Path of the Cancer Data Summit: Thursday

Vision for Smarter Data in the Fight Against Cancer

Where Are We Now? Data Interoperability for Cancer Care and Research

What Could Cause mCODE to Fail?

Making the Vision a Reality by 2022

Next Steps and Call to Action

Solutions and Pathways to the Future

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Solutions and Pathways to the Future
THE CANCER DATA SUMMIT
SMARTER DATA FOR THE FIGHT AGAINST CANCER

OUTERNET PASSCODE: like bark farm skill
Dr. Jay Schnitzer
MITRE Vice President, Chief Technology Officer

Dr. Victor Dzau
President, National Academy of Medicine
Vision for Smarter Data in the Fight Against Cancer

Monica Bertagnolli
Smarter Data in the Fight Against Cancer: Building the Learning Healthcare System

Monica M. Bertagnolli, MD
Dana-Farber/Brigham & Women’s Cancer Center
Alliance for Clinical Trials in Oncology
Current State

Mrs. Smith, a 75 year old generally healthy but obese woman, presented to an emergency room with gastrointestinal bleeding.

Upper endoscopy:
- tumor at the junction of the esophagus and the stomach

Biopsy:
- gastrointestinal stromal tumor
Current State

data entry required:
  demographics/insurance/contacts
  complete medical history

*CT Images not available
Current State

- Sent home, but worried because of no definite treatment plan
  - Next day: Emergency Room visit
    - She lives alone, her daughter misses several days of work to coordinate her care
    - Non-reimbursed medical expenses are increasing
Current State

• 2 days later, her CT scan arrives

Medical Oncology referral
Current State

- Imatinib recommended; genotyping ordered

Result:

Conclusion: Imatinib is not effective
Current State

- Declines clinical trial participation
- Subtotal gastrectomy performed
  - Lengthy post operative recovery
  - No adjuvant therapy, higher risk for disease recurrence
### Outcome of 1000 Patients With Gastrointestinal Stromal Tumor (GIST) Treated by Surgery in the Pre and Post-imatinib Eras

Michael J. Cavnar, MD,* Kenneth Seier, MS†️ Christina Curtin, BS,* Vinod P. Balachandran, MD,* Daniel G. Coit, MD,* Sam S. Yoon, MD,* Aimee M. Crago, MD, PhD,* Vivian E. Strong, MD,* William D. Tap, MD,‡,# Mithat Gönen, PhD,# Cristina R. Antonescu, MD,§ Murray F. Brennan, MD,* Sam Singer, MD,* and Ronald P. DeMatteo, MD*

*Annals of Surgery • Volume XX, Number XX, Month 2019*

<table>
<thead>
<tr>
<th>Genotype</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>KIT exon 9</td>
<td>44 (7.6)</td>
</tr>
<tr>
<td>KIT exon 11 deletion</td>
<td>216 (37.1)</td>
</tr>
<tr>
<td>KIT exon 11 other</td>
<td>117 (20.1)</td>
</tr>
<tr>
<td>KIT exon 13</td>
<td>9 (1.5)</td>
</tr>
<tr>
<td>KIT exon 17</td>
<td>4 (0.7)</td>
</tr>
<tr>
<td>KIT multiple exons</td>
<td>48 (8.2)</td>
</tr>
<tr>
<td>PDGFRA D842V/I</td>
<td>23 (4)</td>
</tr>
<tr>
<td>PDGFRA other</td>
<td>27 (4.6)</td>
</tr>
<tr>
<td>NF1</td>
<td>5 (0.9)</td>
</tr>
<tr>
<td>SDH</td>
<td>3 (0.5)</td>
</tr>
<tr>
<td>Wild-type</td>
<td>86 (14.8)</td>
</tr>
<tr>
<td>Unknown</td>
<td>418 (N/A)</td>
</tr>
</tbody>
</table>
Our Future

• Mrs. Smith presents with a high risk gastrointestinal stromal tumor, complicated by gastrointestinal bleeding

• Well before her visit, her full EHR, including all images, is available to you formatted in a manner identical with the one that your team uses
Our Future

Nonmetastatic gastrointestinal stromal tumor, high risk

Outcomes for 12,345 patients with GIST were captured by CancerLinQ.

Similar patients 914 patients, age-matched >70

Outcomes overall survival rate and common s

Overall survival rates

1 yr 2 yr 5 yr

include only: add/remove

surgery (11) 95% 90% 77%

combine with: select treatments

Imatinib mesylate (70) 97% 95% 90%

*tumor mutational testing may change recommendations, likelihood of this is 15% with gastric location of primary tumor; CLINICAL TRIALS MAY BE AVAILABLE

*recommend pre-operative functional assessment due to age, BMI
Our Future

• PLAN:
  – Genotyping, initiate pre-operative imatinib
  – Home-based fitness program in preparation for surgery in ~6 months
Our Future

Back home, Mrs. Smith is concerned that her bowel movements are a bit dark, and calls her granddaughter, who reports this to the web-based patient support site coordinated by your clinic.
• Tumor genomic characterization results show you that she is unlikely to respond to imatinib

• Treatment change: surgery or treatment on a clinical trial
Avapritinib precision therapy in advanced GIST

NAVIGATOR Study Update
CTOS 2018 Annual Meeting
November 15, 2018
Our Future

- Successful surgery, minimally invasive gastric resection
- Smooth post-operative recovery
Five years later:

- International cohort: 90% of GIST patients,
  - 390 cases with a pD842V mutation

- Prospectively collected overall survival data from clinical trials and EHR-based longitudinal data
Our Future

• Clinical care is **efficient**
• Unnecessary **costs are reduced**
• **Home-based** evaluations and interventions are facilitated
• Patients and families are **engaged and informed**
• **Errors** caused by poor communication **are reduced**
• Research is **facilitated**
• **Learning is integrated** into every-day practice

**WHY IS THIS SO DIFFICULT TODAY?**
Definition: Learning Health System

“An integrated health system which harnesses the power of data and analytics to learn from every patient and feed the knowledge of what works best back to clinicians, health professionals, patients and other stakeholders to create cycles of continuous improvement.”

Friedman CP et al, 2010; Sci Trans Med 2:57
TOOLS AND ANALYTICS

DATA ACCESS

HIGH QUALITY COMPUTABLE DATA
Tools and Data Needed!

Clinical Research:
- Randomized Clinical Trials
- Pragmatic Trials
- Comparative Effectiveness Research
- Observational Research: Longitudinal Cohorts, Registries

Quality Improvement:
- Quality Metrics
- Clinical Pathways/Decision Support

Economic Factors:
- Health Care Resource Utilization

Current state of data acquisition:
Fragmented, Siloed, Expensive, Inefficient
### Tobacco Use Assessment

#### Value | Distinct Patients
--- | ---
Non-smoker | 560,281
Never smoked tobacco | 462,842
Ex-smoker | 373,431
Current smoker | 121,186
Unknown tobacco consumption | 83,550
Smokes tobacco daily | 81,250
Occasional tobacco smoker | 22,607
Heavy smoker | 5,898
Light tobacco smoker | 3,478
Tobacco user | 576
Current tobacco non-user | 212
Chews tobacco | 160
Passive smoker | 140
Smokeless tobacco | 96
Pipe smoker | 23

* >15.5 million entries

**Subset of 51 different representations**

**EMRs:**
- Allscripts
- Epic
- Aria
- Mosaiq
- Centricity
- OncoEMR
- CureMD
- NextGen
### Structured Data Elements from Current EHRs

<table>
<thead>
<tr>
<th>Generally Available</th>
<th>Generally Not Available</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Diagnosis codes</td>
<td>• Surgery</td>
</tr>
<tr>
<td>• Encounter codes</td>
<td>• Radiation Therapy</td>
</tr>
<tr>
<td>• Infused medications</td>
<td>• Imaging results</td>
</tr>
<tr>
<td>• Laboratory tests</td>
<td>• Disease status (progressing, stable, NED)</td>
</tr>
<tr>
<td>• Smoking/Pain assessments</td>
<td></td>
</tr>
<tr>
<td>• Physical exam values</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sometimes Available</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Staging (group and individual elements)</td>
</tr>
<tr>
<td>• Oral medications</td>
</tr>
<tr>
<td>• ER/PR/Her2 tests</td>
</tr>
<tr>
<td>• ECOG performance scores</td>
</tr>
<tr>
<td>• Hospice referral</td>
</tr>
</tbody>
</table>
CAUTION: BAD DATA
BAD DATA QUALITY MAY RESULT IN FRUSTRATION AND LEAD TO DROP KICKING YOUR COMPUTER
Collaboration isn't a 21st century skill.
It's a timeless skill.

Collaboration was critical in the past and it will be critical in the future. Humans had to collaborate in the age of hunter-gathering and we'll need it in the age of artificial intelligence.
Purpose: To develop and maintain standard computable data formats, known as Minimal Common Oncology Data Elements (mCODE), to achieve data interoperability and enable progress in clinical care quality initiatives, clinical research, and healthcare policy development.
mCODE™

Will facilitate data sharing
A wide range of organizations will develop mCODE-enabled tools for data capture, analysis, and clinical application

- Clinical pathways
- Clinical decision support
- Care coordination
- Clinical trials data management
- Clinical registries
- Outcomes research models
- Clinical practice quality initiatives
- Development and implementation of machine learning approaches
will facilitate patient engagement in healthcare

- Consent for research data use
- Patient reported outcomes
- Medical records home
- Patient education

- Care coordination
- Wellness programs
- Chronic disease management
- Rare disease care & research
Who benefits?

- ACADEMIA
- REGULATORY AGENCIES
- CLINICIANS
- PAYERS
- CMS
- PATIENTS
- GOVERNMENT
- HEALTH SYSTEMS
- PRIVATE INDUSTRY
mCODE™

Purpose: To develop and maintain standard computable data formats, known as Minimal Common Oncology Data Elements (mCODE), to achieve data interoperability and enable progress in clinical care quality initiatives, clinical research, and healthcare policy development.
Where Are We Now?
The State of Data Interoperability for Cancer Care and Research

Björn Albrecht
Margaret Van Meter
Gisele Sarosy
Andre Quina
Debi Willis
THE CANCER DATA SUMMIT
SMARter DATA FOR THE FIGHT AGAINST CANCER
What Could Cause mCODE to Fail?

John Halamka  Chuck Jaffe  David Butler  Mary Wilkinson  Deven McGraw
THE CANCER DATA SUMMIT

SMARTER DATA FOR THE FIGHT AGAINST CANCER
Steve Bratt

Making the Vision a Reality by 2022
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- Vision for Smarter Data in the Fight Against Cancer
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- Making the Vision a Reality by 2022
- Solutions and Pathways to the Future
- Next Steps and Call to Action
THE CANCER DATA SUMMIT
SMARter DATA FOR THE FIGHT AGAINST CANCER
Solutions and Pathways to the Future

Aneesh Chopra
Chuck Jaffe
David Butler
Mary Wilkinson
Deven McGraw
Next Steps and Call to Action

Monica Bertagnolli

Brian Anderson
THE CANCER DATA SUMMIT
SMARTER DATA FOR THE FIGHT AGAINST CANCER
<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Speaker(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:45 – 9:00</td>
<td>Welcome</td>
<td>Jay Schnitzer and Victor Dzau</td>
</tr>
<tr>
<td>9:00 – 9:45</td>
<td>Vision for Smarter Data in the Fight Against Cancer</td>
<td>Monica Bertagnolli</td>
</tr>
<tr>
<td>9:45 – 10:45</td>
<td>The State of Data Interoperability for Cancer Care and Research</td>
<td>Bjorn Albrecht, (Moderator) Margaret Van Meter, Andre Quina, Gisele Sarosy, and Mary Wilkinson</td>
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<tr>
<td>10:45 – 11:15</td>
<td>Break</td>
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<tr>
<td>12:15 – 1:30</td>
<td>Lunch and Discussion</td>
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<tr>
<td>1:30 – 3:00</td>
<td>Making the Vision a Reality by 2022</td>
<td>Steven Bratt, (Moderator)</td>
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<tr>
<td>3:00 – 3:30</td>
<td>Break</td>
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<tr>
<td>3:30 – 4:15</td>
<td>Solutions and Pathways to the Future</td>
<td>Aneesh Chopra, (Moderator) David Butler, Charles Jaffe, Deven McGraw, and Mary Wilkinson</td>
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<td>4:15 – 5:00</td>
<td>Next Steps and Call to Action</td>
<td>Monica Bertagnolli and Brian Anderson</td>
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