21\textsuperscript{st} Century Cancer Registry

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Background

CCR’s Data-warehouse contains all state-wide cancer records collected since 1988 as well as pre-1988 data from Los Angeles County and the San Francisco Bay Area

- 6,700,000 cancer case reports
- 5,400,000 tumor records
- 4,700,000 patient records
- 13,600,000 passive follow-up records
  - DMV, Voter Registration, etc...
- 6,000,000 update/correction records
- 9,200,000 active follow-up records
- 5,600,000 geocoding records
- 2,200,000 electronic pathology records
Background

For 2016 CCR expects to collect and process millions of records including ~285,000 new cancer case reports in which we expect to identify ~183,000 new tumors based on state demographics

• 500,000 electronic pathology reports
• 225,000 death certificates
• 1,500,000 passive follow-up records
• 200,000 geo-coding records
• 850,000 active follow-up records
• 700,000 correction/update records

CCR as a “population-based” registry is expected to collect 100% of the expected tumors for each calendar year
What: Move from 19th to late 20th to early 21st Century

• “Real-time” cancer reporting
  • Adapt historical 24 month business practices designed for surveillance research uses
  • Start a cancer case with the first documented diagnosis (i.e. path report).

• Bi-Directional and Interoperable
  • Move away from uni-directional data flowing into CCR
  • Real-time interoperability with a data consortium

• Expand data collection across the cancer care continuum and experience
  • Move beyond “counting” cancer cases
Possibilities

Real-Time Data Across the Cancer Care Continuum

- Diagnostic Community
- Treatment Community
- General Business Data
- Self-Reporting Patient Experience
- Home Care/Hospice Services

- Pathology
  - Imaging
  - Laboratory
  - Bio-markers
  - Genomics
  - Pertinent-Negatives
- Oncology
  - Radiation
  - Surgery
  - Hormonal
  - Clinical Trials
  - Responses to Treatment
- Billing/Claims
  - Demographic
  - Family History
- Blogs
  - Connection to Cancer Community
  - Self-Reporting for Research
- Care-Coordination
  - Quality of Life
  - Pain-Measurement

Real-Time Data Across the Cancer Care Continuum
Real Example

Quality of Diagnostic Staging in Patients With Bladder Cancer: A Process-Outcomes Link

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BACKGROUND: Muscle sampling is often used as a surrogate for staging quality in patients with bladder cancer. The association of staging quality at diagnosis and survival was examined among patients with bladder cancer. METHODS: The clinical records of all individuals within the Los Angeles Surveillance, Epidemiology, and End Results registry with an incident diagnosis of non-muscle-invasive bladder cancer in 2004-2005 were reviewed. Patient demographics, tumor characteristics, staging quality (presence of muscle in the specimen and mention of muscle in the pathology report), and vital status were recorded. With mixed-effects and competing-risks regression analyses, the association of patient and tumor characteristics with staging quality and cancer-specific survival was quantified. RESULTS: The sample included 1865 patients, 335 urologists, and 27 pathologists. Muscle was reported to be present in 972 (52.1%), was reported to be absent in 564 (30.2%), and was not mentioned in 329 (17.7%) of the initial pathology reports. The presence of muscle did not differ according to the grade or depth of invasion. Mortality was associated with staging quality ($P<.05$). Among patients with high-grade disease, the 5-year cancer-specific mortality rates were 7.6%, 12.1%, and 18.8% when muscle was present, absent, and not mentioned, respectively. CONCLUSIONS: The omission of muscle in the specimen or its mention in the pathology report in nearly half of all diagnostic resections was associated with increased mortality, particularly in patients with high-grade disease. Because urologists cannot reliably discern between high- and low-grade or Ta and T1 disease, it is contended that patients with bladder cancer should undergo adequate muscle sampling at the time of endoscopic resection. Cancer 2014;000:000-000. © 2014 American Cancer Society.

KEYWORDS: bladder cancer mortality, pathology, quality of health care, urinary bladder neoplasms.

Cancer Month 00, 2014
Real Example

CONCLUSIONS:

“The omission of muscle in the specimen or its mention in the pathology report in nearly half of all diagnostic resections was associated with increased mortality, particularly in patients with high-grade disease.”
Real Example

- Could Watson Discover Use Case Conditions in Bladder Cancer Pathology Reports and in Near Real-Time Alert both the Diagnosing and Treating Physicians?
- Alert Patients? Alert Data Consortium (you?)
### Results of Real Example

<table>
<thead>
<tr>
<th>Admission ID</th>
<th>Path Report ID</th>
<th>Site</th>
<th>Pathology Information</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>3966901</td>
<td>5446524</td>
<td>C670</td>
<td>null1:13/04%20 Bladder, Cystoscopic Bx%2020 Papillary lesion of low malignant potential. Note%2020 The differential diagnosis includes Benign papilloma &amp; Low grad Pappillary transitional cell ca. There is no lamina propria or skeletal muscle included with the Bx. #1) Prostate Ds 5/9/00 null</td>
<td>YELLOW</td>
</tr>
<tr>
<td>4121461</td>
<td>5527318</td>
<td>C679</td>
<td>null1:17/04%20 A) Bladder Base B) Bladder, Rt Lateral Wall%2020 No Evidence of Malignancy. C) Bladder, Lt Lateral Wall%2020 In Situ Urothelial CA, High Grade, Superficial invasion. D) Bladder Right side. Transurethral resection of #1 Bladder Tumor%2020 No evidence of Malignancy. #2 Inflammation &amp; Atrypia. E) Bladder Base, Transurethral resection of Bladder Tumor%2020 Focal CA. in Situ. F) Bladder, Lt Lateral Wall, Transurethral Resection of Bladder Tumor%2020 #1) Papillary Transitional Cell CA, High Grade, with invasion of the lamina propria. #2) No Muscularis Propria invasion. #3) CA. In Situ present Adjacent to invasive Tumor. Pathologic Stage%2020 T1 NX MX null</td>
<td>YELLOW</td>
</tr>
<tr>
<td>3966902</td>
<td>5446623</td>
<td>C679</td>
<td>null2:9/04%20 Bladder wall, Punch Bx%2020 Urothelial ca, intermediate grade, grade 2-3. Note%2020 Evaluation for invasion is not possible since lamina propria &amp; or fibromuscular stroma are not seen in this Bx null</td>
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</tr>
<tr>
<td>3966903</td>
<td>5440078</td>
<td>C673</td>
<td>null1:29/04%20 Bladder, Bx versus Turb%2020 1) Low-grade &amp; focally high-grade papillary transitional cell ca 2) No Included lamina propria%2020 No included smooth muscle null</td>
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</tr>
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<td>6009193</td>
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<td>C673</td>
<td>null1:29/04%20 Bladder, Bx versus Turb%2020 1) Low-grade &amp; focally high-grade papillary transitional cell ca 2) No Included lamina propria%2020 No included smooth muscle null</td>
<td>YELLOW</td>
</tr>
<tr>
<td>6742325</td>
<td>34050049</td>
<td>C674</td>
<td>GROSS DESCRIPTION%20 Specimen 1 received in formalin are multiple fragments of rubbery tan tissue. Aggregate weight is approximately 75 g. Fragments show smooth tan fragments with some areas which are somewhat papillary. Multiple representative sections in six cassettes. Specimen 2 received in formalin are multiple tan fragments of tissue measuring up to 1.5 cm in aggregate. All submitted in one cassette 1/29/04%2020 Bladder, Bx versus Turb%2020 1) Low-grade &amp; focally high-grade papillary transitional cell ca 2) No Included lamina propria%2020 No included smooth muscle.MICROSCOPIC DESCRIPTION%20 Part 19/5/2020 Numerous representative sections demonstrate diffuse sheets of large cells with vesicular chromatin, prominent nucleoli, and abundant lightly eosinophilic cytoplasm. The tumor cells are present in diffuse solid sheets, with areas that appear more discohesive. A battery of immunohistochemical stains was performed (in multiple stages) and tumor cells are Vimentin+ (strong and diffuse), EMA+, CD34+ (multifocal) and CD117+. The tumor cells are negative for several Keratins (CAM 5.2, Pan Keratin, and CD5/6) making carcinoma unlikely. Additional negative stains include S100 (excludes melanoma), myoginin (excludes rhabdomyosarcoma), ALK1 and CD10 (excludes ALC1), CD31 (an endothelial marker), TdT (no nuclear staining, excludes lymphoblasts), FLAP (along with CD30 excludes germ cell tumor), p63, CD3 and CD20 (helps exclude lymphoma), myeloperoxidase (excludes myeloblasts) and Uroplakin (excludes urothelial carcinoma). LCA stains occasional inflammatory cells and demonstrates surface artifact, but is interpreted as being negative in tumor. Tumor infiltrates smooth muscle. Part 24/5/2020 Tumor is present along with inflammation and squamous metaplastic change. Large malignant cells (40x).</td>
<td>YELLOW</td>
</tr>
<tr>
<td>6022360</td>
<td>22788121</td>
<td>C679</td>
<td>GROSS DESCRIPTION%20 Specimen is received in an unspecified fluid and consists of two 0.3-0.4 cm soft, gray tissue fragments submitted in one cassette.CLINICAL DATA%2020 Recurrent bladder tumors and history of bladder carcinoma. Cystoscopy, transurethral resection of bladder tumor, installation of mitomycin C MICROSCOPIC DESCRIPTION%20 Sections show multiple fragments of urothelial mucosa containing a high-grade papillary urothelial carcinoma. No lamina propria invasion is identified. No smooth muscle is present in the biopsy. See synopsis summary below. SYNOPSIS SUMMARY BLADDER CANCER PROCEDURE Transurethral resection. TUMOR LOCATION Bladder NOS. HISTOLIGIC TYPE Papillary urothelial carcinoma, non-invasive. GRADE High grade. SIZE Multiple tumor fragments, the largest measuring up to 0.2 cm. DEPTH OF INVASION No invasion identified. SM. MUSCLE INVOLVEMENT Not applicable (no smooth muscle identified in specimen). LYMPHOVASCULAR INVASION No invasion identified. AJCC TUMOR STAGE pT1a ADDITIONAL. SPECIMENS Not applicable. ADDITIONAL NOTES QC review provided by Dr. Kanetsuka.</td>
<td>RED</td>
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<tr>
<td>6742403</td>
<td>34244304</td>
<td>C679</td>
<td>The specimen in formalin labeled “bladder tumor” consists of 3 grams of tissue fragments. Totally embedded (A1-A2). GPCRN Bladder tumor. SURGICAL PROCEDURE%2020 Transurethral resection of bladder tumor. Sections show fragments of bladder tissue demonstrating polyloid and papillary fragments of urothelial with moderate to marked nuclear pleomorphism and thickening with underlying chronic inflammation. Urothelial cells have a disorderly arrangement and conspicuous mitotic activity. No invasion is identified. No muscularis propria is included in the fragments.</td>
<td>RED</td>
</tr>
</tbody>
</table>
What could you all do with?

- Near Real–Time Cancer Data
  - Across the Cancer Care Continuum
- Bi-Directional and Interoperable Capabilities
- Patient-Centric Data Model
  - All source documents linked to a patient
  - Structured
  - Standardized
  - Aggregated
- Decision Support Systems