Climbing the Data Mountain to Reach Your Cancer Program’s Highest Potential

Melanie Williams Rogan, CTR
Director of Registry Services
Electronic Registry Systems, Inc.
Objectives

- Understand Industry trends and the importance and value of the cancer registry data to support the cancer program
- Learn how to engage the cancer program’s partners
- Identify how to become a knowledge center and market the registry
- Identify the various uses of cancer registry data
Why do we do what we do?

“Hiding within those mounds of data is knowledge that could change the life of a patient, or change the world.”

- Atul Butte, Director, Institute for Computational Health Sciences, UCSF
Industry Trends: Where are we headed?

Network and Facility Level
• Mergers and acquisitions
• Financial considerations
• CMS initiatives
• Value-based care and reimbursement

Cancer Center/Cancer Registry Level
• Integration with other health systems
• Intelligent casefinding and abstracting
• Concurrent abstracting
• Enterprise-wide data analytics
• Quality initiatives
• Key Performance Indicators
Leverage “Your” Knowledge Center

- Market the Cancer Registry to cancer center administrators, research departments, marketing departments, physicians and other clinicians

- Share the granular detail of information collected in the registry

- Demonstrate the types of reports that can be generated

- Promote quality and research studies
Marketing the Cancer Registry

Who are your customers, clients and partners?

- Cancer Registry administrators
- Cancer Committee
- Tumor Board participants
- Administration
- Physicians
- Clinical Trials and Research departments
- Marketing departments
- Patients
- The community
Engaging Your Partners and Customers

• Create a PowerPoint presentation of what the registry does, collects and data usages
• Set up a meeting with cancer registry administrators
• Present at Cancer Committee meetings
  • Engage with Tumor Boards
  • Create flyers to distribute to “partner’s” departments
  • Promote on social media
  • Create a display in a well-traveled place
• Mailings to the community
Educate and Inform

Core Data Set

<table>
<thead>
<tr>
<th>Patient Demographics</th>
<th>Cancer Identification</th>
<th>Staging at Diagnoses</th>
<th>Treatment Plan and Implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Name</td>
<td>Diagnosis Date</td>
<td>Summary Stage</td>
<td>Surgery Date</td>
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<tr>
<td>Last Name</td>
<td>First Contact Date</td>
<td>Biologic Stage</td>
<td>Complication Status</td>
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<td>Social Security Number</td>
<td>Sequence of Primary</td>
<td>AICC Pathologic Stage</td>
<td></td>
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<td>Medicare Beneficiary #</td>
<td>Primary Site</td>
<td>AICC Post Therapy Stage</td>
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<td>Accession Number</td>
<td>Histology</td>
<td>Lymph Nodes</td>
<td>Treatment Accuracy</td>
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<tr>
<td>MRN</td>
<td>Laterality</td>
<td>Extent of Disease</td>
<td>Surgical Margins</td>
</tr>
<tr>
<td>Current Address</td>
<td>Grade</td>
<td>Tumor Size</td>
<td>Elapsed Days of Treatment</td>
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<tr>
<td>Diagnosis Address</td>
<td>Diagnostic Confirmation</td>
<td>Pediatric Staging</td>
<td>Radiation Start and End Date</td>
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<tr>
<td>Race</td>
<td>Class of Case</td>
<td>Mutation</td>
<td>Radiation to Nodal/Lymph Nodes</td>
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<td>Ethnicity</td>
<td>Categorizing</td>
<td>Source</td>
<td>Radiation to Default Lymph Node</td>
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<td>Marital Status</td>
<td>Do Confirmation</td>
<td>Site Specific Disease Indicators</td>
<td>Radiation to Pelvis</td>
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<tr>
<td>Sex</td>
<td>Admit Date</td>
<td>External Beam Technique</td>
<td>Total Dose</td>
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<td>Age at Diagnosis</td>
<td>Discharge Date</td>
<td>Nbr Fractions</td>
<td>Chemotherapy Toxicity</td>
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<td>Date of Birth</td>
<td>Inpatient Status</td>
<td>Birth Date</td>
<td>Chemotherapy Timing</td>
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<td>Birthplace</td>
<td>Maternal Age</td>
<td>Birth Weight</td>
<td>Chemotherapy Type</td>
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<td>Occupation and Industry</td>
<td>Primary Surgeon</td>
<td>Employment Status</td>
<td>Chemo Date and Codes</td>
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<td>Family Hx</td>
<td>Managing Physician</td>
<td>User Defined Fields</td>
<td>Outcomes and Recurrence Date and Type</td>
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<td>Tobacco Hx</td>
<td>Following Physician</td>
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<tr>
<td>Alcohol Hx</td>
<td>Referring Physician</td>
<td></td>
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<td>Insurance Information</td>
<td>Radiologist</td>
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<td></td>
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<td></td>
<td>Med Oncologist</td>
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<td>Facility Referred</td>
<td>Date and Type of Procedure</td>
<td>Survival Months</td>
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<tr>
<td></td>
<td>Facility Referred To</td>
<td>Date and Type of Procedure</td>
<td>Survival Months</td>
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</tbody>
</table>

Supplemental Data

- Program Accreditation information: COC, NAPBC, NAPRC
- Tumor Board information
- Clinical Trial information
- SCP and Patient Navigation Status
- Genetic counseling, screening and rehab information
- CAP and National treatment guidelines
Cancer Care: The Gold Standard

Cancer Services

- Administrative and Financial
- Information Technology
- Clinical Decisions
- Research and Outcomes

- Quality
- Accreditation
- Community Outreach
- Marketing

CRStar by ERS
Financial Planning

- Identify equipment needs
- Identify In and Out Facility Migration Patterns
- Financial Analysis for Cancer Center
- Identify community needs
- Analyze staffing needs
Real-World Application

From a Community Hospital in Maryland...

CRStar by ERS
Information Technology: Data Warehousing

- Centralized storage system
- Data stored on a mainframe server or in the cloud
- Emphasis on capturing data from different sources
- Combine data used to enhance data quality and consistency
- Cancer registry data can be exported from the database in various formats
- Cancer Registry processes can be automated
Real-World Application

From a major NCI designated cancer center...
Clinical Decisions and Research

- Treatment Decisions
- Clinical Trial Participation
- Research
Real-World Applications

From a Growing Virginia Cancer Center . . .
Quality Initiatives

COC QUALITY MEASURES

ASCO QUALITY MEASURES

COC
ASCO QOPI
CMS
OCM
NCCN
ASTRO
Many more …

Adjuvant chemotherapy received within 2 months of diagnosis by patients with AJCC stage III colon cancer.
Tracking Program Accreditation Standards

Program Accreditation information: COC, NAPBC, NAPRC

- Tumor Board information
- Clinical Trial information
- Survivorship Care plan status
- Patient Navigation Status
- Genetic counseling
- National treatment guidelines
- Screening information
- Rehab services
- CAP guideline status
Cancer Registry Data can be utilized for community outreach to include education, prevention, early detection and screening information.

**Prevention Need**

- Educate on the effects of smoking on lung tissue
- Provide information on smoking cessation and benefits of quitting
- Provide healthy lifestyle tips to prevent lung cancer
- Discuss screening information as well as signs of lung cancer

**Cancer Registry Data**

Provide information on incidence of lung cancer and mortality rate due to late stage disease.
Community Outreach (cont)

Screening Need

Low Dose CT Lung screening

Cancer Registry Data

Provide survival information to show mortality based on stage

Observed Survival for Lung Cases Stage 0-4

- Stage 0 Cases
- Stage 1 Cases
- Stage 2 Cases
- Stage 3 Cases
- Stage 4 Cases

Begin % Year1 Year2 Year3 Year4 Year5
Real-World Applications

From a Community-Centered Florida Cancer Center . . .
Marketing

- Cancer Program Annual Report and social media
- Advertise new equipment, screening programs
- Promote partnerships with other facilities
- Advertise new satellite facilities
- Announce new physician staff

<table>
<thead>
<tr>
<th>Diagnosis County</th>
<th>Lung</th>
<th>Breast</th>
<th>Skin</th>
<th>Prostate</th>
<th>Colon</th>
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<tr>
<td>Douglas</td>
<td>118</td>
<td>138</td>
<td>95</td>
<td>89</td>
<td>88</td>
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<tr>
<td>Atkinson</td>
<td>22</td>
<td>24</td>
<td>19</td>
<td>14</td>
<td>7</td>
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<td>Baldwin</td>
<td>12</td>
<td>3</td>
<td>18</td>
<td>13</td>
<td>1</td>
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<td>Brantley</td>
<td>14</td>
<td>9</td>
<td>3</td>
<td>5</td>
<td>10</td>
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<tr>
<td>Gordon</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>6</td>
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<tr>
<td>Any Others</td>
<td>24</td>
<td>11</td>
<td>0</td>
<td>8</td>
<td>6</td>
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<td>Overall Totals</td>
<td>195</td>
<td>190</td>
<td>140</td>
<td>131</td>
<td>118</td>
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</table>
Cancer Committee

- Quality control initiatives
- NCDB Data Completeness reports
- Quality metrics, benchmarks, survival
- Annual caseload volumes
- COC special studies

2018 COMPLETED CASES

- 27% Breast
- 23% Bronchus & Lung
- 13% Prostate gland
- 9% Colon
- 8% Lymph nodes
- 6% Urinary bladder
- 5% Brain
- 4% Pancreas
- 3% Blood & bone marrow
- 2% Corpus uteri
- 2% Other endocrine glands
- 1% Other

2019 PROJECTED CASES

- 22% Breast
- 17% Bronchus & lung
- 12% Prostate gland
- 10% Lymph nodes
- 7% Skin
- 5% Colon
- 5% Other endocrine glands
- 5% Other
- 5% Blood & bone marrow
- 5% Urinary bladder
- 5% Corpus uteri
Nurse and Patient Navigation

Provide data for Navigation Metrics

Help show ROI For facility

Help to prevent gaps in Navigation program

Collaborate to ensure facility is meeting patient needs

Help access patient barriers

Helpful Registry Data

- Site by Sex, Race Ethnicity and Primary Payer
- Out migration patterns
- Site by Class of Case 00
- Time from Diagnosis to Surgical Consult
- Time from Diagnosis to First treatment
- Time from end of treatment to survivorship
Benchmarking

Four Keys of Benchmarking

- NCDB Benchmark reports
- American Cancer Society Facts and Figures
- State Data comparisons
- Within your network of health systems
- With Competing Facilities

Identify

Evaluate

Collect and Analyze

Implement
NCDB Benchmarks

- Compare year, class of case, site, type of facility and geographical region

- Compare up to 3 data analysis variables including gender, race, histology, treatment and more

- Public access for non approved programs

### Gender by Stage of Colon Cancer Diagnosed in 2016

<table>
<thead>
<tr>
<th>Gender</th>
<th>Stage</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>O</td>
<td>I</td>
<td>II</td>
</tr>
<tr>
<td>Male</td>
<td>104</td>
<td>261</td>
<td>372</td>
</tr>
<tr>
<td>Female</td>
<td>92</td>
<td>306</td>
<td>369</td>
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<tr>
<td>TOTAL</td>
<td>196</td>
<td>567</td>
<td>741</td>
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</table>

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### Sex by Summary AJCC Stage Group for 2016 Colon Cases

<table>
<thead>
<tr>
<th>Sex</th>
<th>IN SITU</th>
<th>STAGE 1</th>
<th>STAGE 2</th>
<th>STAGE 3</th>
<th>STAGE 4</th>
<th>UNKNOWN</th>
<th>All Others</th>
<th>Total Values</th>
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</thead>
<tbody>
<tr>
<td>Male</td>
<td>5 (6.65%)</td>
<td>0 (0%)</td>
<td>19 (23.13%)</td>
<td>23 (28.75%)</td>
<td>35 (43.75%)</td>
<td>9 (11.25%)</td>
<td>8 (10.00%)</td>
<td>95 (60.00%)</td>
</tr>
<tr>
<td>Female</td>
<td>2 (3.83%)</td>
<td>0 (0%)</td>
<td>14 (21.21%)</td>
<td>17 (25.76%)</td>
<td>19 (30.79%)</td>
<td>2 (3.08%)</td>
<td>12 (18.18%)</td>
<td>66 (40.00%)</td>
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<tr>
<td>Overall Totals</td>
<td>7 (4.24%)</td>
<td>0 (0%)</td>
<td>33 (20%)</td>
<td>40 (24.38%)</td>
<td>54 (21.23%)</td>
<td>11 (6.67%)</td>
<td>20 (12.44%)</td>
<td>165 (100%)</td>
</tr>
</tbody>
</table>
Real-World Applications

From a Progressive Alabama Cancer Center . . .
American Cancer Society Facts and Figures

- Estimated number of new cancer cases
- Published each year
- Compares top 10 sites by state and total cases in USA
Market Shares

Compare cases diagnosed in your county compared to surrounding counties and all counties in your state

- Most states will supply registries with these types of data requests
- Reuse graph template for other sites
Within Your Hospital Network or Competing Facilities

Treatment Done at Surrounding Hospitals for Breast Cases in 2018

My Hospital Network Incidence by Site and Facility

<table>
<thead>
<tr>
<th>Site Code</th>
<th>Number</th>
<th>(%)</th>
<th>Number</th>
<th>(%)</th>
<th>Number</th>
<th>(%)</th>
<th>Total Values</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>1523</td>
<td>(67.55%)</td>
<td>123</td>
<td>(5.16%)</td>
<td>30</td>
<td>(1.34%)</td>
<td>1676</td>
<td>(72.41%)</td>
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<tr>
<td>Skin</td>
<td>1706</td>
<td>(74.43%)</td>
<td>92</td>
<td>(1.13%)</td>
<td>26</td>
<td>(1.48%)</td>
<td>1824</td>
<td>(76.03%)</td>
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<tr>
<td>Bronchus &amp; Lung</td>
<td>1376</td>
<td>(62.17%)</td>
<td>132</td>
<td>(5.80%)</td>
<td>56</td>
<td>(2.49%)</td>
<td>1564</td>
<td>(68.42%)</td>
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<td>Prostate-Gland</td>
<td>1177</td>
<td>(51.72%)</td>
<td>67</td>
<td>(2.84%)</td>
<td>34</td>
<td>(1.56%)</td>
<td>1278</td>
<td>(55.22%)</td>
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<tr>
<td>Blood &amp; Bone Marrow</td>
<td>1237</td>
<td>(53.40%)</td>
<td>35</td>
<td>(7.80%)</td>
<td>26</td>
<td>(2.07%)</td>
<td>1258</td>
<td>(53.82%)</td>
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<td>Corpus Uteri</td>
<td>800</td>
<td>(68.66%)</td>
<td>26</td>
<td>(2.06%)</td>
<td>13</td>
<td>(1.05%)</td>
<td>839</td>
<td>(69.47%)</td>
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<tr>
<td>Lymph Nodes</td>
<td>883</td>
<td>(55.15%)</td>
<td>22</td>
<td>(1.46%)</td>
<td>10</td>
<td>(0.79%)</td>
<td>919</td>
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<td>Kidney</td>
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<td>57</td>
<td>(1.98%)</td>
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<td>(1.08%)</td>
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<td>Urinary Bladder</td>
<td>533</td>
<td>(44.73%)</td>
<td>24</td>
<td>(1.97%)</td>
<td>19</td>
<td>(1.58%)</td>
<td>576</td>
<td>(45.86%)</td>
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<tr>
<td>Liver &amp; Bile Ducts</td>
<td>552</td>
<td>(53.12%)</td>
<td>34</td>
<td>(3.15%)</td>
<td>12</td>
<td>(1.17%)</td>
<td>598</td>
<td>(52.88%)</td>
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<td>234</td>
<td>(1.62%)</td>
<td>55</td>
<td>(0.68%)</td>
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<td>(49.21%)</td>
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<td>(42.91%)</td>
<td>741</td>
<td>(4.06%)</td>
<td>458</td>
<td>(2.73%)</td>
<td>16604</td>
<td>(100%)</td>
</tr>
</tbody>
</table>

My Network Comparison by County at Diagnosis

- **Central County**
  - First Facility: 715
  - Second Facility: 350
  - Third Facility: 650

- **South County**
  - First Facility: 350
  - Second Facility: 150
  - Third Facility: 1250

- **North County**
  - First Facility: 450
  - Second Facility: 300
  - Third Facility: 850

- **West County**
  - First Facility: 1250
  - Second Facility: 750
  - Third Facility: 300

- **East County**
  - First Facility: 500
  - Second Facility: 500
  - Third Facility: 250
In Conclusion … Or Just the Beginning

- Become a Knowledge Center for your cancer program
- Engage and Educate your partners
- Market the hidden jewel from within the registry
- Get to know your data
- Take advantage of available resources
- Anticipate the requestor’s needs
- Make the registry and yourself invaluable
“To teach is to learn twice”… Joseph Joubert

“Being Knowledgeable is good. Being knowledgeable and savvy is the BEST” … Ankur Kumar

“Trust yourself. You know more than you think you do” … Unknown
Thank You

Melanie Rogan, CTR
mrogan@mycrsstar.com
(336) 946-2379