

# MITRE

**PIONEERING A  
HEALTHIER FUTURE**

MITRE is transforming data  
into insights to improve the  
health system and reinvent the  
healthcare experience.

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

**Andre Quina**  
**Brian Anderson**

mCODE™



**Standard Health  
Record™**

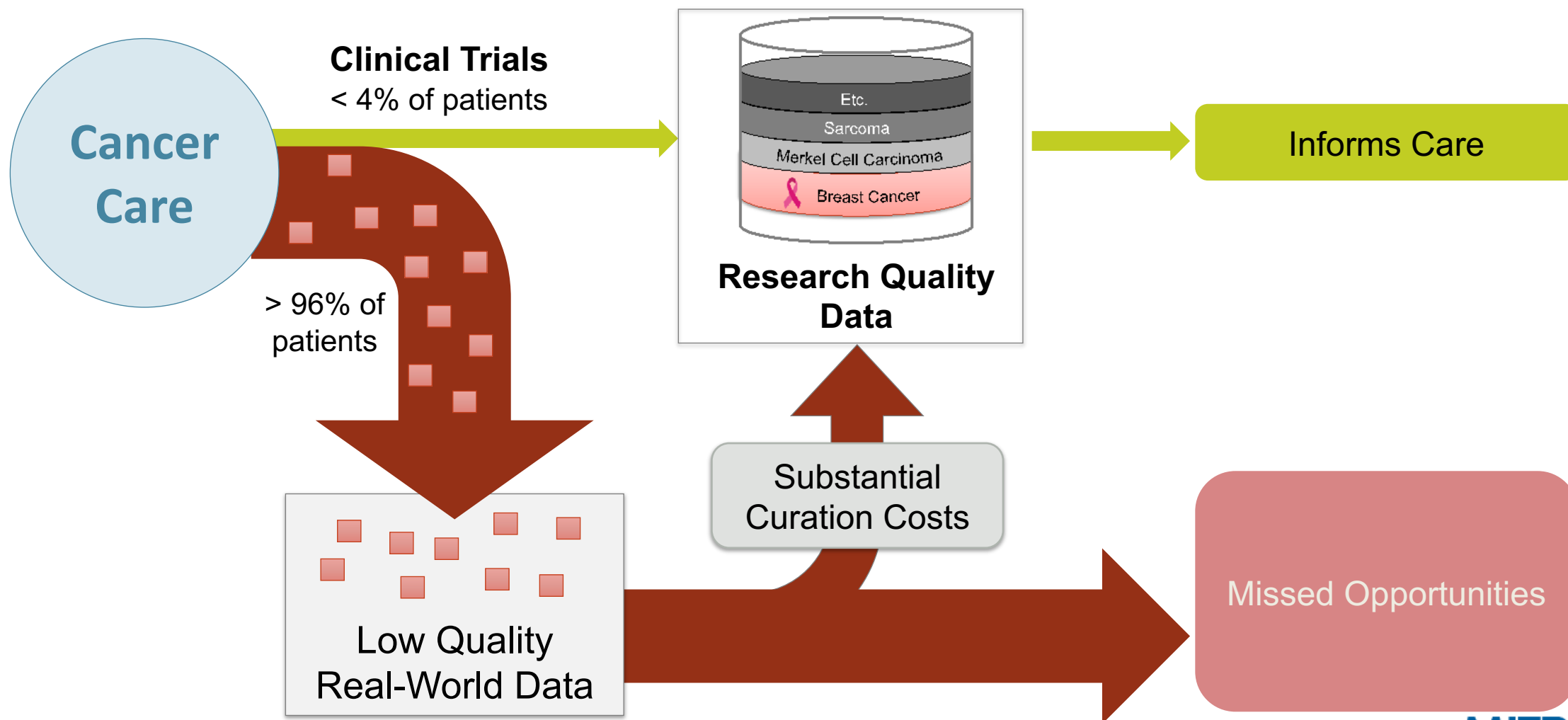


**Compass™**

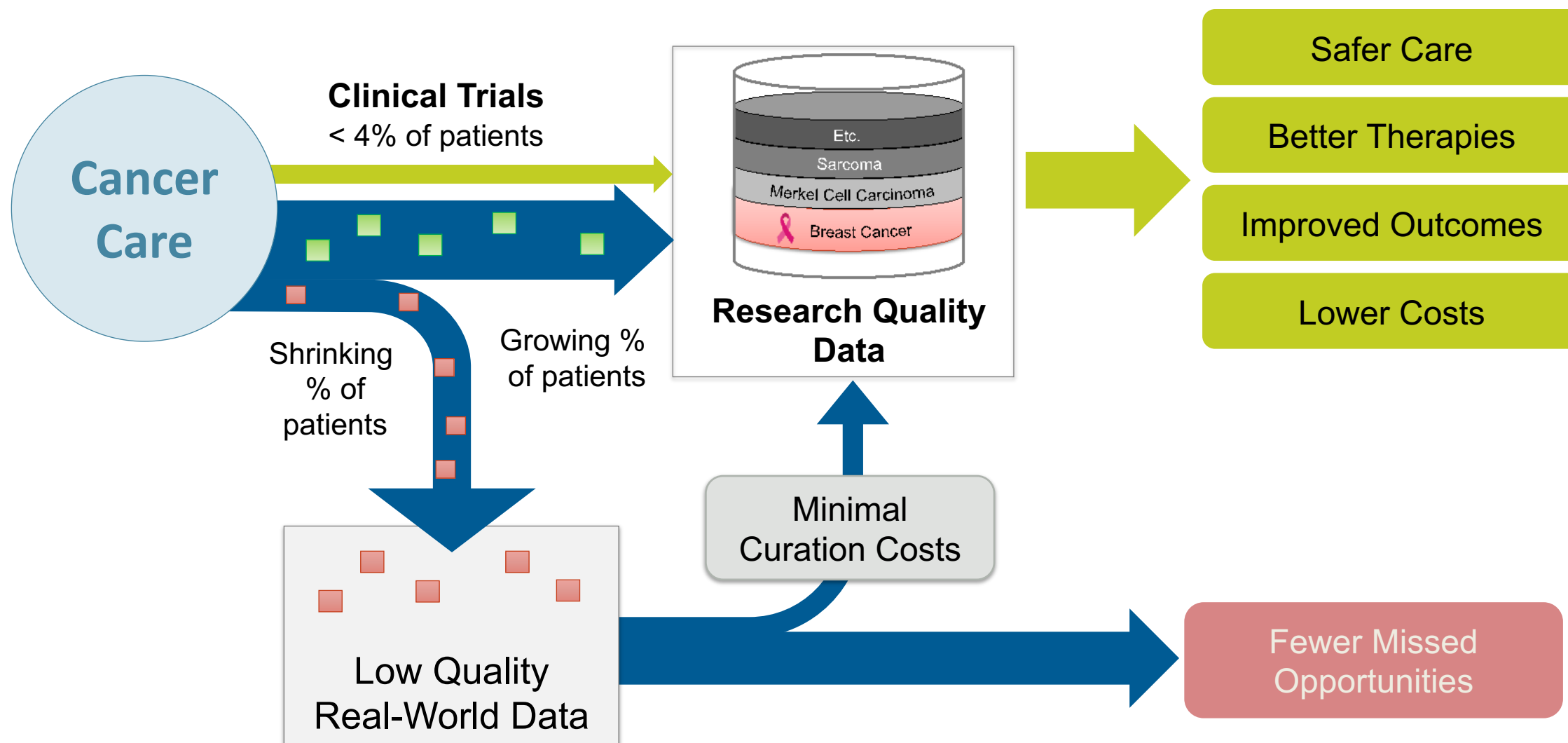
# Patient-Provider Conversation



# Current State

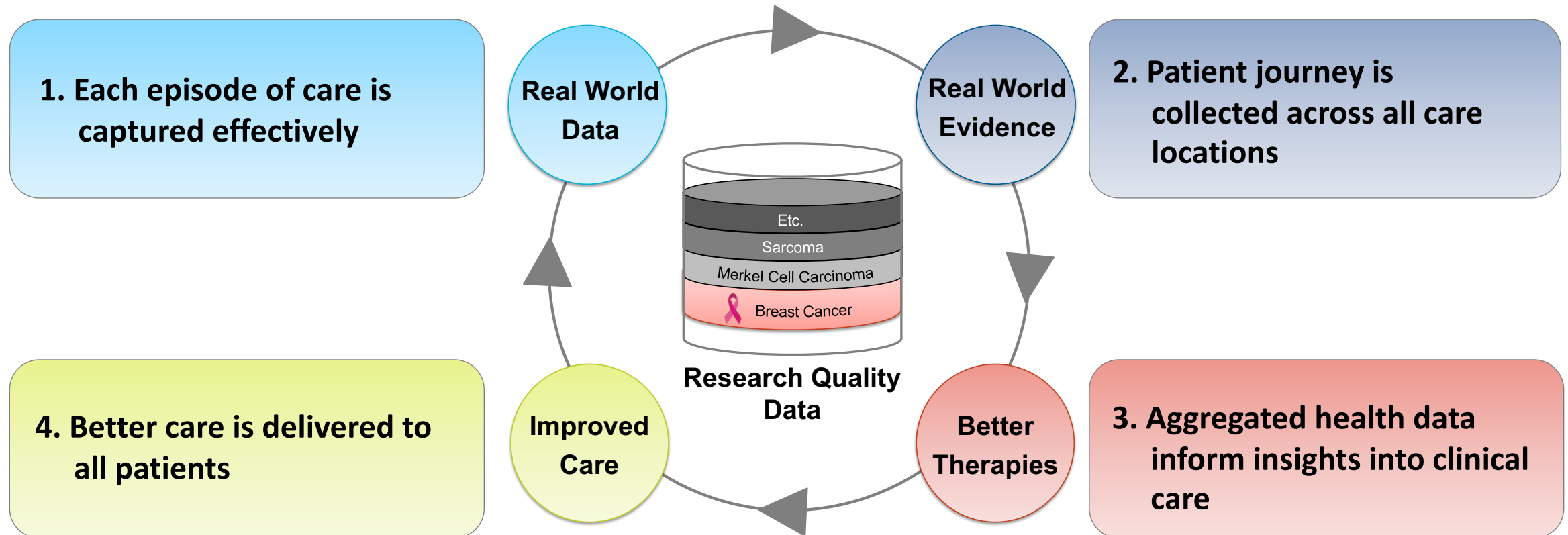


# Future State



# Vision

“Every patient’s journey improves all future care”





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



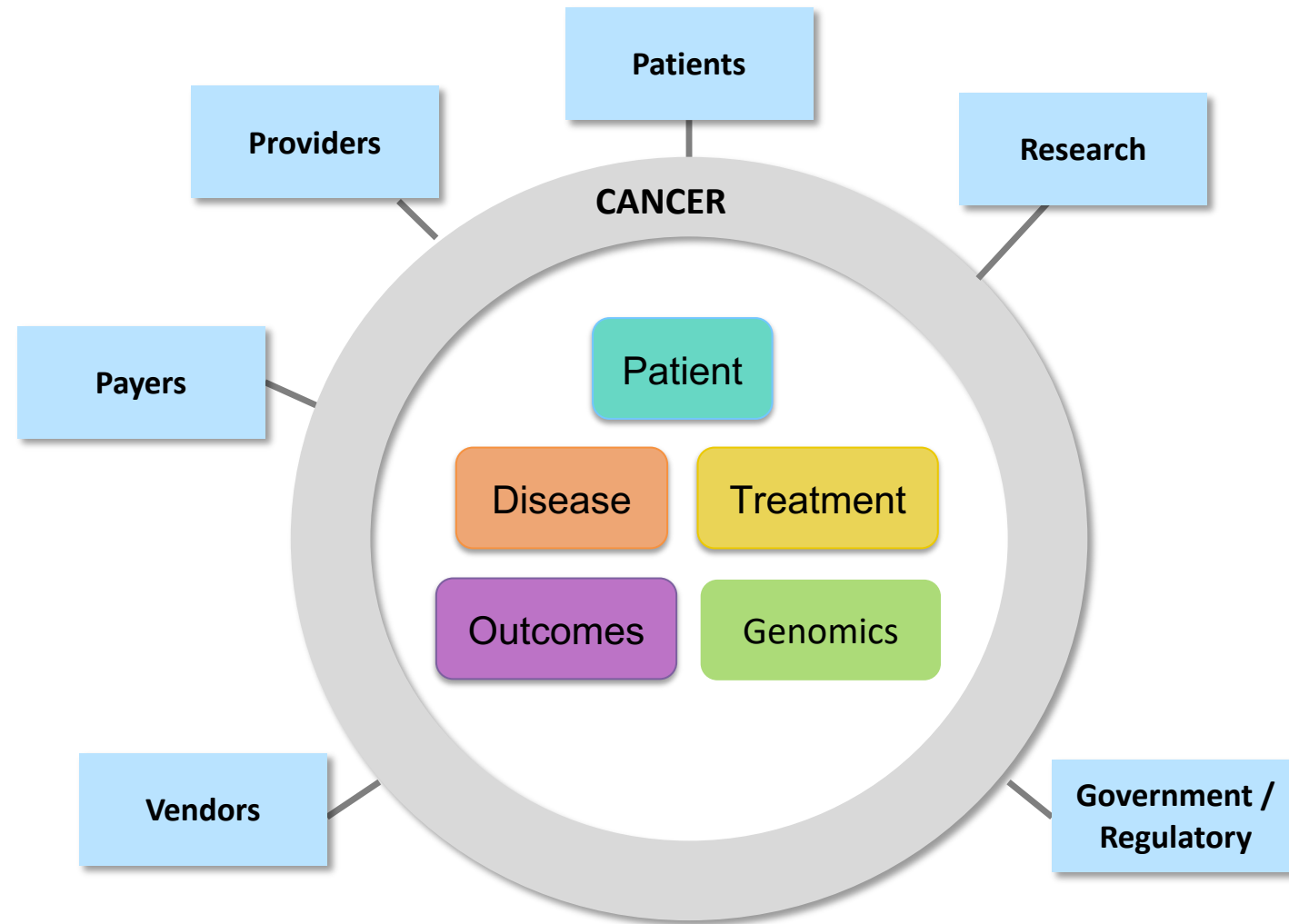
**Mission:** A public interest, not-for-profit company, working to discover new possibilities, create unexpected opportunities and lead by pioneering together for the public good to bring innovative ideas into existence. MITRE's mission-driven team is dedicated to solving problems for a safer world.

# Coordinated Approach to Cancer Data

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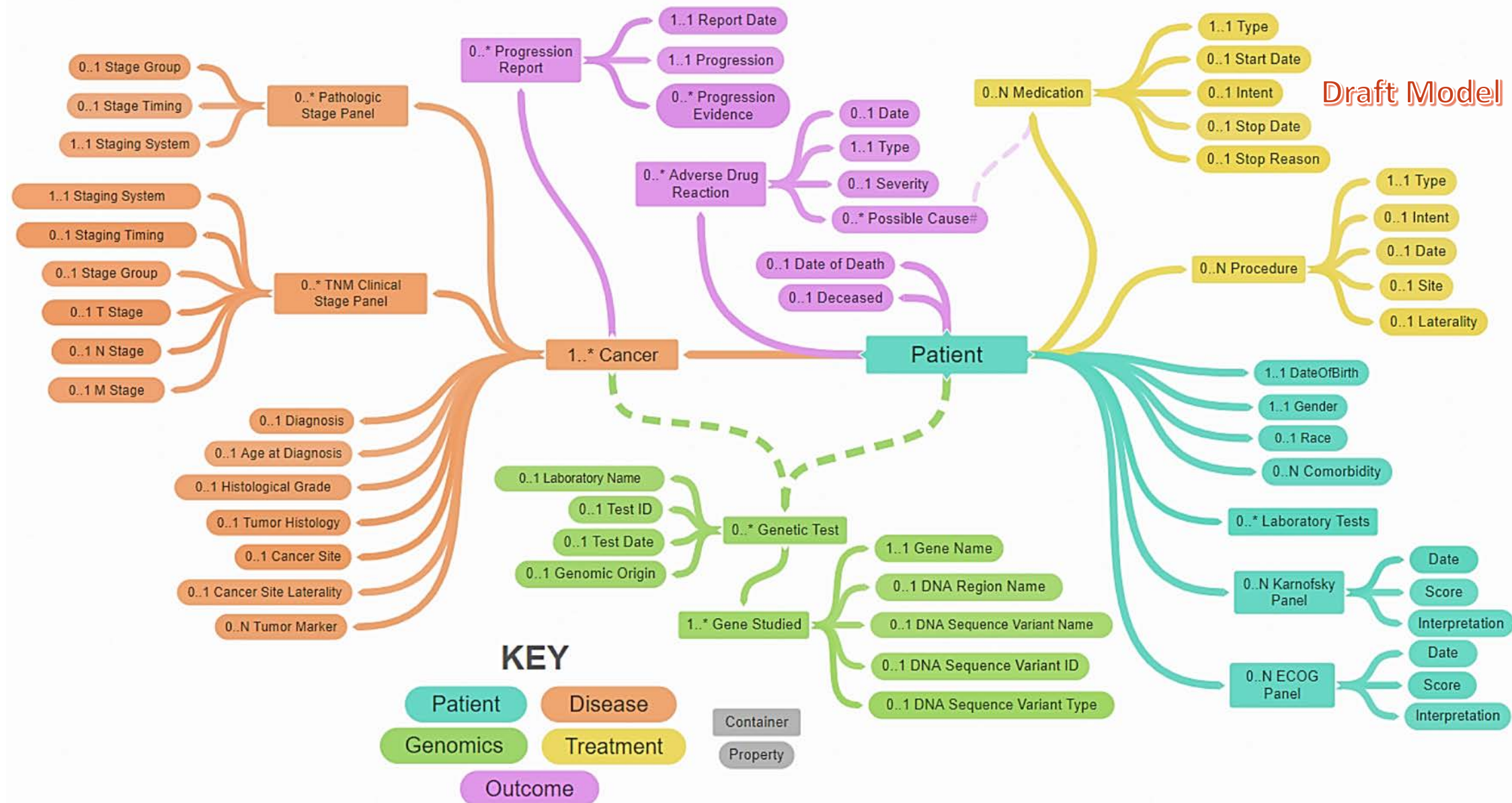


- **A standard health record for Oncology**
  - Created by a collaboration between ASCO and MITRE, with input from diverse stakeholders across the oncology ecosystem
- The minimal set of data elements applicable to all cancers, and collected for:
  - standardized information exchange among oncology information systems
  - use by multiple stakeholders
- Oncology data element domains: patient, disease, treatment, outcomes, genomics





# mCODE™ Logical Model



# mCODE™-Enabled Use Cases and Projects

## Clinical Research



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)

ST. JOSEPH MERCY  
ANN ARBOR  
SAINT JOSEPH MERCY HEALTH SYSTEM

metro-minnesota  
**MMCORC**  
community oncology research consortium

**ThedaCare**™  
Medical Center-Waupaca

**St. Elizabeth**  
HEALTHCARE



**DANA-FARBER**  
CANCER INSTITUTE



## Clinical Care



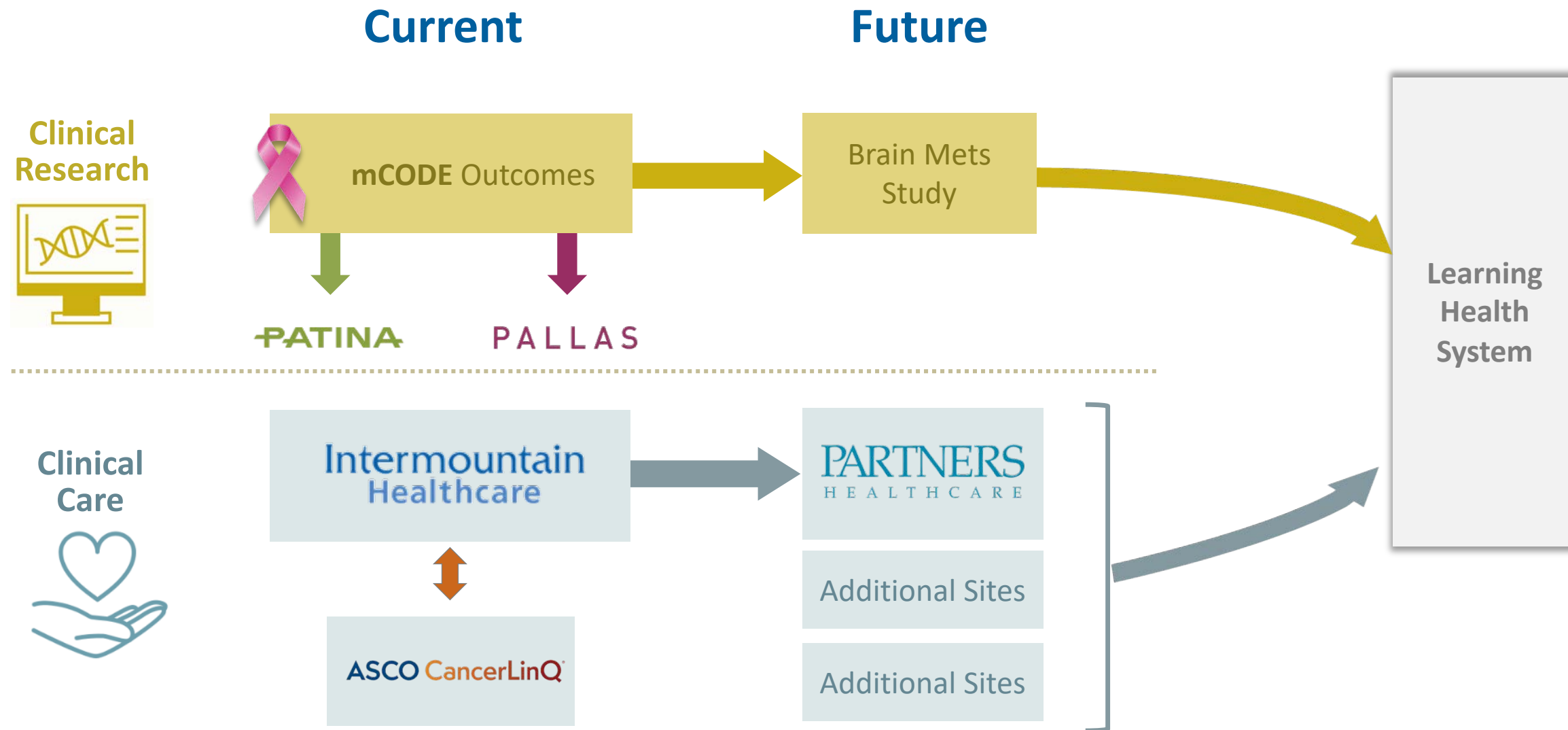
Demonstrate the use of mCODE elements to allow providers and patients to make informed, shared, data-driven decisions and provide data back to generate new knowledge

**MITRE**

**ASCO CancerLinQ**  
Shaping The Future Of Cancer Care

**Intermountain**  
Healthcare

# Enabling a Learning Health System






# Compass

MCODE Pilot

Dr. Mona341 Brown483



Jane Bradshaw146 (026-DH-678986)  
DOB: 5 Apr 1966 (52)  
Admin. Sex: Female  
Location: Boston, MA

Condition

Invasive ductal carcinoma of breast

Search Jane's record

Edit

Overview

Active Conditions

Procedures

Treatment Options

Procedures

Invasive ductal carcinoma of breast

Procedure	When
PET/CT scan	27 Dec 2018
Percutaneous automated vacuum assisted biopsy of breast with ultrasonic guidance	18 Dec 2018
Mammography	11 Dec 2018

Treatment Options

Invasive ductal carcinoma of breast

Outcomes and criteria for 934 patients with Invasive ductal carcinoma of breast were collected by CancerLinQ

Similar patients

163 patients

select all

unselect all

demographic

2/4

age: 42-62

age at diagnosis: 42-62

race: white

gender: female

pathology

5/5

ER: negative

PR: positive

HER2: positive

grade: 3

size (mm): 10-20

genetics

2/2

BRCA1: negative

BRCA2: negative

treatment history

3/3

had surgery: yes

received radiation therapy: yes

received chemotherapy: yes

medical history

1/1

ECOG score: 2-3

		Overall survival rates			Reporting severe side effects	
		1 yr	3 yr	5 yr	all	leading cause
chemo	(16)	100%	100%	87% <span>+16%</span>	100%	Nausea/Vomiting (93%) Fatigue (87%)
chemo & radiation	(14)	100%	100%	78% <span>+7%</span>	85%	Fatigue (78%) Weight Loss (50%)
hormonal	(24)	91% <span>-9%</span>	87% <span>-13%</span>	83% <span>+11%</span>	95%	Hot Flashes (87%) Decreased Libido (70%)
none (actively monitoring)	(7)	100%	100%	71%	71%	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)



# MITRE

## PIONEERING A HEALTHIER FUTURE

MITRE is transforming data into insights to improve the health system and reinvent the healthcare experience.

health.mitre.org

Join us to advance the nation's progress toward an integrated health system with improved access and quality at a sustainable cost.

Learn more at [www.mitre.org](http://www.mitre.org) and [health.mitre.org](http://health.mitre.org)



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# Backup

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# The Problem

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**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