Setting the stage for change: upgrading the physician cancer case reporting application in New York

April Austin
New York State Cancer Registry (NYSCR)
Bridging the Path to the Future of Cancer Surveillance

200 Hospitals & 50 Radiation Treatment Centers (Med Oncology)

Dermatology Practices

Smaller Hem/Onc Practices

NYSCR

100 Ambulatory Surgery Centers & 200 Pathology Laboratories

Urology Practices

Aerial view of Thousand Islands, New York
Objectives

- Describe the extent of cancer case reporting by physicians to the NYS Cancer Registry (NYSCR) and the importance to case ascertainment and describing NY’s cancer burden
- Illustrate the current Physician Cancer Case Reporting System
- Explain approach for decisions related to redesign
- Outline next steps
Extent and Importance of Physician Reporting
On NYSDOH’s secure Health Commerce System (HCS)

Deployed in 2011

Users include:
- NYS licensed physicians or their designees
- Registry staff (abstracting paper reports from physicians)

2013: initiated statewide outreach to targeted specialists (dermatologists, urologists, hematologists, oncologists)
Physician office submissions since 2011

58,151 case reports

- 39,954 (68%) new (unsolicited) reports
- 18,197 (32%) lab follow-back reports (through dx year 2015)
- 42,323 (73%) electronic submissions by external users
- 15,828 (27%) paper reports abstracted by NYSCR staff
- 3,498 NY physicians (license numbers)
- 1,040 unique HCS user IDs
In situ melanoma, non-Hispanic white males, New York, 2001-2014

- Overall rate
- No unsolicited physician reporting
- No lab and physician follow-back
- No lab or physician reporting
Invasive melanoma, non-Hispanic white males, New York, 2001-2014

Age-adjusted incidence rate per 100,000 population

- Overall rate
- No unsolicited physician reporting
- No lab and physician follow-back
- No lab or physician reporting


Overall rate: 31.1, 28.7, 26.1
### Sub-analysis of tumors diagnosed 2015 – 2016 and at least one source report (unsolicited) is from a physician office

<table>
<thead>
<tr>
<th>Cancer Group</th>
<th>Total Tumors</th>
<th>Physician Only Source*, N</th>
<th>Physician Only Source*, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>OVERALL</td>
<td>10,895</td>
<td>4,393</td>
<td>40.3</td>
</tr>
<tr>
<td>DERMATOLOGY</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Melanoma-in situ</td>
<td>2,750</td>
<td>2,250</td>
<td>81.8</td>
</tr>
<tr>
<td>Melanoma-invasive</td>
<td>1,944</td>
<td>861</td>
<td>44.3</td>
</tr>
<tr>
<td>UROLOGY</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>3,035</td>
<td>730</td>
<td>24.1</td>
</tr>
<tr>
<td>Urinary bladder-in situ</td>
<td>210</td>
<td>73</td>
<td>34.8</td>
</tr>
<tr>
<td>Urinary bladder-invasive</td>
<td>152</td>
<td>22</td>
<td>14.5</td>
</tr>
<tr>
<td>HEMATOLOGY/ONCOLOGY</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hodgkin lymphoma</td>
<td>13</td>
<td>1</td>
<td>7.7</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>144</td>
<td>50</td>
<td>34.7</td>
</tr>
<tr>
<td>Myeloma</td>
<td>63</td>
<td>31</td>
<td>49.2</td>
</tr>
<tr>
<td>Lymphocytic leukemia</td>
<td>67</td>
<td>56</td>
<td>83.6</td>
</tr>
<tr>
<td>Myeloid/other leukemia</td>
<td>33</td>
<td>22</td>
<td>66.7</td>
</tr>
<tr>
<td>Other Hematopoietic</td>
<td>79</td>
<td>64</td>
<td>81.0</td>
</tr>
</tbody>
</table>

* Excluding pathology or death certificate reports; as of March 2018
Current Physician Cancer Case Reporting System
Welcome page:

- Report new cases
- Respond to lab follow-back requests
### Three tabs (forms)
- Patient info
- Cancer info
- Treatment info

### Data fields
- 66 fields, 20 required
- Selection lists/text
- Hover/help buttons
- Simple data checks (edits)
6 Site specific modules:
- Melanoma
- Prostate
- Leukemia
- Lymphoma
- Hematopoietic – Other
- Other type of Cancer

Data collected:
- Primary site, histology, behavior, diagnosis date
- Site specific factors
- Stage of disease (currently SEER Summary, TNM, CS items)
<table>
<thead>
<tr>
<th>Treatment info Tab</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Summary treatment status</td>
</tr>
<tr>
<td>➢ Biopsy</td>
</tr>
<tr>
<td>➢ Lymph node involvement</td>
</tr>
<tr>
<td>➢ Surgery</td>
</tr>
<tr>
<td>➢ Other treatment modalities</td>
</tr>
</tbody>
</table>

Referral and other information
Approach for Decisions Related to Redesign
Review 2018 NAACCR standards

- 2018 Implementation Guidelines
- NPCR data requirements
- SEER data requirements
- NYSCR requirements for other types of reporting sources
- Site specific data items (SSDIs)
- Grade
- Extent of disease (EOD)
- SEER Summary stage 2018
- AJCC 8th edition stage items
- ICD-O-3 Histology revisions
Design considerations

- Focus on collection of data for cases we do not get from hospitals or treatment facilities
- Use selection lists when possible - users are not CTRs (no coding)
- Expect user variability in medical knowledge and experience
- Recognize that items collected need to be readily available in medical records and/or pathology reports
- Be mindful of providers’ time - minimize reporting burden as much as possible
Considerations: Example - Melanoma fields

- Most likely to include bolded items
- Unlikely to include post therapy items
- Others included based on complexity of item, user experience, reasonableness

<table>
<thead>
<tr>
<th>Current Application Items</th>
<th>2018 NAACCR Items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Site Specific Disease Items</strong></td>
<td></td>
</tr>
<tr>
<td>- Breslow Thickness</td>
<td>- Breslow Thickness†</td>
</tr>
<tr>
<td>- Ulceration</td>
<td>- Ulceration†</td>
</tr>
<tr>
<td>- Mitotic Rate</td>
<td></td>
</tr>
<tr>
<td>- LDH Pretreatment Lab Value</td>
<td>- LDH Pretreatment Lab Value</td>
</tr>
<tr>
<td>- LDH Upper Limits of Normal</td>
<td>- LDH Upper Limits of Normal</td>
</tr>
<tr>
<td>- LDH Pretreatment Level†</td>
<td>- LDH Pretreatment Level†</td>
</tr>
<tr>
<td>- Grade (Clinical, Pathological, Post Therapy)</td>
<td>- Grade (Clinical, Pathological, Post Therapy)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Extent of Disease Items</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Tumor Size Summary</td>
<td>- Tumor Size (Clinical, Path, Summary)</td>
</tr>
<tr>
<td>- CS Tumor Extension</td>
<td>- EOD Primary Tumor†</td>
</tr>
<tr>
<td>- CS Regional LN Involvement</td>
<td>- EOD Regional Nodes†</td>
</tr>
<tr>
<td>- CS Metastasis at Diagnosis</td>
<td>- EOD Mets†</td>
</tr>
<tr>
<td></td>
<td>- Summary Stage</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>AJCC TNM Stage Items</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Clinical T, N, M, Stage Group</td>
<td>- Clinical T, N, M, Stage Group</td>
</tr>
<tr>
<td>- Pathologic T, N, M, Stage Group</td>
<td>- Pathologic T, N, M, Stage Group</td>
</tr>
<tr>
<td></td>
<td>- Post Therapy T, N, M, Stage Group</td>
</tr>
</tbody>
</table>

† Seer Program Coding and Staging Manual (Appendix C)
Example - Melanoma fields, cont’d

- Mitotic Rate
  - Not required for staging
  - Values are a mixture of numbers and characters

- Lactate Dehydrogenase (LDH) laboratory test
  - Prognostic factor for Stage IV melanoma; expect to receive from hospitals or treatment centers
  - LDH Pretreatment Level: elevated versus not elevated; easy to complete
Example - Melanoma fields, cont’d

- Grade
  - Routinely noted in pathology reports of melanoma?

- Tumor Size
  - Not required for staging
  - Observed confusion with Breslow thickness field

- Summary Stage
  - Can be derived
  - Reasonable to collect similar data multiple ways?
Next Steps
Next Steps - Design

- Perform similar approach to field selection for other five site-specific modules
- Consider more required fields/edit checks to improve quality without hindering user experience
- Think about potential for additional modules (e.g., bladder)
- Consider additional fields to assist with gaps of information related to spectrum of patient care (e.g., laboratory performing examination; state-specific “class of case”; specific fields related to referral information)
- Consult with leaders of case processing team
Next Steps - Technical

- Provide new specifications to our technical team
- Work with technical team to design a workflow that will meet our data needs and continue to maintain a user-friendly environment
- Propose functionality to display former versus new cancer diagnosis tab form based on diagnosis year
- Upgrade HCS account authentication processes to allow reporting by NYS-licensed nurse practitioners and physician assistants
Bridging the Path

to the Future of Cancer Surveillance

The future holds promise for new data sources (claims data, EHR data, prescription data, historical address information), technological advances (natural language processing, big data, more automation), and collaboration.

As long as cancer-care providers maintain private businesses outside larger healthcare organizations, our Physician Cancer Case Reporting Application will continue to bridge the gaps in case ascertainment.
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Questions? (April.Austin@health.ny.gov)