Creating a Core Cancer Data Model to Enable a Learning Health System

Andre Quina
Brian Anderson
Current State

Cancer Care

Clinical Trials
< 4% of patients

Research Quality Data

Etc.
Sarcoma
Melan cell Carcinoma
Breast Cancer

> 96% of patients

Substantial Curation Costs

Missed Opportunities

Low Quality Real-World Data

Informs Care
Future State

Cancer Care

Clinical Trials
< 4% of patients

Shrinking % of patients

Growing % of patients

Low Quality Real-World Data

Research Quality Data

Minimal Curation Costs

Safer Care

Better Therapies

Improved Outcomes

Lower Costs

Fewer Missed Opportunities

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Vision

“Every patient’s journey improves all future care”

1. Each episode of care is captured effectively
2. Patient journey is collected across all care locations
3. Aggregated health data inform insights into clinical care
4. Better care is delivered to all patients
Key Collaborators

**Mission:** To conquer cancer through research, education, and promotion of the highest quality patient care. ASCO is the world’s leading professional organization for physicians and oncology professionals caring for people with cancer.

**Mission:** To reduce the impact of cancer by uniting a broad community of scientists and clinicians from many disciplines, committed to discovering, validating and disseminating effective strategies for the prevention and treatment of cancer.

**Mission:** The Biden Cancer Initiative mission is to develop and drive implementation of solutions to accelerate progress in cancer prevention, detection, diagnosis, research, and care, and to reduce disparities in cancer outcomes.

**Mission:** To serve the needs of our local and global community, providing the highest quality health care to patients and their families, expanding the boundaries of medicine through research, and educating the next generation of health care professionals.

**Mission:** To provide expert, compassionate care to children and adults with cancer while advancing the understanding, diagnosis, treatment, cure, and prevention of cancer and related diseases.

**Mission:** A public interest, not-for-profit company, working to discover new possibilities, create unexpected opportunities and lead by pioneering together for the public good to bring innovative ideas into existence. MITRE’s mission-driven team is dedicated to solving problems for a safer world.

**Mission:** Empowering the oncology community to improve quality of care and patient outcomes through transformational data analytics. CancerLinQ’s vision is to create a learning health system where evidence-based innovation changes the future of cancer care.

**Mission:** To protect the public health by ensuring the safety, efficacy, and security of human and veterinary drugs, biological products, and medical devices; and by ensuring the safety of our nation’s food supply, cosmetics, and products that emit radiation.

**Mission:** Helping people live the healthiest lives possible. Intermountain is widely recognized as a leader in clinical quality improvement and in efficient healthcare delivery.

**Mission:** To coordinate with professional health societies to develop a single Standard Health Information Model library that is open source, can be implemented and used by anyone, and enables innovation.

**Mission:** To develop standards that empower global health data interoperability.

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Coordinated Approach to Cancer Data
A standard health record for Oncology
- Created by a collaboration between ASCO and MITRE, with input from diverse stakeholders across the oncology ecosystem

The minimal set of data elements applicable to all cancers, and collected for:
- standardized information exchange among oncology information systems
- use by multiple stakeholders

Oncology data element domains: patient, disease, treatment, outcomes, genomics

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mCODE™ Logical Model

KEY

Patient
Disease
Genomics
Treatment
Outcome

Draft Model
mCODE™-Enabled Use Cases and Projects

**Clinical Research**

**ICAREdata™**

EHR-based clinical trials endpoints collection:
Develop and validate data elements that define clinical utility (treatment response, toxicity, change in treatment, deviation from clinical pathway)

**Clinical Care**

**Compass™**

Demonstrate the use of mCODE elements to allow providers and patients to make informed, shared, data-driven decisions and provide data back to generate new knowledge

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Enabling a Learning Health System

Current

- mCODE Outcomes
  - PATINA
  - PALLAS

Future

- Brain Mets Study

Learning Health System

Clinical Research

Clinical Care

Intermountain Healthcare

ASCO CancerLinQ

Additional Sites

Additional Sites
### Procedures
**Invasive ductal carcinoma of the breast**

<table>
<thead>
<tr>
<th>Procedure</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td>PET/CT scan</td>
<td>27 Dec 2018</td>
</tr>
<tr>
<td>Percutaneous automated vacuum assisted biopsy with ultrasonic guidance</td>
<td>18 Dec 2018</td>
</tr>
<tr>
<td>Mammography</td>
<td>11 Dec 2018</td>
</tr>
</tbody>
</table>

### Treatment Options
**Invasive ductal carcinoma of the breast**

Outcomes and criteria for 934 patients with invasive ductal carcinoma of the breast were collected by CancerInQ.

#### Similar patients **163 patients**

- **demographic**
  - Age: 42-62
  - Age at diagnosis: 42-62
  - Race: white
  - Gender: female

- **genetics**
  - BRCA1: negative
  - BRCA2: negative

- **pathology**
  - ER: negative
  - PR: positive
  - HER2: positive
  - Grade: 3
  - Size (mm): 10-20

- **medical history**
  - ECOG score: 2-3

#### Overall survival rates

<table>
<thead>
<tr>
<th></th>
<th>1 yr</th>
<th>3 yr</th>
<th>5 yr</th>
<th>Reporting severe side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>chemo</td>
<td>100%</td>
<td>100%</td>
<td>87%</td>
<td><strong>all</strong></td>
</tr>
<tr>
<td>chemo &amp; radiation</td>
<td>100%</td>
<td>100%</td>
<td>78%</td>
<td>100% Nausea/Vomiting (93%)</td>
</tr>
<tr>
<td>hormonal</td>
<td>51%</td>
<td>67%</td>
<td>33%</td>
<td>85% Fatigue (78%)</td>
</tr>
<tr>
<td>none (actively monitoring)</td>
<td>100%</td>
<td>100%</td>
<td>71%</td>
<td>95% Hot Rashes (87%)</td>
</tr>
</tbody>
</table>

#### Reporting severe side effects

- **Nausea/Vomiting (93%)**
- **Fatigue (87%)**
- **Hot Rashes (87%)**
- **Decreased Libido (70%)**
- **Fatigue (57%)**
- **Weight Loss (42%)**
Cancer Data Modeling Summit

**Goal:** Identify and execute strategies that leverage standardized cancer data to improve clinical care of patients

- **When:** Planned for later this year
- **Where:** Boston, MA
- **Who:** A group of leaders from different sectors including health thought leaders, patients, government agencies, investors, startups, entrepreneurs and executives

- **Annual Summit to:**
  - Identify additional near-term strategic initiatives that support growth in adoption and expansion of cancer models
  - Develop and execute a roadmap adoption to support cancer data capture and interoperability via FHIR
  - Share insights and develop partnerships to further improve cancer care
  - Identify improvements and maturation of cancer data based on new research, technology and other discoveries
How to Get Involved with the mCODE Movement

- We are looking for those interested in:
  - Being an mCODE pilot site
  - Helping to define the mCODE model
    - [https://www.surveymonkey.com/r/ASCO_mcode_feedback](https://www.surveymonkey.com/r/ASCO_mcode_feedback)
  - Sharing use cases for mCODE
  - Attending the summit

- Please contact us if interested in learning more about getting involved in mCODE
  - Andre Quina [aquina@mitre.org](mailto:aquina@mitre.org)
  - Brian Anderson [briananderson@mitre.org](mailto:briananderson@mitre.org)
  - Robert Miller [robert.miller@asco.org](mailto:robert.miller@asco.org)
Join us to advance the nation's progress toward an integrated health system with improved access and quality at a sustainable cost.

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Backup
The Problem

Growing need for data to inform treatment

Clinical care of cancer patients requires data

Prospective randomized controlled trial (RCT) data are insufficient

Real world, clinical treatment data are even worse

The way health data are collected and used today cannot drive better cancer care

The opportunity exists to harness the power of real world clinical treatment data to support development of new therapeutics