SUMMARY
What We Discovered
The Cancer Data Summit was held in McLean, Virginia, on October 2-3, 2019. It was hosted by MITRE and the American Society of Clinical Oncology (ASCO).
The Cancer Data Summit
Event Summary

On October 2-3, people from many different organizations came together to discuss ways to achieve a common goal: Collect standard, computable oncology data from millions of cancer patients and share the data across interoperable systems to make a step-change improvement in cancer research and care.

“People's lives are depending on what we do and what this data tells us,” Dr. Monica Bertagnolli, keynote speaker for the event. Dr. Bertagnolli is a surgeon at Dana Farber/Brigham and Women’s Cancer Center, a professor of surgery at Harvard Medical School, and Chair of the Board of the American Society of Clinical Oncology (ASCO).

She described the ways she, and other oncologists, treat patients today, as well as a vision for treating them in the future. It’s possible to achieve this vision in the near future if the stakeholders for cancer care come together around a single standard for collecting, sharing, and using cancer data.

The core of the event was how to accelerate the adoption of the minimal Common Oncology Data Elements (mCODE™) as the data standard and common language for cancer data.

In energetic and highly interactive discussions, representatives from across the community described the barriers that could prevent this vision from becoming real and identified ways to break down those barriers.

The outcome of the event was a set of recommendations that could be carried out in the next year. These ranged from motivating adoption of mCODE among major cancer centers through pilots that highlight the value of mCODE to building a community of implementers capable of meeting the demand for data collection, sharing, and leveraging mCODE data.
Cancer Care Today

Dr. Bertagnolli shared some of the issues that she and a patient experienced recently, including:

- Patient’s medical records and pathology reports could not be transferred online to Dr. Bertagnolli because of incompatible EHR systems. Dr. Bertagnolli’s staff had to type patient’s entire health history into their system.
- The clinician had to wait for CT scans (or order duplicates), which prolonged decisions about first steps, which increased patient’s anxiety.
- Because the patient’s tumor had a rare mutation, and patient was anxious, options were limited, and surgery was more difficult.

Cancer Care Tomorrow

In Dr. Bertagnolli’s vision, cancer care in the future with mCODE, would work like this:

- Before the patient arrives for first visit, the doctor will have received all the medical records and recent scans—formatted in a way the doctor’s EHR system can access and read.
- At the patient’s first visit, Dr. Bertagnolli and her patient will discuss the size of the tumor, which necessitates a visit to a medical oncologist, who orders genotyping.
- Finding out the tumor has a rare mutation, Dr. Bertagnolli will use an mCODE-related tool to pull data about patients around the world who were treated for the same cancer and mutation to see what treatment worked best for them. She can narrow the search to those with her patient’s demographics.
Dr. Bertagnolli and her patient will review the data together and make decisions that align with best practices, save time, and seek to improve the patient’s outcome.

The patient’s results are automatically added to her health records and are available to millions of other doctors and patients who can learn from her outcomes over time.

In addition, we believe adopting the mCODE standard will mean:

• Clinical care is more efficient
• Duplication of effort and unnecessary costs are reduced
• Communications is improved and errors reduced
• Home-based evaluations and interventions are facilitated
• Patients and their families are more informed and engaged
• Research is facilitated and advanced
• Learning is integrated into everyday practices.

Why is this so difficult to achieve? We lack high-quality, information-rich, computable data from thousands of patients. This will enable many different tools, for analyzing data, sharing data, and engaging patients in making decisions and owning their healthcare plans. With enough data, we can learn from every patient, and patient and clinicians can work together to choose the right treatment at the right time.

The rest of the day was spent identifying the barriers to the future vision and looking for ways to tear them down and move toward the vision.
Barriers/
Convergence on Standard

- Competing standards. Unclear incentives for stakeholders to use the same standard for data sharing
- Lack of metrics to prove value.
- No government mandate to use it
- Competing demands on delivery network.

Clinical Burden/
Culture Shift

- It’s not so much a technical problem as a legal, regulatory, workflow problem.
- Resistance to change at most organizations, particularly among clinicians
- Clinicians must not only use mCODE but demand that it’s available in products they purchase and use.
Vendor Implementation

- There are business disincentives to use open standards in commercial systems.
- Financial cost of changing systems to include mCODE (delayed ROI)
- Not enough info about mCODE in the community (what is the value proposition?)
- Competing IT priorities
- Challenge of mapping to other existing standards.

Privacy/Security/Ethics

- No consistent process for determining when we need to ask patients if we can share and use their data
- Some organizations use privacy as an excuse, or a shield, when they really want to use their data for competitive advantage
- Lack of transparency—patients don’t understand why we want to share the data and what value it can provide to their care and that of future patients.
- Over-consideration of privacy, which could cause mCODE to fail, preventing interoperability.
There are many different efforts to develop health IT standards, including across the oncology community. No one standard emerges.

Experts from ASCO and MITRE come up with the idea for one standard that would collect data on all cancers, including whether a treatment worked.

The mCODE team engages various stakeholders in the development of the standard and a common language. The goal is to ensure mCODE benefits all stakeholders.

mCODE team launches Codex™ as a new HL7 FHIR™ accelerator (using the same approach as the DaVinci accelerator, which brings together different stakeholders). This initiative supports government’s goal to accelerate infrastructure around FHIR.

mCODE version 0.9 is available now on GitHub for developers to test.

The Cancer Data Summit brought together representatives from many mCODE stakeholders to involve them in implementing mCODE.
Recommendations
Results from the “Making the Vision a Reality by 2022” Workshop

Convergence on Standard
- Create an open community for evolving and building on mCODE.
- Make mCODE the standard of care, with a community to support it as it evolves.
- Create incentives (“carrots”) for using mCODE, including market demand, regulations, and financial incentives.
- Leverage “sticks,” such as regulatory requirements.
- Map mCODE to other standards.
- Make clear to patients how the data will be used, how valuable it can be to them and future patients.

Vendor Implementation
- Develop a way to apply mCODE to retrospective data.
- Encourage developers to build apps based on mCODE, both to supply data and consume data (e.g., for automation of processes). Work with them to ensure ease of adoption/use.
- Spur vendors to offer mCODE as a competitive advantage in products.

Clinical Burden/Culture Shift
- Demonstrate the utility of mCODE for clinicians and patients.
- Find ways to make data collection easier for clinicians.
- Show that mCODE is uncomplicated and easy to use (especially for clinicians).

Privacy
- Educate stakeholders on privacy issues. (Privacy is bigger than mCODE.)
- Establish a set of norms for the use of mCODE (and ethical use framework) and leverage existing HL7 frameworks.

"WE NEED TO HARNESS THE VAST AMOUNT OF USEFUL INFORMATION IN EHRS BY OVERCOMING BARRIERS TO COLLECTING AND SHARING THAT VALUABLE PATIENT DATA."

DR. VICTOR DZAU, PRESIDENT, NATIONAL ACADEMY OF MEDICINE
Recommendations
Continued

Cross-challenge
• Communicate. Speak with a unified voice. Show the value proposition broadly across the community—create a unified demand from providers, clinicians, patients, payers.
  - Promote benefits
  - Reach all stakeholders with targeted communications
  - Highlight champions
• Don’t wait until everything is solved. Encourage organizations to be part of the early real-world testers for mCODE so they can help shape its future.
• Need clear evidence on the value of the data we can collect through mCODE (e.g., can reduce the need for some clinical trials, which cost millions to execute and are not comprehensive). Value could include: efficiency, quality, cost, engagement, research.

“CANCER PATIENTS ARE WILLING TO SHARE THEIR DATA IN HOPES OF FINDING SOLUTIONS, NOT JUST FOR THEMSELVES BUT FOR PATIENTS IN THE FUTURE.”

DEBI WILLIS, CEO AND FOUNDER OF PATIENTLINK ENTERPRISES AND A CANCER SURVIVOR
How can we first prioritize and then act on these recommendations together? Each stakeholder group, each organization, brings something to the table in mCODE’s development. We need all of you to join the effort.

**We Need Your Help to Succeed**

- Test out [mCODE version 0.9.1](#), and give feedback. (MITRE has committed to getting mCODE version 1.0 on the HL7 in 2020.)

- Join [CodeX](#), the HL7 FHIR Accelerator, to help shape the future of mCODE for important use cases (e.g., clinical pathways, prior authorization, personal data management, real-word-data research, etc.).
  - Health System organizations can join through a special Committee of Practice to discuss basic implementation of mCODE for care and research.

- Ask to join the mCODE Council to help build, maintain and promote the mCODE core standard.

- Suggest and participate in pilots of mCODE and related tools, for example:
  - Become an ICAREdata site for demonstrating the value of real-world data in clinical trials.
  - Test new data collection approaches, to ensure they are low burden and effective.
  - Participate in retrospective conversion of previously collected data into mCODE.

- Share the vision of mCODE in your communications.

- Let us know if you would be interested in joining a Working Group to take on some of the recommendations above in one of the barrier areas.
For More Information

“A MAJOR COMPONENT OF HIGH-QUALITY CANCER CARE IS TO ENSURE DELIVERY OF THE RIGHT TREATMENT TO THE RIGHT PATIENT AT THE RIGHT TIME.”

DR. VICTOR DZAU, PRESIDENT, NATIONAL ACADEMY OF MEDICINE

For more information about any of the items in this summary, please contact Steve Bratt, who leads MITRE’s Health Standards and Interoperability Group, as well as the Cancer Data Summit program and efforts to build a community (CodeX) around mCODE.

- sbratt@mitre.org
- mcode@mitre.org