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Learning Health System in Crisis: Lessons From the COVID-19 Pandemic

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The coronavirus disease 2019 (COVID-19) pandemic is the gravest public health crisis that the United States has seen in more than a century. Health care delivery systems are the focal point for interfacing with COVID-19; however, many were and remain unprepared for this or similar outbreaks. In this article, we describe the learning health system (LHS) as an ideal organizing principle to inform an evidence-based response to public health emergencies like COVID-19. We further describe barriers and challenges to the realization of the LHS and propose a call to action for a substantial investment in the LHS, with a focus on public health. Specifically, we advocate for a learning health network that promotes collaboration among health systems, community-based organizations, and government agencies, especially during public health emergencies. We have approached this commentary through the unique lens of researchers embedded within a large, integrated health care delivery system, with direct experience working with clinical and operational units in response to the COVID-19 pandemic.

A PUBLIC HEALTH CRISIS OF HISTORIC PROPORTIONS

After its initial detection in Wuhan, China in December 2019, the COVID-19 outbreak, caused by the severe acute respiratory syndrome coronavirus 2, rapidly spread across the world.[1] On March 11, 2020, the World Health Organization officially declared the COVID-19 outbreak a global pandemic,[2] the worst seen in the United States since the influenza pandemic of 1918, which claimed approximately 675,000 American lives. It is currently believed that the first COVID-19 fatality in the United States was on February 6, 2020, in California's San Francisco Bay area, a month prior to the initially purported first

death in Washington state,[3] suggesting that the virus was spreading earlier than experts had previously believed.

In a brief time, the United States surpassed China and several other nations with the highest number of COVID-19 cases globally. Around the time of publishing this article, the United States had cumulatively reported more than 19 million COVID-19 cases and over 330,000 deaths.[4] With only 4% of the world's population, the United States Currently Claims approximately 25% of all COVID-19 cases and 20% of COVID-19—related deaths.

Across the United States, COVID-19 cases are still rising. The Institute for Health Metrics and Evaluation of the University of Washington (Seattle) estimates that cumulative deaths could climb to nearly 500,000 cases by February of 2021.[5] This projection is very concerning, especially as capacity and resources to treat infected individuals continue to deplete. Complicating matters, early in the pandemic, the United States lagged behind many other countries with regard to community-based testing, making it nearly impossible to implement informed risk mitigation policies to contain the spread of the virus.

Health care delivery systems are the focal point for interfacing with the COVID-19 pandemic and thus are vital for mounting an evidence-based response. However, many were and remain unprepared for this or similar outbreaks. In the era of the electronic health record (EHR) and more than a decade after the Institute of Medicine (IOM) formalized the concept of the LHS, why was the United States not better prepared for its worst public health emergency in more than a century?

THE PROMISE OF THE LHS

In recent years, there has been an intensifying interest in the LHS paradigm, evidenced by

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the establishment of an open-access journal in 2017 dedicated to the topic, aptly named *Learning Health Systems*,[6] and $40 million in grant funding awarded by the Agency for Healthcare Research and Quality and the Patient-Centered Outcomes Research Institute to conduct research on patient-centered outcomes within the context of the LHS.[7]

The IOM, now called the National Academy of Medicine, conceptualized the LHS in 2007 as a novel approach to health care delivery, evidence generation, and a conduit toward value-based care.[8] The LHS is an environment 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."[8] The LHS paradigm, as envisaged by the IOM, has 3 core elements: (1) foundational elements of *data infrastructure*, including the ability to collect and (re)use data, primarily from the EHR; (2) *care improvement targets* that assist learning and health through clinical decision-making activities; and (3) a *supportive policy environment* in which financial incentives reward high-value care and promote performance transparency.

The LHS paradigm is an ideal organizing principle to inform a unified and data-driven response to national public health emergencies like COVID-19, given that the cornerstone of an LHS is its data used to inform and improve care. The LHS can facilitate a continuous learning cycle of generating data (collected via the EHR, patient registries, or other sources), interpreting data using robust analytics, planning and coordinating data-driven solutions, and implementing an informed and systematic response.

In 2011, the IOM released a report on digital infrastructure for the LHS to facilitate continuous learning.[9] The report brings into the fold the aforementioned data sources, as well as other digital information including health portals, electronic monitoring devices, and biobanks. Each of these additional sources "adds important capacity for clinical care, clinical and health services research, public health surveillance and intervention, patient education and self-management, and safety and cost monitoring."[9] Presently, the EHR is the most mature of all the data sources proposed by the IOM and holds the most promise for data collection and analytics in the context of an LHS. Thus, we primarily focus on EHR data in this commentary.

In the following sections, we discuss the role of each of the core elements of the LHS paradigm in responding to the COVID-19 pandemic and other public health crises in general.

Data Infrastructure

Health systems that successfully operationalized the LHS paradigm would be well prepared to serve as sentinels for disease surveillance, enabling early detection in shifts away from the norm, and well positioned to anticipate an impending rise in the epidemiological curve of an outbreak within their communities. To achieve this goal, the necessary data infrastructure, namely the EHR, must be in place.

Over the past decade, there has been a steady adoption of EHRs. Between 2008 and 2017, office-based health care professionals using an EHR increased from 42% to 86%.[10] This shift is primarily attributed to the American Reinvestment and Recovery Act of 2009, and specifically the Health Information Technology for Economic and Clinical Health (HITECH) Act,[11] which has incentivized EHR adoption through financial payments for meeting specific "meaningful use" metrics and penalties for not meeting these metrics.[12]

With widespread adoption of the EHR, health systems—especially large integrated systems—are able to generate vast amounts of data that can be repurposed for disease surveillance. Moreover, data from other existing sources can be used to track key resources, including staffing, beds, ventilators, medications, testing kits, and other vital supplies.

Care Improvement Targets. With data infrastructure and prespecified metrics in place, health systems are poised to conduct surveillance, which should begin prior to the start of a pandemic. Continuous monitoring of metrics can be used to detect emerging signals, applying sophisticated methods such as artificial intelligence and machine learning. For example, real-time analysis of increases in expected cases of pneumonia, intensive care unit

bed occupation, utilization of ventilators, or even cases of suspected influenza (compared with previous years) could reveal important signals that a novel and potentially communicable disease is circulating and further investigation is needed. Using the EHR, a recent study has reported the ability to detect signals of COVID-19, evidenced by excess visits with the word "cough" documented as the primary reason for a health care visit, as well as hospitalizations for acute respiratory failure.[13]

These data must get into the hands of decision makers early and often so that planning is proactive, swift, and evidence based. Timeliness during disease outbreaks is vital, as we have learned from the current pandemic. Had initial shelter-in-place policies been put into effect even a week earlier, tens of thousands of lives could have been saved.[14]

Supportive Policy Environment. During a public health crisis, communication and transparency across health care systems, public health agencies, and other institutions are needed to facilitate strategic and coordinated responses. Health care systems must not operate in silos during such times. Rather, information should be shared. We offer several pertinent examples. First, during the early stages of an epidemic, if one health care system detects an emerging signal, quickly alerting other health systems and public health departments, especially those in the same geographic region, may help to halt the spread of infection and contain an outbreak early. Second, as the epidemiological curve rises and resources become increasingly limited within one health care system (eg, intensive care unit beds or ventilators reaching maximum capacity), a contingency plan to channel patients and/or resources to other facilities could accommodate the need. Third, health care systems could notify government agencies in real time about shortages of testing kits, medication, and personal protective equipment to alert those responsible for local, state, or national supply chains.

With the core elements of the LHS in place, ideally health care systems should be well-equipped for challenges like the COVID-19 pandemic—early and rapidly identifying cases (signal detection), modeling and

assessing the potential impact, and proactively planning a systematic and iterative response—informed largely by warnings from other modern-day, global disease outbreaks (severe acute respiratory syndrome [2003], influenza A virus subtype H1N1 ["swine" flu; 2009], Middle East respiratory syndrome [2014]).[15] This scenario, however, was not the case in the context of the current pandemic for health care delivery systems in the United States or the health care system as a whole. This failure raises questions about why prior warnings were not heeded and whether the LHS, after 13 years, is still an abstract concept rather than a reality.

THE REALITY OF THE LHS: BARRIERS AND CHALLENGES

Notwithstanding efforts to encourage the materialization of the LHS in the United States, there is little evidence of its successful implementation.[16] Historically, one barrier has been lack of information technology, or the so-called foundational elements of data infrastructure of the LHS paradigm, namely the EHR. Despite the advancements achieved through the HITECH Act, EHR adoption in the United States is not complete, with lower use among health care professionals in rural or impoverished communities.[17,18] Even with an EHR in use for clinical care, many health care professionals and systems do not have the resources and infrastructure to repurpose data for applied analytics. Thus, for some institutions it is nearly impossible to use these data to detect early signals of disease outbreaks or to quickly assess facility resourcing needs. Again, professionals in rural and impoverished communities are less likely to have the requisite resources to conduct analytics and thus are at a disadvantage during disease outbreaks like COVID-19, exacerbating already prevalent inequities. This issue underscores the importance of data sharing.

Another barrier to the implementation of the LHS has been the structure of the US health care system. Although the LHS is considered a conduit to value-based care, a supportive policy environment that embodies value-based care and transparency is required to promote the development and successful implementation of an LHS. The US health care system, or more accurately the multiple

systems that comprise the overall health care system, is largely a fee-for-services delivery model that has been slow to embrace value-based payment structures. During a public health crisis, health care systems must view each other as partners rather than competitors. Yet a competitive marketplace that rewards volume creates disincentives for necessary communication and coordination among health care systems. Even when organizations are willing to share data, privacy rules imposed by the Health Insurance Portability and Accountability Act (HIPAA) and other regulations, while necessary to protect patient confidentiality and data security, have to some degree impeded information exchange.[19]

Although we cannot expect a complete overhaul of the US health care system any time soon, much progress has been made in the adoption of value-based care in recent years.[20] Between 2011 and 2018, the number of states implementing value-based care programs increased from 3 to 48.[20,21] This uptake can be attributed to the Medicare Improvements for Patient and Providers Act of 2008, which enabled the Centers for Medicare and Medicaid Services to incentivize health care professionals for quality of care delivered, as opposed to volume.[22]

Furthermore, advances have been made over the past decade in the development of distributed data models that promote data sharing (using processes compliant with the Health Insurance Portability and Accountability Act) and large-scale analytics across health care systems, insurance payers, and others in the private sector. The Sentinel initiative, the National Patient-Centered Clinical Research Network, and the Health Care Systems Research Network are 3 such examples.[23,24] These networks are models that should inform how LHSs can collaborate to rapidly generate data needed to detect signals and initiate a collective response to disease outbreaks.

The health care landscape today differs greatly from its 2007 counterpart, when the IOM first conceptualized the LHS paradigm. With widespread adoption of information technology and momentum toward value-based care, now—more than ever—is the time and place where the LHS has the potential to thrive. That said, translating knowledge into action remains an additional barrier to implementation. To overcome this problem, we propose that the Department of Health and Human Services, or appropriate federal agency, establish a formal certification process through which health care systems are appraised on their ability to collect, analyze, interpret, and share data in order to be designated as an official LHS. This certification would provide a standard for which health systems can strive and create tangible and objective criteria needed to achieve the formal designation.

A CALL TO ACTION: THE LEARNING HEALTH CARE NETWORK

In the context of COVID-19, it has become abundantly clear that public health agency surveillance alone is insufficient. An early analysis of the US response to this pandemic from *The New York Times* points to aging technology, a fractured public health reporting system, and pervasive miscommunication.[25] *The Times* succinctly and pointedly reports, "The technology was old, the data poor, the bureaucracy slow, the guidance confusing…The disconnect between hospital record-keeping systems, the [Centers for Disease Control and Prevention] and state and local public health departments delayed sharing critical information that could help patients." We should be able to rely on health care systems, not only to care for patients during public health emergencies but also to participate in an informed, national response.

With this situation in mind, we reimagine the LHS paradigm as a learning health network (LHN). The LHN builds on the framework of the LHS, which traditionally applies to individual organizations, by emphasizing communication, collaboration, and coordination among institutions.

The concept of such a network is not necessarily new. Mullins et al[26] proposed a transition from an LHS to a learning health care community (LHCC), which adds a fourth core element (to the original 3) of community engagement and participation. The learning health care community builds on the LHS by bringing into the fold underinsured or uninsured individuals to promote a more inclusive health care delivery system.[26] This is a step in

the right direction but falls short of creating a larger network that encompasses government agencies, especially those responsible for public health. In addition, Britto et al[27] previously described "learning networks" that have been formed to address health issues for targeted populations, specifically for pediatric and youth patients.

Our proposal of an LHN is novel in that it addresses a broader goal of public health and disease surveillance as a proactive effort against future pandemics and public health crises. To this end, the LHN can support the aforementioned continuous learning cycle of generating and interpreting data, planning and coordinating data-driven solutions, and implementing systematic responses, with each organization serving as one node of a larger, integrated system. The LHN should emphasize:

- the broad inclusion of diverse health care and community settings to address potential inequities (*inclusivity*);
- data sharing across organizations (*collaboration*);
- the development of solutions that can be implemented across organizations (*standardization and coordination*);
- leveraging existing resources, including the EHR, registries, and distributed data models (*efficiency*);
- rapid, agile, and proactive responses (*expediency*); and
- the patient's voice (*patient-centered*).

The development of an LHN is complex and will require much work to realize. Even when we are able to overcome barriers of data infrastructure, a supportive policy environment, and translating knowledge into action, the LHN presents issues of funding, governance, membership, and participation.

With regard to funding, we propose that the LHN may be funded by federal and/or state tax dollars as part of a larger initiative to build a more robust public health infrastructure in the United States. For governance, we envisage the LHN as a federated network that is governed by representatives from member organizations. The governing board would set criteria for participation in the network and regulations for data collection, sharing, and reporting. To facilitate data analytics across multiple systems, a universal common data model should be established, with one member organization elected by the governing board to serve as a data coordinating center.

Members of the LHN should comprise organizations with data infrastructure that allows for active data contribution, as well as those that are consumers of data. Data contributors, for example, may include health care delivery systems (especially individual "certified" LHSs) and public health agencies at the local, state, and federal level. Data consumers may include community-based organizations, such as patient advocacy groups, to ensure that the patient voice is represented, and social service agencies, which are uniquely prepared to address issues of housing and food insecurity in local communities, especially during times of crisis.

Lastly, with regard to participation, government agencies should be required to participate in the LHN, whereas private entities may require incentives. These incentives should ideally be set at the federal level. Large health care delivery systems with the necessary infrastructure to contribute data ought to be incentivized through certification as an LHS, as previously mentioned, and/or with implications for quality ratings and Centers for Medicare and Medicaid Services reimbursement rates. Smaller organizations, without the ability to contribute data, could be incentivized to participate with contracts to develop data infrastructure. Other organizations may be motivated to participate as consumers of the data, to the extent to which they stand to benefit from the information generated by the LHN.

CONCLUSION

In this commentary, we have advocated an LHN, drawing from the framework of the LHS, to establish a more coordinated and informed national response to public health emergencies like COVID-19. This pandemic has been and will continue to be an important test for the US health care system. We are at a crossroads for how we will respond to the next wave of COVID-19 and to future major pandemics. Will we heed this call to action?

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