site	Number of required chart audits	Primary cancer site	Number of required chart audits
Breast	3	Lung	3
Brain	3	Melanoma	1
Cervix	3	Multiple primary	4
Colon	3	Prostate	3
Kidney	1	Ovary	2
Leukemia	2	Rectum	2
Liver	3	Urinary bladder	2
Lymphoma	3	Unknown primary	2

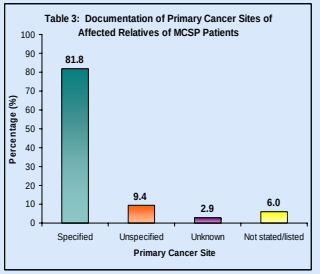
  - 10% of the total number of cases submitted by each facility were audited, with a minimum of 40 cases and a maximum of 80 cases
  - Field representatives reviewed chart information relative to the patient's diagnosis and/or treatment of cancer (e.g., discharge summary, history and physician examination report, pathology reports, etc.)
- Charts were reviewed for documentation of presence or absence of family history of cancer
  - When a ***family history*** of cancer was ***present***, information about the ***affected relative*** was collected and included:
    - Relationship to the patient
      - Categorized as gender-specific (e.g., grandmother, brother) or non gender-specific (e.g., family, cousin)
    - Primary site of cancer
      - Categorized as specific (e.g., lung, breast) or non-specific (e.g., neck, 'female cancer')
    - Age at diagnosis
    - Date of diagnosis

Results

- The mean age of patients from the chart abstraction was 64 years; approximately 67% were aged 50 years and older
- The majority of patients were White (95.3%), and over half were women (56.3%)
- **82.5%** of charts that were audited ***documented the presence or absence of any family history of cancer*** (Table 1)
- Of these, 30.4% of charts indicated a positive family history of cancer (Table 1)
- Among the patients with a family history of cancer, approximately 89% were gender-specific in identifying the affected relative's relationship to the patient (Table 2)
- In the same manner, an estimated 82% of those with a positive family history had specific information regarding the relative's primary cancer site (Table 3)
- Conversely, among those with a documented family history, 94.3% of charts were missing information on the relative's age at diagnosis, and 99.5% of charts were missing information on the relative's date of diagnosis







Conclusions

- The presence and/or absence of ***family history of cancer was largely documented and available*** in the majority of audited patient charts in the MCSP
- Information regarding the affected relative(s) was ***frequently gender- and site-specific***, perhaps indicating provider vigilance in obtaining this key information from patients
- However, information regarding affected relative's ***age and date of diagnosis were often missing***
  - Diagnosis at a younger age than usually observed for a particular cancer type is often characteristic of inherited forms of cancer
  - Lack of this information limits the assessment of family cancer risk
- Although risk assessment based on family history could not be ascertained from the chart audit process, this project provided useful information regarding the collection and availability of family health history data among MCSP charts
- Findings suggest that if family history of cancer were added to the MCSP, family risk could potentially be examined more thoroughly with respect to genomic information
- Next steps include:
  - Explore the reasons for incomplete collection of family history of cancer information (age and date of affected relative's diagnosis)
  - Evaluate the validity, usefulness, and cost-effectiveness of including family history of cancer as a required data element in the MCSP
  - Engage appropriate stakeholders, such as hospital-based tumor registrars and reporting facilities, in discussions of incorporating family history of cancer information in the MCSP

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