review article

CancerLinQ: Origins, Implementation, and Future Directions

abstract

Rapid-learning health systems have been proposed as a potential solution to the problem of quality in medicine, by leveraging data generated from electronic health systems in near-real time to improve quality and reduce cost. Given the complex, dynamic nature of cancer care, a rapid-learning health system offers large potential benefits to oncology practice. In this article, we review the rationale for developing a rapid-learning health system for oncology and describe the sequence of events that led to the development of ASCO's CancerLinQ (Cancer Learning Intelligence Network for Quality) initiative, as well as the current state of CancerLinQ, including its importance to efforts such as the Beau Biden Cancer Moonshot. We then review the considerable challenges facing optimal implementation of a rapid-learning health system such as CancerLinQ, including integration of rapidly expanding multiomic data, capturing big data from a variety of sources, an evolving competitive landscape, and implementing a rapid-learning health system in a way that satisfies many stakeholders, including patients, providers, researchers, and administrators.

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BACKGROUND: WHY ONCOLOGY NEEDS A RAPID-LEARNING HEALTH SYSTEM

There are a variety of deficiencies in the efficiency, quality, and delivery of cancer care in the United States. As oncology increasingly relies on the dynamic fields of genetics and molecular biology, an era of precision medicine in which treatments are tailored to individual patients and tumors is possible. However, if the current system for delivering cancer care is not overhauled, we will squander a great opportunity. Lengthy delays in translating the latest scientific knowledge into clinical practice can lead to patients getting suboptimal care.[1,2] As few as 3% of patients currently participate in clinical trials, which are typically carried out on cohorts of patients that underrepresent critical demographics such as the elderly, racial minorities, and patients with numerous comorbidities; as a result, the patients in an adult oncology trial typically do not represent those in an oncology practice.[3-8] Despite this, many successful trials have led to a bewildering array of treatment choices, with little guidance available other than expert opinion. The systemic challenges facing the cancer care system clearly require a modern solution. A rapid-learning health system offers the potential for a systemic fix to these vexing problems.

In this article, we review the impetus behind and inception of ASCO's CancerLinQ (Cancer Learning Intelligence Network for Quality) initiative. Google Scholar and the National Center for Biotechnology Information PubMed databases were queried with the search items "CancerLinQ" and "Rapid-learning health systems." Articles germane to the topic at hand were selected and included in this review. Where relevant, articles cited by these articles were also included in this review. We review the background of rapid-learning health systems and CancerLinQ's strategy for initial design and implementation, early returns from CancerLinQ, and potential avenues for the future direction of CancerLinQ. Although we generally limited our analysis to the published literature, certain unpublished details of CancerLinQ were gathered through personal communication.

WHY A RAPID-LEARNING HEALTH SYSTEM MAKES SENSE FOR ONCOLOGY

A rapid-learning health system, as originally defined by Etheredge et al[9] in a 2007 *Health Affairs* article, involves the collection of real-time data from millions of patients to generate shared databases. The system draws on similar concepts to the Plan-Do-Study-Act cycle for iterative organizational improvement developed in the 1990s and since successfully applied in a variety of industries.[10,11] A rapid-learning health system is rapid learning because it is able to analyze point-of-care data in near-real time to catch inefficiencies and give feedback to providers; such feedback would most typically be generated algorithmically and will occur

in a matter of minutes (for a prespecified quality metric) but can take longer (for example, if a new inefficiency is discovered that requires de novo research to investigate). It is also a system, because the data originate in a variety of sources, including electronic health records (EHRs), claims databases, pharmaceutical clearinghouses, and clinical trial databases. The newest and potentially richest source, as measured by kilobytes generated, is patient-generated health data. Each of these high-level categories themselves often involve complex, multifaceted subsets of data; for example, pharmaceutical data in oncology could involve prescription fill patterns, adverse event reporting databases such as the US Food and Drug Administration's Sentinel Initiative, and individualized dose modifications.[12] The US oncology community has also built several vast registry operations, most notably the Centers for Disease Control and Prevention's National Program of Cancer Registries, the National Cancer Institute's SEER program, and the Commission on Cancer's National Cancer Database.[13,14]

A rapid-learning health system can serve a variety of purposes, ranging from quality improvement to hypothesis-driven research to hypothesis-generating data mining. Users, including clinicians, clinical researchers, and practice administrators, can interrogate the system to efficiently answer clinical questions, evaluate quality, and quantify costs, in turn generating clinical decision support mechanisms that are accessible at the point of care. Such a system can enable users to examine the degree to which the idealized environments of clinical trials apply to the real world, rapidly disseminate new research findings, and ensure that these findings are reproducible.[15] In the coming age of personalized medicine, rapid-learning health systems could allow users to examine the root causes of disparities in outcomes as well as granular treatment effects of individual patient characteristics, including genetic information, to a degree that would be difficult to achieve in randomized controlled trials.[3]

Prototypical rapid-learning health systems have been developed in oncology and have been shown to be useful for quantifying variability in clinical practice (eg, methodology of postmastectomy radiation therapy), tracking mutation-specific outcomes (eg, recapitulating the expected superior survival outcomes for epidermal growth factor receptor [*EGFR*]–mutated lung cancer) and discovering new prognostic subgroups (eg, inferior survival with guanine nucleotide binding protein [*GNAQ*]–mutated melanoma).[16,17] Given the severity, universal impact, and cost of cancer care, as well as the complex requirements to integrate personalized information down to the genetic level with clinical outcomes, oncology practice is an ideal avenue for implementing a rapid-learning health system.[9,18]

CANCERLINQ—FROM CONCEPT TO IMPLEMENTATION

A number of factors have coalesced to make the development of a rapid-learning health system for cancer care plausible. EHR usage has expanded dramatically over the past several years. From 2008 to 2015, EHR usage increased from 9% to 96% for hospitals and 17% to 78% for physician offices.[19] Increasing amounts of clinical data are now accessible in searchable databases that are ripe for reuse. The last several years have seen an increased availability of electronic resources for oncology throughout the health care system, both in the private and public sectors. Federal funding for health information technology and comparative effectiveness research has also increased significantly, with one example being the Health Information Technology for Economic and Clinical Health (HITECH) Act, passed as part of the American Recovery and Reinvestment Act in 2009.

Contemporaneous to the developments above, ASCO was conceiving its vision of a rapid-learning health system. ASCO developed a prototype for its rapid-learning health system, CancerLinQ, which evolved out of ASCO's well-established Quality Oncology Practice Initiative (QOPI). QOPI was designed as a measurement tool, deriving data from provider surveys as well as sample-based chart abstraction methodologies, to track adherence with a variety of evidence- and consensus-based practice benchmarks.[20] QOPI was successful in promoting adherence with these benchmarks, including both patient-collected data and clinician-generated documentation, with some of the early measurement programs focused on quality of care at the end of life, documentation of informed consent, and adherence to guidelines on hematopoietic growth factor administration.[20,21] Interestingly, improvements seemed to be greatest when reporting features were integrated into the EHR.[22]

Although a useful concept for measuring adherence to quality, QOPI metrics could not be linked with cost and quality data necessary to use those metrics to drive system-wide improvements; the sample-based approach was also recognized as inadequate for oncology practice, which is characterized by edge cases, such as rare sarcomas or

idiosyncratic reactions to chemotherapy. At the same time, manual abstraction is labor intensive and could never scale to the level needed for comprehensive coverage. Thus, it was recognized that data integration would require a rapid-learning health system.[23] Such integration would require uniformity and interoperability of critical data elements that were not features of EHRs in use at the time. Joint efforts in 2009 between the National Cancer Institute and ASCO resulted in the Clinical Oncology Requirements for the EHR (CORE), the first attempt to approach this problem.[24] Informed in part by QOPI as well as the CORE standards, a prototype for CancerLinQ was developed and unveiled at the ASCO Quality Care Symposium in 2012. Using 130,000 patients with breast cancer from 14 different practices, the prototype could extract data from a variety of EHRs, offer real-time clinical decision support, and measure QOPI compliance, and was useful for querying the data set for adverse effects associated with a common regimen.[3] CancerLinQ was piloted in 2013 and started ingesting data in 2015, in collaboration with a large technology partner, the German software company SAP.[3,25,26]

EARLY RESULTS AND FUTURE DIRECTIONS

CancerLinQ was launched in 2015 and to date has been adopted by approximately 85 oncology practices, academic institutions, and integrated care networks.[27] Given that a large academic practice such as ours (Vanderbilt University Medical Center) sees approximately 5,000 new patients with cancer as well as > 20,000 established patients in follow-up annually, the number captured by CancerLinQ represents an impressive volume of patients. Data are collected from practices by one of two main mechanisms: passive collection from EHRs used by participating practices by a third-party listener application (pull) or direct extraction and deposition of data from a practice's EHR or clinical data warehouse (push). Extracted data are normalized using the quality data model and Observational Medical Outcomes Partnership common data model.[28] Clinical notes are extracted in large text blocks, which can include unstructured text as well as templated or semistructured documents. CancerLinQ also asks for externally sourced documents (eg, pathology reports, operative reports, radiation summaries, external laboratory reports, and so on); these are accepted in machine-readable or PDF formats. The bulk of these data are stored in a data lake, where they await further normalization and natural language processing (personal communication, A. Stewart and R. Miller, May 2017). Ultimately, numerous additional data sources, including genomic data, financial data, and claims data, will be added to CancerLinQ.[26]

One of CancerLinQ's main selling points is that it is transparent to the workflow of the practice; it collects patient information on an asynchronous basis in the background without affecting the performance of the clinical systems. This approach works when the quantity of data being moved is small; if data such as genomic sequencing or large unstructured text or large image files are being moved, transmission bandwidth and other concerns become an issue. Informatics solutions, such as compression strategies or on-demand data feeds, need to be investigated, because the pace of data generation currently far exceeds the pace of bandwidth expansion.[29]

The rollout of CancerLinQ has also coincided with an expected windfall of public funds for cancer research. Former Vice President Biden's $1 billion Beau Biden Cancer Moonshot, launched in February 2016, is aimed at reducing time-to–oncology innovation by half.[30] One of the Moonshot's major initiatives is to "build a cancer data ecosystem"; given its rapid growth and already large repository of patients, CancerLinQ is potentially a critical part of such an ecosystem.[31,32] The Moonshot's Blue Ribbon panel convened a working group on enhanced data sharing, which anticipates that the initial building blocks of such an ecosystem will be in place within 2 years of the Moonshot's announcement.[33]

There are a number of barriers to developing a data ecosystem, relating not only to the design and technical compatibility of each database but also to data governance. For example, CancerLinQ uses an opt-out approach to informed consent, in which patients have to voluntarily decline consent for their data to be excluded from the registry.[34] By contrast, other large cancer data sets, such as the Oncology Research Information Exchange Network (ORIEN), use opt-in consent as opposed to the opt-out approach used by CancerLinQ.

CHALLENGES TO IMPLEMENTING CANCERLINQ

Despite offering the promise of significant improvements in health care research, quality, and cost, significant structural barriers exist to the implementation of CancerLinQ. These include improving data interoperability and utility, mitigating legal and user trust issues, and remaining competitive in an ecosystem of learning health systems (Table 1).

Improving Data Interoperability and Utility

A rapid-learning health system is most effective when it is able to synthesize large amounts of data across a variety of practice settings and between a variety of EHRs. For this to be effective, data elements from different EHRs must be syntactically and synthetically uniform.[35] Although standards exist to create an interoperable ecosystem, such as LOINC (Logical Observation Identifiers Names and Codes) and C-CDA (Consolidated-Clinical Document Architecture), in practice it is evident that they are not yet widely or consistently implemented.[36,37] This can make sharing even basic laboratory data difficult. More complicated concepts, such as chemotherapy naming conventions, can be wildly disparate between systems; consider, for example, the many ways that commonly used regimens such as FOLFOX (infusional fluorouracil, leucovorin, and oxaliplatin) or R-CHOP (rituximab plus cyclophosphamide, doxorubicin, vincristine, and prednisone) can be represented in structured and narrative clinical documentation. To capture the greatest number of outcomes, data will need to be accessed from nonacute, nonclinical settings, such as hospice, home health agencies, and skilled nursing facilities—many of which do not have EHRs; integrating these transsectoral data into a rapid-learning health system will be challenging.

Although the genetics and molecular biology advancements that are driving innovation in oncology are exciting, putting these data to optimal use remains a major challenge for CancerLinQ. As genetic sequencing gets more affordable, increasing amounts of genomic data will be generated. Careful coordination is required to ensure the uniformity of format and meaning that is essential to a functional rapid-learning health system and to prevent potential information overload for providers.[18,38,39] This can potentially be mitigated by the development of intuitive clinical decision support systems accessible at the point of care; an important example is the personalized cancer therapy program developed by Uzilov et al[40] at Mount Sinai. Such clinical support systems are potentially malleable by a rapid-learning health system, particularly if new information gleaned from the rapid-learning health system renders the guidelines on which the support system was made impractical to a given clinical scenario.[41]

Mitigating Legal and User Trust Issues

As CancerLinQ expands its usage, legal issues may arise. Data will need to be shared across state lines and will have initially been subject to different regulatory standards (especially regarding genomic data). Questions of intellectual property and data ownership may also become prominent. Patient privacy is a major consideration, and compliance with the Health Insurance Portability and Accountability Act, as well as other health care data regulations, was a prime consideration when developing the regulatory framework of CancerLinQ.[34] The regulatory pathway used by CancerLinQ was developed in 2014, designed to balance the competing interests of patient privacy (including Health Insurance Portability and Accountability Act compliance) while enabling data sharing primarily for the purposes of quality improvement (noting that any data used for research purposes must have originally been collected for this purpose), noting that prior clinical data registries had been broadly supported by patients as well as the various stakeholders.[34] The new Common Rule

Table 1. Challenges to Implementing CancerLinQ

Challenge Area	Examples of Specific Problems	Potential Solutions
Improving data interoperability and utility	Data elements are not uniform across EHRs.	Better implementation of standards such as LOINC, C-CDA
	Multiomic data can result in information overload.	Development of better intuitive clinical support systems
Mitigating legal and user trust issues	HIPAA compliance is a major concern when sharing data.	New Common Rule provides a cursory legal framework for issues of privacy and consent
	Providers and patients are somewhat wary of sharing data with external providers.	As familiarity with the system increases, user trust in learning health systems tends to improve.
Staying competitive	Practices will have to choose between individual registries, because participating in any given registry requires significant time and money.	Ongoing engagement with the larger oncology community as well as coordination between coexisting rapid-learning health systems
	Current cost model may not be viable long term.	Possibility for change, including fee scales, to attract more practices

Abbreviations: C-CDA, Consolidated-Clinical Document Architecture; EHR, electronic health record; HIPAA, Health Insurance Portability and Accountability Act; LOINC, Logical Observation Identifiers Names and Codes.

also allows for providers to obtain broad consent for research, enabling patient data to potentially be used for future studies unspecified at the time of consent.[42] This provides a legal framework for using rapid-learning health systems to generate and answer new clinical questions in near-real time.

Oncologists, who will be the primary providers of data, and who will translate conclusions drawn from them into practice, need to trust that CancerLinQ is operating with high standards for security and is being used to conduct clinically useful operations and research.[43,44] With respect to the critical issue of user trust, preliminary results have been mixed. Surveys conducted about CancerLinQ since its implementation indicate that although most patients with cancer support the use of a rapid-learning health care system, they also consistently expressed concern regarding the opt-out system of consent as well as the ways in which pharmaceutical companies and insurers use their data.[45] This has been shown in another recent study, in which the patients surveyed were most wary of sharing data when their consent was not obtained and when it was being shared with pharmaceutical companies.[46] Providers share concerns regarding patient privacy and sharing data with external stakeholders.[47] Notably, both patients and providers became more comfortable with CancerLinQ as their familiarity with the system increased.[45,47]

Staying Competitive

There are multiple registry-like systems such as CancerLinQ, both within oncology (eg, the Medicare Innovation Center's Oncology Care Model registry, the American Urological Association's AQUA registry, and the American Academy of Ophthalmology's IRIS registry), and outside of oncology (eg, the All of Us Research Program of the Precision Medicine Initiative). Furthermore, in the absence of a national patient identifier, probabilistic approaches will be needed to prevent spurious conclusions.

Although involvement in a rapid-learning health system has clear advantages to an individual practice, involvement in numerous large registries simultaneously will be impractical, requiring increasing amounts of time, effort, and resources. For example, CancerLinQ's precursor, QOPI, optionally involves a rigorous certification process costing up to $15,000, not to mention data submission costs ranging up to $20,000; although some of these costs might be reduced by automation involved in a rapid-learning system, they will not go to zero.[23] Currently, the individual systems have different benefits (eg, CancerLinQ's transparency and Oncology Care Model integration with claims data) that may appeal to different practices, depending on preferences. When choosing which rapid-learning health systems to participate in (for example, between CancerLinQ and commercial solutions such as TriNetX), practices will need to balance a variety of potentially competing considerations, including economies of scale, network externalities, data security, and pricing. Invariably, the future of rapid-learning health care systems will inevitably involve numerous parallel, competing registries, whose coexistence will require careful coordination, to share data in a way that minimizes both duplicated and missing data to maximize quality for the system as a whole. CancerLinQ has remained engaged with the larger oncology community to minimize potential fallout from such a hypercompetitive environment, but it remains an ongoing challenge. It is possible that, if the ecosystem becomes too compartmentalized and competitive, this will compromise the utility of each individual rapid-learning health system, including CancerLinQ.

The cost model of CancerLinQ may evolve over time to remain viable. Other rapid-learning health systems, such as TriNetX, have a model that is supported through the provision of deidentified data to the pharmaceutical industry. CancerLinQ LLC is a nonprofit subsidiary of ASCO, but it may charge fees for practices that use its quality-improvement platform or analysis of quality-improvement data, with the potential for fee scales depending on the level of access desired by a particular user. Given that the risk of reidentification cannot be nil, changes in capturing cost data may result in identified data being inadvertently shared with industry, which presents an additional challenge.[48,49]

SUMMARY

Because of the multidisciplinary nature of oncology, and requirements to integrate data across a wide array of dimensions, oncology is the ideal environment for a rapid-learning health system, such as CancerLinQ. Since its launch, CancerLinQ has grown rapidly and is generally supported by the patients and providers who are contributing to the system. A number of challenges remain to optimal implementation of CancerLinQ, including integration with the Biden Cancer Initiative's cancer data ecosystem. Although the published literature on CancerLinQ remains quite preliminary, we anticipate that this will rapidly change as the system matures.

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