ASCO's Approach to a Learning Health Care System in Oncology

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Over the past several years, a great deal of interest has been focused on the topic of the learning health care system. The Institute of Medicine (IoM) has held 12 separate workshops around this topic, culminating in a landmark report, “Best Care at Lower Cost: The Path to Continuously Learning Healthcare in America.”¹ Recognizing that proliferation of electronic health records (EHR) has created unprecedented potential for, in essence, a national “digital health utility,” the IoM seeks “development of a learning health system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation—with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience.”^{2(p39)} The promise of this vision in oncology is shared by Abernethy et al³ and others.⁴

ASCO's Board of Directors and leaders see the utility of this approach for oncology and believe the time is right to pursue it. A recent ASCO survey revealed that 90% of oncology practices either have an EHR or plan to implement one within the next year,⁵ making oncology an ideal setting to implement such a system. By collecting clinical data in real time, analyzing and comparing it with existing guidelines, and feeding that information back to participating physicians, we can drive higher quality and value, improving outcomes for our patients. ASCO's initiative, a logical successor to the Quality Oncology Practice Initiative (QOPI), is called CancerLinQ (a *learning information network for quality*). Following is an overview of the system and our experience with a prototype designed to demonstrate proof-of-principle for some of CancerLinQ's key features.

What Does a Learning Health Care System Look Like?

The key features of a learning health care system in oncology are represented in Figure 1. The larger of the two circles is a classic feed forward–feedback quality cycle. Data are captured at the point of care through the transfer of electronic health information in a manner consistent with the Health Insurance Portability and Accountability Act. They are interpreted and transformed as needed, then combined and aggregated with other data from other practices or other sources (eg, billing or pharmacy data). Data are analyzed, and reports are provided to

Figure 1. CancerLinQ process model. The learning health care system in oncology can be represented schematically as two interlocking circles.

participants. Compliance with recognized guidelines and benchmarks, along with national or regional peer comparison, can be available in near real time. Clinical decision support embedded in the EHR can be available at the point of care. With practices' permission, reports could be sent to payers as a means of demonstrating compliance with quality reporting or meaningful EHR use or to specialty boards (eg, American Board of Internal Medicine) for purposes of recertification.

The key to a true learning system is the smaller circle. Because CancerLinQ will capture both what was done (process) and what happened (outcome), the opportunity to gather knowledge from clinical data will be readily at hand. Information specialists working with clinical and outcomes researchers can review data, spot trends, generate new hypotheses, and allow guidelines to become more accurate. We can fill gaps in information, understanding how care plays out in important subsets of patients. For example, close to 30% of patients with cancer are 75 years old or older, yet they represent fewer than 10% of patients on clinical trials. It is likely that this important and growing subset of patients may respond to standard therapy differently than their younger counterparts. These differences could be captured by CancerLinQ and could, in turn, inform

Figure 2. Using an electronic medical record to display decision support. When case data on a simulated patient with breast cancer are entered, clinical decision support (CDS) messages can be opened, if desired, to guide treatment decisions.

Figure 3. Compliance with performance measures. By clicking on a quality measure, data for compliance appear in real time and level of adherence to the measure is displayed.

the design of prospective studies or exploration of additional and possibly confirmatory independent data sets.

ASCO volunteers, led by an Advisory Committee and supported by expert staff and outside consultants, have embarked on a series of efforts to build CancerLinQ. These have included crafting a business plan, addressing data governance and standards, conducting legal analysis, and developing a technology strategy. The team has also consulted with a range of experts and organizations, both private and governmental, that have a stake in this project. Finally, the ASCO Board supported the need to build a system prototype to test feasibility of the concepts and attributes illustrated in Figure 1. The prototype has been built and was first shown at the ASCO Quality Care Symposium in late November 2012.

CancerLinQ Prototype

In creating the prototype, we had five goals: (1) Capture and aggregate complete longitudinal patient records from any

source, in any format, and make use of the data; (2) provide real-time clinical decision support based on clinical guidelines and integrate that into a demonstration EHR system; (3) measure clinical performance on a subset of QOPI performance measures; (4) explore and generate hypotheses from clinical data; and (5) provide lessons learned about technical and logistical challenges of a full CancerLinQ implementation. We have met each of these goals as detailed below

1. Capturing and understanding data from any source. To test this goal, we accumulated 130,000 previously treated breast cancer cases using data from five large practices and a compilation of data from 14 additional practices. The system successfully acquired case data independent of the specific EHR used to capture it at the practice level. Modeled after statistical functions and an artificial neural network, the prototype and staff were able to learn, structure, and dynamically map data fields as the data were acquired. This feature, once fully automated and

embracing the IoM's vision of a learning health care system. ASCO's initial foray into realizing this vision for oncology shows great promise.

Acknowledgment

Presented at the ASCO Quality Care Symposium, San Diego, CA, November 30-December 1, 2012.

Authors' Disclosures of Potential Conflicts of Interest

Although all authors completed the disclosure declaration, the following author(s) and/or an author's immediate family member(s) indicated a financial or other interest that is relevant to the subject matter under consideration in this article. Certain relationships marked with a "U" are those for which no compensation was received; those relationships marked with a "C" were compensated. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.

Employment or Leadership Position: Joshua T. Mann, American Society of Clinical Oncology (C) **Consultant or Advisory Role:** None

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Stock Ownership: Peter Paul Yu, IBM **Honoraria:** None **Research Funding:** None **Expert Testimony:** None **Other Remuneration:** None

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DOI: 10.1200/JOP.2013.000957

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