Getting Started with mCODE

Thank you for your interest in mCODE® (minimal Common Oncology Data Elements). The mCODE data standard, once adopted across the oncology community, promises to greatly increase the amount of high-quality shareable data for all cancer types, allowing data to be collected once and used for multiple purposes by clinicians and researchers to support patient care.

Here’s how to get started:

- **Participate in the CodeX / mCODE Community of Practice** to get updates on mCODE and presentations by the community on their use of mCODE to improve cancer care and research.
- **Learn more about the mCODE HL7 Standard** via the “Quick Links” on this page and through the links below.
- **Become a Member of CodeX**. Help drive Use Case Projects - ranging from collection of patient data for clinical trials based on EHR data, matching patients with trials, and registry reporting. This is work engages the community, helps them leverage mCODE, and demonstrates the potential to improve care and research via mCODE and new workflows.
- **Contact us** (CodeX@hl7.org) with any other questions!

What is mCODE®?

mCODE is a core set of non-proprietary, open-source structured data elements for oncology that establishes minimum recommended standards for the structure and content of health record information across use cases and users. The goal of mCODE is to improve the overall quality and consistency of cancer data available to clinicians, patients, researchers, and other stakeholders in the fight against cancer.

mCODE, which is both a common language and a model, facilitates patient care and informs research by enabling analyses of data across the lifetime of a single cancer patient and across patient cohorts.

mCODE was established as the standard, use-case-driven data element set that should be used to populate all electronic health records (EHRs) for patients with cancer. mCODE is based on an important data standard called FHIR® (Fast Healthcare Interoperability Resources), created by Health Level 7 International (HL7), a widely recognized standards development organization working to improve global health data interoperability.

mCODE is open source, non-commercial, and highly collaborative. The mCODE initiative seeks to engage with, not replace, broader standards initiatives. The mCODE community evaluates potential use cases, provides guidance on improvement to interoperability and data collection, and provides advice on how better data can improve the quality of care.

Please see the mCODE reference paper, “Improving Cancer Data Interoperability: The Promise of the Minimal Common Oncology Data Elements (mCODE®) Initiative,” for a history of the mCODE initiative and other important details.

Why do we need mCODE?

Cancer is among the leading causes of death worldwide. According to the National Cancer Institute, in the United States, 39.5 percent of men and women will be diagnosed with cancer at some point during their lifetimes. In 2020, an estimated 1,806,590 new cases of cancer will be diagnosed in the United States and 606,520 people will die from the disease. While these numbers are staggering, the silver lining in the wide prevalence of cancer is the potential to learn from treatment of millions of patients. If we had research-quality data from all cancer patients, it would enable better health outcomes. Today, we lack the data models, technologies, and methods to capture that data.

How can I access mCODE?
Full details about the data specification are available in the HL7 mCODE® FHIR Implementation Guide, including a conceptual diagram, data dictionary (available in Microsoft Excel), data elements, value sets, and implementation guidance. A full list of versions, both historical and current, is available in the Directory of published versions.

How can I get involved?

One way is to join the CodeX™ community. CodeX is a member-driven HL7 FHIR Accelerator and community of diverse organizations that collaborate to develop interoperable data modeling and applications using mCODE. Details about CodeX are available here. We invite you to join the CodeX Community of Practice, a group of health systems and other stakeholders interested in learning more about mCODE and developing new use cases. The Community of Practice is free to join and holds monthly Zoom meetings open to all interested parties.

Who developed mCODE?

mCODE is being developed by a multidisciplinary group of subject-matter experts, including oncology clinicians, informaticists, health services researchers, experts in data standards and interoperability, and others under the auspices of MITRE and the American Society of Clinical Oncology (ASCO). This team has formed an Executive Committee, consisting of a small, agile group of four to seven public and private entities. They have voluntarily come together to further mCODE adoption and include the Alliance for Clinical Trials in Oncology Foundation; ASCO and its nonprofit subsidiary, CancerLinQ LLC; the MITRE Corporation; the American Society for Radiation Oncology (ASTRO); and the Society of Surgical Oncology (SSO).

Who maintains mCODE?

The mCODE Executive Committee will continue to oversee the development and maintenance of the official mCODE data dictionary for various use cases. However, as an open-source concept made available under Creative Commons License, the vision is that users will adopt, adapt, and improve on the versions of mCODE released by the Executive Committee to drive implementation of the mCODE standard and improve the quality and consistency of cancer data across platforms and use cases.

The mCODE Technical Review Group, a standing volunteer body appointed by the Executive Committee, is charged with development and maintenance of the mCODE Data Dictionary. This group works closely with CodeX community to expand and periodically evaluate the data dictionary.

How is mCODE different?

We believe that the intersection of available technology and collaboration across stakeholders will make a difference for health data interoperability. Twenty years ago, the health care industry began developing interoperability standards to improve health care information exchange. However, there were many barriers, including the lack of data consistency. Years of lessons learned went into the creation of mCODE.

Because of the great variety of the data models within EHR systems, transferring information from one health IT system to another frequently results in information distortion or loss, blocking of critical details, or introduction of erroneous data. In addition to capturing too much information as free text, today’s health IT systems contain semantically incompatible information. This prevents practitioners and others from accessing relevant information across a patient’s journey, which in turn affects quality of care.