

Leading Health and Technology Organizations Release Common Cancer Data Standards to Enable Sharing Across EHR Systems and Improve Patient Care

mCODE™, a collaboration between ASCO, MITRE, and the Alliance for Clinical Trials in Oncology Foundation identified a core set of data elements that should be routinely captured in a standardized format in the electronic record of every cancer patient

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Chicago In an effort to advance cancer data sharing and improve the quality and coordination of patient care, three of the nation's leading health and technology organizations have established a core set of data elements and recommended technical specifications (the Minimal Common Oncology Data Elements, or "mCODE") that are essential for capturing and reporting the characteristics, treatments, and outcomes of every cancer patient and should be contained in each patient's electronic health record (EHR). The mCODE™ initiative, a collaboration between the American Society of Clinical Oncology, Inc. (ASCO®), its wholly owned nonprofit subsidiary CancerLinQ LLC, the MITRE Corporation, and the Alliance for Clinical Trials in Oncology Foundation (Alliance Foundation), released the initial set of common cancer data standards and specifications today at ASCO's 2019 Annual Meeting in Chicago and published them online at mCODEinitiative.org.

Data from most of the nearly 15 million individuals living with cancer in the U.S. is contained in EHRs of some kind. But many EHR systems in use prioritize the collection of different types of data, or use different terms to describe the same type of data, or collect data in different formats, making them incompatible with one another. This incompatibility dramatically limits the ability of cancer researchers and doctors to learn from patient records, hinders care coordination, and adds to the administrative burdens and costs for all users, but especially practices and patients.

"Progress and quality care for patients with cancer can hinge on our ability to seamlessly share

patient data among doctors, hospitals, and researchers. But data sharing is much more difficult, if not impossible, when EHR systems contain incompatible information,” said ASCO President Monica M. Bertagnolli, MD, FACS, FASCO. “With mCODE, we’re bringing the oncology community together around common data standards that will bring us one step closer to our goal of learning from every patient with cancer.”

mCODE is being developed collaboratively and the mCODE elements are available for use free of charge. mCODE’s data elements are designed using standard, widely available medical terminologies, which means that a physician’s clinical query across different EHRs that each use mCODE should convey the same meaning and retrieve similar patient details. The mCODE data elements are grouped into six main areas to describe the patient’s cancer journey: “patient” (demographic and other characteristics), “disease” (specific details regarding the cancer), “genomics” (molecular characteristics), “labs/vitals” (relevant laboratory tests and vital signs), “treatment” (surgery, radiation, and drug and other treatments), and “outcomes” (e.g., current cancer status and survival).

“Publishing mCODE is an important step towards realizing incredible insights into treatment that the 97% of cancer patients not participating in clinical trials could generate,” said Jay J. Schnitzer, MD, PhD, MITRE’s chief technology officer. “Through wide adoption and integration of cancer data standards, and the application of technologies like Fast Healthcare Interoperability Resources (FHIR), shared treatment experiences could be turned into information that patients and clinicians can use to better navigate care options.”

To incorporate these standards, mCODE will provide both a common data language and an open source, nonproprietary data model based on FHIR for interconnectivity across EHR systems. The standard elements also support EHRs in capturing and processing increasingly complex genomic data generated by advances in molecular diagnostics and treatment.

“The Alliance Foundation is pleased to be implementing mCODE data structures in a research program that integrates clinical data captured via the EHR with data obtained during conventional prospective cancer clinical trials,” said Steven Piantadosi, MD, PhD, who is the Scientific Director of the Alliance Foundation ICAREdata Project. “This work will validate the use of mCODE as a tool for clinical research and will also establish a platform for conducting research that includes many patients not currently represented in conventional prospective clinical trials.”

mCODE is currently being piloted at cancer centers across the country, including Partner’s Healthcare in Boston and Intermountain Healthcare headquartered in Salt Lake City. In the coming months the results of these pilots will be used to refine mCODE as it is deployed more broadly.

To help guide the evolution of mCODE, the mCODE Executive Committee created the mCODE Council. The Council will advise the Executive Committee, sponsor use cases, and provide input regarding future data elements and use cases. More information, including an application to join the Council, is available at mCODEinitiative.org.

About ASCO:

Founded in 1964, the American Society of Clinical Oncology, Inc. (ASCO®) is committed to making a world of difference in cancer care. As the world's leading organization of its kind, ASCO represents nearly 45,000 oncology professionals who care for people living with cancer. Through research, education, and promotion of the highest-quality patient care, ASCO works to conquer cancer and create a world where cancer is prevented or cured, and every survivor is healthy. ASCO is supported by its affiliate organization, the Conquer Cancer Foundation. Learn more at www.ASCO.org, explore patient education resources at www.Cancer.Net, and follow us on Facebook, Twitter, LinkedIn, and YouTube.

AboutCancerLinQ LLC

CancerLinQ LLC is a wholly-owned, non-profit subsidiary of the American Society of Clinical Oncology (ASCO) and the only non-profit, physician-led big-data technology initiative in oncology. CancerLinQ® collects and analyzes real-world cancer care data from multiple healthcare IT systems in order to deliver insights to physicians, improve the quality of patient care, and drive new research. To learn more, visit www.cancerlinq.org.

AboutMITRE

MITRE's mission-driven teams are dedicated to solving problems for a safer world. Through public-private partnerships, as well as the operation of federally funded R&D centers, we work across government to tackle challenges to the safety, stability, and well-being of our nation.

About ASCO

The Alliance for Clinical Trials in Oncology Foundation is a not-for-profit corporation whose goal is 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. For more information, visit Allianceforclinicaltrialsinoncology.org.
