

Lessons from Learning Health Care Systems and Recommendations for Successful Implementation



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About the Duke-Margolis Center for Health Policy

The Robert J. Margolis, MD, Center for Health Policy at Duke University is directed by Mark McClellan, MD, PhD, and brings together expertise from the Washington, DC, policy community, Duke University, and Duke Health to address the most pressing issues in health policy. The mission of Duke-Margolis is to improve health, health equity and the value of health care through practical, innovative, and evidence-based policy solutions. Duke-Margolis catalyzes Duke University's leading capabilities, including interdisciplinary academic research and capacity for education and engagement, to inform policymaking and implementation for better health and health care. For more information, visit healthpolicy.duke.edu.

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Executive Summary

The health care field continuously generates a large amount of real-world data, and the increasingly digitized nature of health care presents opportunities to leverage that data to actively drive iterative improvements in care practices. While the concept of “a learning health systems (LHS)” has been present for some time, broad implementation of learning health principles has fallen short of expectations. In this paper, we explore the current status of real-world data (RWD) use in a subset of U.S. health systems with the aim of gaining a clear understanding of the current state of implementing LHS enabled by real-world data. Additionally, we sought to identify current health system practices that involve collecting, acquiring, and leveraging real-world data to achieve systematic and intentional data collection and actionable evidence generation and implementation. Based on these findings, we provide recommendations pertaining to infrastructure development, supportive payment models, informed consent considerations, and workforce training needs.

How This Paper Was Developed

This paper draws upon insights from the 2022 Real-World Evidence (RWE) in Learning Health Systems workstream within the Duke-Margolis Center for Health Policy’s RWE Collaborative. The workstream aimed to identify opportunities for collaboration, coordination, consistency, and quality of RWD/RWE within a learning health care system. The workstream also sought to contribute subject matter expertise that may inform impending RWE regulatory guidance documents and frameworks, supplement a growing knowledge base based on a totality of lessons learned from demonstration projects and clinical trials, and foster opportunities to conduct broad studies at the point-of-care. Appendices A and B contain a list of 2022 Learning Health Systems workstream members and RWE Collaborative Advisory Group members who contributed their expertise to the development of this concept, study, and publication.

Introduction

The proliferation of both quantitative and qualitative real-world data (RWD) in routine health care delivery presents unparalleled opportunities for efficiently conducting health research and fostering real time learning. RWD encompasses information about patient health and health care delivery.¹ These insights are used to generate real-world evidence (RWE), which can provide evidentiary context for health care decision makers.² Unfortunately, only a fraction of RWD meeting abstracts and journal articles reach clinical audiences, but academic literature is not the only avenue by which RWE can reach care providers and other health system decision-makers.³ RWE derived from RWD collected within health systems and settings holds significant value for guiding both immediate and future health care decision-making. With the right balance of

resources, stakeholder engagement, and subject matter expertise, RWE has the propensity to promote a culture of ‘learning-by-doing’ across a broad range of health settings.

The Agency for Healthcare Research and Quality (AHRQ) defines a LHS as “a health system in which internal data and experience are systematically integrated with external evidence, and that knowledge is put into practice.”⁴ A LHS relies on sustained data collection and analytic methods to generate knowledge, engage relevant stakeholders, and implement changes that continuously improve system sustainability and patient outcomes.^{5,6,7} These systems can integrate internally and externally generated or acquired RWD to compile and implement actionable evidence across broad health system functions and operations (e.g., research,

quality assurance, care delivery, resource allocation, finance/billing, etc.).⁸

Real-world data is intrinsic to the development of LHSs because it serves as the lifeblood of these innovative health care frameworks. Diverse RWD sources such as electronic health records (EHRs), wearables, patient-reported information, and even genomic data, provide crucial insights into the effectiveness of treatments, patient populations, disease trends, and health care processes. This wealth of information empowers health care providers, administrators, and researchers to make evidence-based decisions, identify best practices, and adapt to evolving health care challenges. By being internal to the development of LHSs, real-world data not only enhances individual patient care but also contributes to the broader goal of advancing health care.

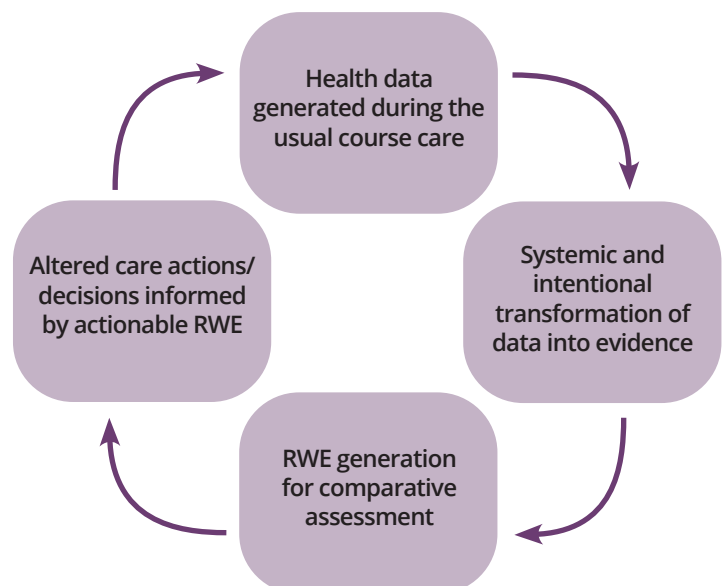
Currently, defining and mapping core milestones along a uniform pathway toward an RWE-enabled and -informed LHS presents challenges for several reasons. First, discordance exists in defining core LHS components across both the research literature across organizations. Additionally, the consistent use of RWE within health systems varies significantly due to the unique capabilities of each system and their identified mission and goals. Third, LHS principles and digital technologies that can enable their implementation (e.g., centralized platforms curating clinical evidence) have become more accessible in the past decade; however, the extent to which health systems have integrated these technologies is variable.^{9,10} While such variation might be predictable depending on a health system's geographic location, the patient population(s) being served, and finite levels of resources available, even predictable variation may not lend to a uniform pathway toward an RWE-enabled and -informed LHS.

Despite the lack of consensus in formally defining an LHS, extant research and expert commentaries are helpful in determining the current state of LHS implementation as it is enabled or informed by RWE. In fact, general takeaways can be gleaned from the literature, which include:

- Classifying an organization as an LHS relies on building knowledge and evidence that is usable for both immediate and future decision-making across operations and workflows—including, but not exclusively, health system quality improvement and patient/family engagement.^{11,12}
- Active patient communication and feedback loops play a crucial role in successful health system research, and research conducted at LHSs is often pragmatic (i.e., conducted at the point-of-care) and executed to provide actionable answers to precise questions.^{13,14}
- Reported RWE studies frequently involve secondary uses of RWD, which informs broader strategies and/or specific methods for leveraging RWD in research.¹⁵

Mechanisms for stakeholders to collect RWD, transform it into RWE, and act upon that RWE have been described in existing LHS frameworks. These frameworks illustrate a cyclical relationship across four pillars to address two synchronistic goals: 1) systematic and intentional data collection, and 2) actionable evidence generation and implementation (see **Figure 1**).

Figure 1: Cycle of Real-World Evidence Generation and Use Within a Learning Health System



Health systems continuously need state-of-the-art information and resources to inform decisive decision making.^{16,17} This process includes policy and regulatory efforts from the U. S. Food and Drug Administration (FDA), Centers for Medicare & Medicaid Services (CMS), and other federal agencies, that foster the groundwork for continuous learning among and across health systems.^{18,19,20} It also includes weighing patient input. If LHSs ultimately strive to improve patient outcomes, feedback loops monitoring continuous health system improvement must incorporate patients and caregivers as partners—not just sources of data. To contribute to LHS developments and efforts and maximize LHS benefits, establishing theoretical cohesion and progress towards standardized LHS principles is important. This effort includes a better understanding of what drives health system

operations, procedures, and guidelines, which help assess opportunities and shortcomings for LHS integration.

In this white paper, we report findings from a mixed methods study to explore how RWD and RWE are used to inform LHSs. Our study inquired about which RWD sources health systems collected and used to better understand how RWD can serve health system advancement and improvement. By engaging health system stakeholders and RWE Collaborative members, our primary goal was to understand the current state of RWD/E-enabled LHS implementation. Our secondary goal was to identify current health system practices that involve collecting, acquiring, and leveraging RWD infrastructure and resources for systematic and intentional data collection plus actionable evidence generation and implementation.

Study Methods

The LHS Workstream met monthly from April through July 2022 to level set on the current state of RWE implementation across LHSs. In addition to a concurrent landscape review of the state of play for LHSs, feedback and commentary from workstream discussions were used to inform the project methodology. Participants recruited for the study included clinicians and non-clinicians with oversight and/or engagement in health system data management and/or operations.

Study Phases

Study activities were completed in four phases including: (1) initiation; (2) survey distribution; (3) follow-up interviews; (4) analysis phase. The initiation phase for the study consisted of one-hour video calls during which the investigating team and pilot participants walked through the content of the quantitative survey questions, enabling participants to provide live feedback as they completed the pilot survey. After incorporating feedback collected during the pilot phase of the study into the final iteration of the survey (**Appendix C**), the study progressed to the survey distribution phase. The survey was

distributed to eligible participants using the platform Qualtrics. Eligible participants also were invited directly by email and personal referrals, including from members of the RWE Collaborative. The study relied on two primary recruitment methods across each phase of the study. The first entailed directly sending recruitment emails to individuals referred by members of the RWE Collaborative. Participants completed the survey anonymously online. Snowball sampling was used to identify and recruit additional survey participants. The subsequent study phase involved inviting (via email) all survey respondents to participate in follow-up interviews. Interviews were conducted subsequently with survey respondents who elected to participate. Follow-up interviews were conducted to capture contextual themes that corresponded with survey responses. The final study phase involved analyzing the qualitative and quantitative findings.

Sample Identification

Participants across each phase of the study were individuals 18-years-old or older that reside in the continental United States. The researchers

targeted a wide range of individuals who would be traditionally found employed within a health system, except for patients. Examples of health system participants that were targeted as part of the study include, but were not limited to: practitioners (e.g., doctors, nurses, etc.) researchers, administrators, and technical staff. The researchers also identified individuals classified as data informaticians, providers, and health system experts who currently work at health systems that self-identify as LHSs (per publicly available, online information). The second recruitment mechanism was snowball sampling, where respondents to the quantitative survey were prompted to identify individuals within or outside of their health system who may be appropriate for participation.

Survey and Interview Data Analysis

Quantitative survey results were analyzed by generating descriptive statistics within the Qualtrics XM platform.²¹ All survey questions were optional for respondents to answer and some questions were gated based on specific responses.

Analyses in this paper indicate the number of responses provided for individual questions. A copy of the survey can be found in **Appendix C**. Qualitative interview data were analyzed using a grounded theory approach. Two lead coders analyzed interview data using inductive data coding methodology and constant comparative analysis in accordance with the grounded theory approach.²² Deductive data coding was used to identify responses that could be categorized within themes identified in the literature and during LHS Workstream discussions. A third coder assessed interrater reliability and percent agreement among coders. The resulting codes were distilled into categorical themes, which which underwent extensive deliberation among the research team until strong (> 95 percent) agreement was reached.

Ethics Review

This study was reviewed and approved by the Duke University Institutional Review Board under protocol #2023-0135.

Survey Results

Overall Demographics

The total sample of survey participants included N = 21 health system representatives representing or serving patients within all 50 states in the U.S. as well as U.S. subdivisions and territories (e.g., Puerto Rico). Most participants represented health systems located in the Southwestern U.S., with the largest proportion headquartered in Texas (n = 11). Most participants represented nonprofit health systems (n = 19; 90 percent). When asked to select all that apply, respondents predominantly identified their health systems as academic medical centers (n = 12; 57 percent) rather than nonacademic medical centers (n = 8; 38 percent), or Federally Qualified Health Centers (n = 2; 10 percent). In addition to these settings, the sample also includes respondents representing community clinic networks, faith-based nonprofit medical centers, and integrated health systems. The majority of respondents identified themselves

as executive leaders at their health systems (n = 13; 62 percent), followed by researchers (n = 10; 48 percent), care providers (n = 5; 24 percent), health administrators (n = 3; 14 percent), and informaticians (n = 1; 5 percent).

When asked about tenure, the majority of respondents indicated having worked within their health system for one to five years (n = 7; 33 percent), with the remainder reporting six to 10 years (n = 5; 29 percent), 11 to 15 years (n = 5; 24 percent), 21 or more years (n = 2; 10 percent), 16 to 20 years (n = 0; 0 percent), and less than one year (n = 1; 5 percent). Respondents reported a wide range of practice settings that are directly impacted by their work duties, including significant representation across primary care, inpatient, and specialty care settings. Respondents also reported influence across a number of ancillary clinic settings including mobile care units, hospice care, and home-based care services.

General Data Practices

The consensus among the majority of respondents (n = 19; 95 percent) was that their health care system actively collects a broad spectrum of data pertaining to care and service quality. In contrast, a solitary respondent (n = 1; 5 percent) held a different view. Regarding the use of data for improving care and service quality, the majority of respondents indicated that their health system currently integrates information about care and service quality for the purposes of improving overall system functioning, with (n = 12; 60 percent) indicating strong agreement with the statement and (n = 6; 30 percent) reporting general agreement. One of the respondents (n = 1; 5 percent) was neutral.

Survey respondents generally agreed with a statement (n = 17; 85 percent) that their health system has processes for collecting feedback directly from employees for shaping data processes. However, a small subset (n = 3; 15 percent) indicated that their health system currently does not have a mechanism. A breakdown of these responses can be found in **Figure 2**. The majority of respondents generally agreed that their health system currently compares its data on care and service quality with data from other health systems (n = 15; 83 percent). A small minority of respondents were either neutral (n = 1; 6 percent) or disagreed with this statement (n = 2; 11 percent). All respondents reported that their health system uses quality benchmarks to evaluate quality improvement (n = 17; 100 percent). Respondents largely agreed with a statement indicating that their health system uses data on care outcomes for compensation-related decision-making (n = 14; 74 percent). However, a small subset of respondents reported being neutral (n = 2; 11 percent) or disagreeing (n = 1; 5 percent) with the statement.

Health System Leadership

Responses across health systems indicated that health care provider leadership is personally involved in quality improvement efforts (n = 19; 95 percent). Respondents also generally reported that executives seek suggestions and information on needs for quality improvement from external customers, including patients and families (n = 15; 75 percent), with a small subset reporting being neutral (n = 2; 10 percent) or disagreeing with the statement (n=3; 15 percent). Most survey respondents indicated that the leadership within their health care systems have articulated a clear vision for the improvement of care and service quality (n = 16; 80 percent).

Patient Safety

The majority of respondents indicated (see **Figure 3**) that their health system routinely collects patient safety information (n = 16; 89 percent), and routinely uses this information to improve clinic operating procedures (n = 15; 88 percent). A small minority of participants indicated that their health system does not collect patient safety data (n = 1; 6 percent) or use this data to improve clinical operating procedures (n = 1; 6 percent). Similarly, most respondents (n = 16; 89 percent) indicated that their health system uses patient safety data to improve clinic services, and a small minority of respondents reported that their health system does not use (n = 1; 6 percent) data about patient safety to inform clinical services. In line with these trends, respondents broadly indicated that their health systems use adverse event reporting systems (n = 16; 94 percent) and that adverse clinical events data are used to improve clinical operating procedures (n = 14; 87 percent).

Figure 2: Respondent Level of Agreement with Statement Indicating Health System Collects Feedback from Employees that Shapes Data Practices (n = 17)

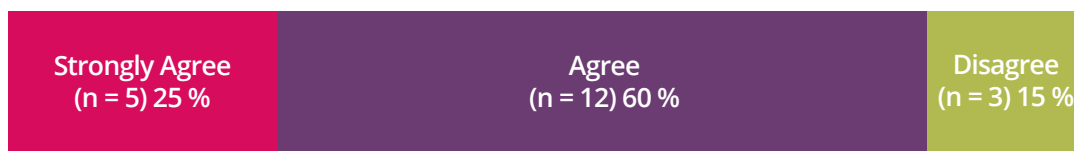
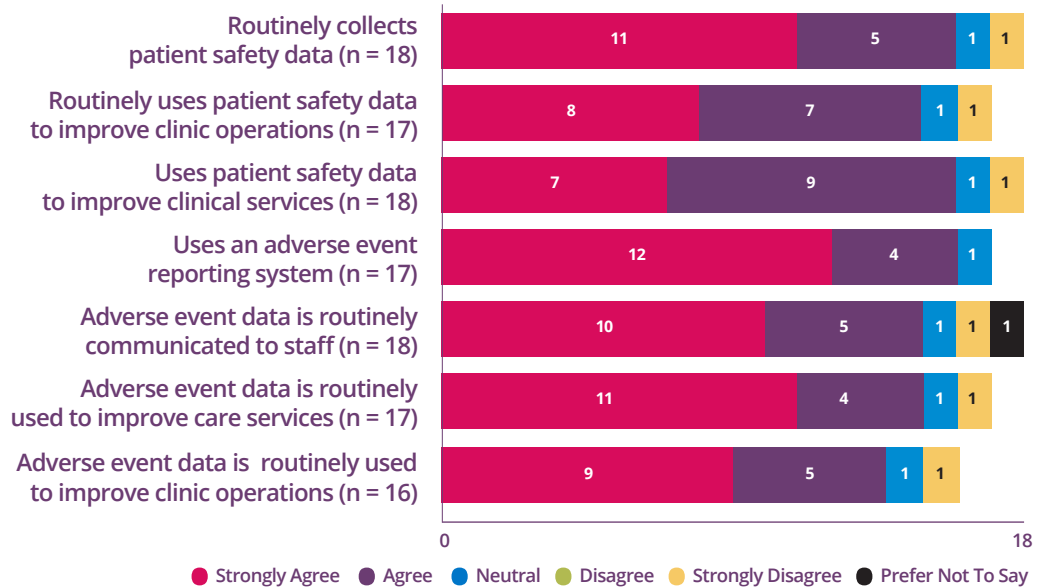


Figure 3: Respondent Level of Agreement with Statements on Health System and Patient Safety Data Collection Activities



Electronic Health Record Utilization

All respondents (n = 20; 100 percent) reported that their health system currently uses an electronic health record (EHR) system. The majority of respondents reported that their health system currently uses Epic as a service provider (n = 19; 95%), followed by Cerner (n = 4; 20 percent), MEDITECH (n = 3; 15 percent), Allscripts (n = 3; 15 percent), GE Healthcare (n = 2; 10 percent) and EClinicalWorks (n = 2; 10 percent) and athenahealth (n = 1; 5 percent).

Respondents reporting EHR utilization (n = 20) indicated that the EHR system currently used by their health system is partially linked across clinics/sites (n = 4; 100 percent). The majority of respondents indicated that the EHR(s) used by their health system uses clinical decision support tools (n = 16; 80 percent) to inform care delivery. A small subset of respondents reported being unsure (n = 3; 15 percent) about whether the EHRs used by their health system uses clinical decision support tools, and (n = 1; 5 percent) reported that the EHRs used by their health system did not have clinical decision support tools.

Regarding the use of EHR data for patient care delivery, the most frequently cited care domains

endorsed within the survey are summarized in **Table 1** (n = 16). All respondents (100 percent) reported using EHR data to support diagnostic and therapeutic decision making, as well as to access and document patient information. Respondents reported using EHR data to obtain patient feedback about care experiences at least frequently (38 percent).

Table 1: Health System Uses of EHR Data to Inform Patient Care Delivery (n = 16)

Supporting diagnostic and therapeutic decision making	100%
Accessing and documenting patient information	100%
Accessing and using clinical support tools	88%
Providing clinical alerts and reminders to patients	88%
Prescribing treatments and follow-up regimes	88%
Communicating with colleagues about matters related to patient care	88%
Accessing or creating aggregated information about patient outcomes	81%
Distributing and/or obtaining questionnaires or measures	69%
Accessing and searching medical literature	56%
Obtaining feedback about care experiences from patients	38%
Other/Unspecified	13%

Nearly all respondents (n = 17; 85 percent) indicated that their health system uses EHR data for purposes beyond delivering patient care. Respondents reported that the most routine uses for EHR data outside of patient care domains were for financial and operational management and quality improvement. Responses suggested that EHR data also were frequently used for quality improvement and patient safety reporting and monitoring purposes. Regarding respondents' impressions of how their health systems plan to expand the use of EHR data in the future, a wide range of uses were reported including:

- System-wide quality improvement efforts (e.g., improved system integration and analytic capabilities) (n = 3)
- Clinical research expansion efforts (n = 2)
- Improving care delivery (n = 2)
- Participation in research-based collaboratives (n = 1)
- Initiating data standardization efforts (n = 1)
- Expansion of data warehouse capabilities (n = 1)
- Improved Centralized Device and Services Support (CDSS) (n = 1)
- Expanding data analytic capabilities in specialty care (n = 1)
- Improving clinical decision support tools (n = 1)

Claims Data Utilization

Respondents reported that the largest sources of claims data used by their health system included Medicare, private health insurance companies, and Medicaid. Other private health insurance companies and public health insurance companies also were identified as frequent sources of claims data. The majority of respondents reported that claims data is currently used to inform patient care delivery within their health system (n = 12; 60 percent). Study participants reported that the patient care domains where claims data is most frequently used include:

- Examining patient outcomes,
- Evaluating care quality, and
- Facilitating the use of predictive analytics

Additionally, survey respondents reported that claims data usage at their health systems include cost comparison across health systems and evaluation of quality and operational management.

Relatedly, most survey respondents (n = 14; 70 percent) reported that their health system uses claims data for purposes beyond patient care delivery. A small subset of respondents reported uncertainty about whether their health system uses claims data for purposes beyond patient care delivery (n = 5; 25 percent), with the smallest minority (n = 1; 5 percent) indicating that their health system did not use claims data for purposes beyond patient care delivery. Beyond patient care delivery, survey respondents indicated that the most routine usage of claims data at their health systems was for financial and operational management purposes. Results also indicated that claims data were frequently used for clinical research and quality improvement purposes. Regarding plans for expanding the use of claims data within the next year, a small subset of respondents reported plans to explore the availability of broader claims data sources (n = 1), to increase the number of patients and payers with which the health system currently interacts (n = 1), and to track performance and evaluation (n = 1).

Alternate Data Source Utilization

In addition to claims and EHR data, survey respondents reported that their health systems used a wide array of alternate data sources. The most frequently cited included laboratory data (n = 20; 100 percent), patient-reported outcome data (n = 15; 75 percent), and registry data (n = 16; 80 percent). A subset of respondents also noted frequent use of retail prescription history data (n = 9; 45 percent), patient generated data from devices (n = 13; 65 percent), and genomic data (n = 6; 30 percent).

Respondents largely reported that these data sources (registry data, laboratory data, and patient-reported outcome data) were used often for clinical research purposes by their health systems. Survey responses indicated periodic use of data from patient-reported outcomes, registries, consumers, retail prescribing, and genomics for financial

and operational management purposes. A small minority of respondents noted routine use of data from labs, patient-reported outcomes, and retail prescription histories for financial and operational management purposes. Responses suggested that a subset of health systems represented within the survey periodically use laboratory data for patient safety monitoring purposes. A small minority of respondents also reported frequent use of laboratory data, patient-reported outcomes, patient-generated data from other devices, and consumer-generated data.

Regarding plans for expanding the use of additional data sources, a notable proportion of respondents

reported that their health systems plan to expand the use of registry data, laboratory data, patient reported-outcome data, and patient-generated data from devices. Regarding plans for expanding the use of the additional data sources, respondents provided a diverse array of responses, including plans for including patient-reported outcomes (n = 1), plans to include patient generated data from devices (n = 1), expanding the use of registry data (n = 1), incorporating artificial intelligence and machine learning techniques to analyze unstructured data (n = 1), and expanding the use of laboratory data (n = 1).

Follow-Up Interview Results

Overall Participant Characteristics

A total of (n = 5) health system representatives participated in follow-up interviews. Seven emergent themes were identified based on follow-up interviewee responses, which are discussed below and illuminated with quotes. The quotes included below have been lightly edited for clarity. An overview of identified themes is included below.

- Data and metrics utilization
- Engagement in external collaborative partnerships
- Data source selection
- Incentives determination
- Advance organizational culture
- Strategic planning
- Respond to internal and external barriers to implementation

Theme 1: Data and Metrics Utilization

A LHS involves the continual integration of available data and metrics to achieve predetermined goals or benchmarks identified by a health system. Within our sample, common applications emerged for addressing patient, process, and research needs. Respondents indicated that they routinely used data to evaluate patient outcomes, behavior, treatment, and experiences. Data also were leveraged to inform or implement quality improvement efforts and initiatives. Responses also indicated emerging efforts to integrate disparate internal and external data sources for supporting new areas of empirical inquiry or identify intervention targets relevant to patient outcomes.

“Every day, we’re pulling data to help drive those conversations and those systematic improvement efforts. And then I would say, research questions are probably lower tier, we’re trying to use it rather than extant data collection. But I would say, just the nature of us as a primary mission is care delivery, so, we use the datasets primarily to inform our operations.”

Theme 2: Engagement in External Collaborative Partnerships

A key strategy for successfully scaling a LHS is pursuing external partnerships with groups and organizations with the resources or know-how to support broader data access or analytic capabilities for the health system. Additionally, partnerships with groups like external health systems, health adjacent services (e.g., pharmacies), research organizations, and data analytic companies also were identified as partnerships that assisted with building a LHS. Health systems also identified partnerships with government agencies and external funding sources as beneficial for improving LHS processes and overall execution.

“Social determinants of health, also regional registries that are by zip code give us insight into socio economics and immunization data we utilize, and we also have some agreements with other collaborators like [redacted]. We get all of our patients and our registries immunization data directly from [redacted] and download it into our EHR.”

Theme 3: Data Source Selection

LHSs are driven by a variety of real-world data sources. Stakeholders reported several strengths and weaknesses associated with frequently used data sources that include electronic health record data, registry data, data from wearables, claims data, patient-reported data, and data from external sources (e.g., government agencies, pharmacies, external health systems). Strengths that were frequently outlined across data sources included: the proliferation of up-to-date real time insights, the ability to extract longitudinal insights, and the ability to generate large representative sample sizes. Limitations included: data fragmentation due to challenges with interoperability, concerns about data quality and fitness for purpose, and concerns about patient privacy. Despite the limitations associated with each of these data sources, health systems acknowledged the key contributions they make to achieving LHS goals.

“The EHR records can be useful, but it’s a pretty heavy lift. And that is the result of issues around trying to develop data standard[s], then implementing data standards within the EHR, and because we’re a federated system and have [a] substantial number of EHRs.”

Theme 4: Incentive Determination

Identifying and implementing incentives is a key strategy for garnering buy-in and encouraging alignment at various levels of a health system seeking to adopt LHS principles. Health systems sampled identified key internal stakeholders to incentivize, including care providers and individuals across various levels of the health system leadership structure.

“But I think people are very skeptical. And they need a demonstration of this in real life. Because I think, senior executives, you’re used to hearing from everybody about whatever they’re invested in, like this is going to yield ROI in some way or other. And, in cases where it’s pretty clear, that that’s going to be the case in terms of dollars and cents, why that’s an easier case to make. But I think some of it is demonstrating that value, creating these use cases for value, bringing those forward and saying this is what research is, applying these principles to a program that shows that we actually got from a solution that we’ve proposed, we’ve got the results, and being able to demonstrate that in pretty clear terms.”

Theme 5: Incentive Determination

Although individual health system operational practices and goals vary, integrating LHS principles requires an organizational culture that supports routine feedback and open communication across all levels and departments, aligned mission priorities, and supportive leadership willing to drive change.

“I tell you why it works with physicians—all this data sharing—is because we share it in a certain way. So, in every practice, we have all our practices broken down to large, medium, and small, and we show them the aggregate how the [redacted] is doing. And then if you’re a large practice, we show your practice compared to all the others. So you can compare your practice to all the others. And then on the next, we compare all the doctors in that practice with your name under your data very transparently. So, it works because they’re very competitive.”

Theme 6: Strategic Planning

Advancing the adoption of LHS principles within a health system requires a clearly defined mission that informs both short- and long-term strategic planning. Health systems within our sample described routine processes for defining and communicating short- and long-term goals across various levels within the health system and suggested policy changes that may assist with advancing the widespread adoption of LHS principles.

“Every single month, we strategically decide what are we going to work on. What data are we sharing with the physicians at the practice and at the physician level? In that practice, we have a calendar of, okay, we’re going to focus on IDI utilization, we’re going to focus on quality, we’re going to focus on how you’re coding for your HCC and route scoring...We share data on whatever our focus area is each month with the physicians.”

Theme 7: Respond to Internal and External Barriers to Implementation

Across thematic areas, health systems identified several barriers as well as facilitators to developing LHS capacity and implementing LHS principles. Examples of these barriers included the current structure and format of funding mechanisms that support health and health system research, lack of personnel with training in research and statistical methods within many health systems, and limited understanding of health system operations and implementation science. Examples of facilitators included pursuing partnerships with institutions that have the capacity to provide research or administrative support and leveraging existing internal data sources for new areas of inquiry.

“I think it’s promote that workforce development and really highlight the need for it as the gap because again, this is a learning health system, it’s not a project, it’s not something you do and you finish it in six weeks, it really needs to become how you operate in your daily business. And to do that, we need to have a workforce that thinks like that.”

Discussion

This mixed-method study evaluated the current LHS landscape by gathering perspectives from diverse stakeholders, including health system leadership, care providers, and health care data infrastructure sectors across the U.S., and U.S. subdivisions and territories (e.g., Puerto Rico). Respondents reported various data uses and practices, with laboratory data, patient-reported outcome data, and registry data emerging as the most prominent. These data served multiple purposes, including improving patient safety, driving care delivery, and informing health system quality improvement efforts. Consistent with prior literature, respondents emphasized that the overarching goal of LHS implementation is to access and leverage past lessons and insights collected from internal and external data sources for short-, medium-, and long-term planning. Several core elements emerged as either key barriers or facilitators to LHS implementation. While many factors pertained to internal health system resources, processes, and practices, some barriers were related to broader policies, laws, and regulations governing data collection, storage, and use.

Although the findings from this study contribute significantly to the understanding of core LHS principles, several important limitations require acknowledgement. First, the generalizability of study findings may be limited due to the small sample sizes and selection bias within both the quantitative and qualitative portions of the study. The sole representation of health systems within the U.S. and U.S. territories further limits

the generalizability of study findings. Therefore, the insights obtained from the study may not be generalizable to health systems across the U.S. and globally. Additionally, the cross-sectional nature of the study means that these insights provide a snapshot of the current LHS landscape from the perspectives of the sampled health systems and may not be representative of all time periods and contexts. Nevertheless, this study possesses several strengths that are important to note.

Participants in the study represented health systems serving all 50 U.S. states, along with other U.S. subdivisions and territories, providing valuable insights into LHS implementation across the United States. The mixed method approach captured practical and contextual aspects of LHS implementation from a diverse range of stakeholder groups (e.g., providers, administrators, informaticians, etc.) with nuanced understandings of current barriers and facilitators for LHS implementation across disparate health systems and settings. Additionally, the study highlighted the pivotal role that real-world data (e.g., EHR data, registry data) plays in LHS implementation and scaling by revealing the types of data used by health systems in the sample, and the role this data plays in improving safety, and setting priorities. These preliminary but practical insights contribute to the broader movement of cultivating new and current health system efforts leveraging RWD/E for continuous learning and health system research. Likewise, insights described in **Table 1** show opportunities to maximize the potential of EHRs to inform patient care delivery within a LHS.

Data Infrastructure and Interoperability

Respondents stressed that RWD and RWE should be easy to enter, store, and query across multiple compatible platforms. Policies should incentivize interoperability among health care datasets, promote widely understood and applicable data processes, and facilitates a data infrastructure that supports widespread LHS

adoption. Currently, even singular health systems can suffer from interoperability challenges due to the use of differing EHRs and registries. Meanwhile, common processes for curating RWD are still being debated in larger RWE discussions on data quality, validity, transparency, etc. Many parts of the health system landscape are still building data

infrastructure, presenting an opportunity to design systems with interoperability and enhanced data sharing capabilities in mind. Resources such as the Healthcare Information and Management Systems Society Electronic Medical Record Adoption Model (EMRAM) maturity model and related offerings provide a useful starting point for health systems to assess their current capacity.²³

Many parts of the health system landscape are still building data infrastructure, presenting an opportunity to design systems with interoperability and enhanced data sharing capabilities in mind.

Participants generally agreed that their health system has processes for collecting feedback from employees to shape health data protocols. Since EHRs appeared to be the foremost source of patient data for health systems, they may be an ideal starting point for reforming processes and building upon existing infrastructure. This opportunity is especially apparent as individual health systems indicated broad access to data throughout the organization through linkage and interoperability across health system sites. Health systems, that are similar to those sampled, can incorporate EHR lessons as they expand use of registry data, lab data, patient-reported outcomes, and patient-generated health data from devices.

In addition to individual and health system perspectives provided in surveys and interviews, experts have posited key barriers to embedding pragmatic trials, and resultant learnings, into health system procedures. A primary barrier is data system design. The current data infrastructure prioritizes billing and reimbursement over evidence generation, a sentiment echoed in the study results. Despite known challenges of turning real-world data into decision-grade evidence, interviews indicated that LHSs are built on RWD, making data infrastructure paramount for LHS implementation. Individual health systems could be an ideal place to begin building sophisticated infrastructure that encourages data sharing. Evidence generation may need to be spearheaded

by private partners, as federal and state agencies lack universal health schemes that aggregate data uniformly. Data infrastructure decision-makers must start by identifying which types of data are siloed and why, and lead coordinated efforts with providers and others across their health systems to standardize processes and reconcile methods and resources to enhance efficiency. This effort requires cooperation and buy-in across the health system. Leadership and external partners should be engaged to share perspectives on perspectives on available resources and how they can make the health system's job easier and produce more desirable outcomes. Furthermore, health system information technology (IT) and data scientists should understand the EHR and software landscape and choose platforms offering universality and customization for different stakeholders.

What will incentivize providers within the health systems to use the platforms? IT staff will need dedicated resources to conduct comprehensive reviews to identify the changes that will propel the health system forward. Likewise, providers will need to utilize the data infrastructure and procedures available to them for gathering RWD that can be transformed for learning. Incentives like salary bonuses and fostering positive, internal, inter-, and intra-departmental competition could encourage LHS infrastructure adoption. Intuitive patient portals that allow reporting and auditing of health information can widen the information available for care decision-making. Still, patients must be informed of interoperability's upside and of the legal structures that make them the ultimate decider of whether to allow the collection of and access to their data.

New legal avenues have, advanced the interoperability of patient data interoperability and intentional data integration. The 21st Century Cures Act has spawned new rules (e.g., CMS-9115-F) that mandate greater provider and patient access to data.²⁴ Health systems and data companies must make a patient's data easily transferable as the patient desires. Government efforts to push interoperability and enable data movement (while ensuring Health Insurance Portability and Accountability Act compliance) will advance the

ability of health systems to incorporate information beyond the traditional doctor's notes and EHR. For example, the Medicare Promoting Interoperability Program uses a point system to evaluate health system adherence to EHR rules and embrace of new technologies.²⁵ Additionally, the Office of the National Coordinator for Health IT (ONC),

within the U.S. Department of Health and Human Services is driving work to establish standardized sets of data elements to enable increased interoperability through the United States Core Data for Interoperability (USCDI) initiative.²⁶

Fostering Partnerships Between Stakeholders at the Intersection of Health Systems

While LHSs can operate independently, significant potential exists for health systems to collaboratively generate evidence. When multiple systems aim to address the same question, pooling resources and expertise can reduce redundancy and provide larger datasets for analysis.

During the COVID-19 pandemic, some providers hesitated to prescribe therapeutic treatments like molnupiravir because they found it difficult to decipher the complex pharmacology.²⁷ Pharmacists played a crucial role in assisting, but logistical issues arose while trying to coordinate within a short three-day treatment window.²⁸ The government was able to facilitate partnership during the public health emergency, but liability and reimbursement is an issue for pharmacists whose expertise goes untapped in many cases. Creating systems that allow pharmacies to continuously access patient data and for providers to learn from pharmacist decision-making will allow patients to experience the strengths of both organizations more seamlessly. Prescription drug monitoring programs (PDMPs) have been created to monitor controlled substance prescriptions within states.²⁹ State governments could build upon these surveillance systems to share greater EHR data with pharmacists. This data sharing could help monitor adverse events and misused medications as well as identify outcome patterns that may otherwise go unreported when patient data is siloed between pharmacies and hospitals.

Government partners also emerged as valuable external funding sources that support health system pursuits. One example is government-managed databases (e.g., national registries),

which health systems can access to supplement internally generated data. Further focusing on health system-level actions, partnerships with data analytic companies can bolster a LHS's ability to analyze all the data that partnerships and improvements in data infrastructure will yield. A consistent barrier to LHS advancement indicated by individual health system leaders, and reflected in the survey, is a lack of expertise. Forming partnerships with data curators and experts will ease some of the burden placed on health system staff who face a steep learning curve to maximizing their data's evidence potential.

Forming partnerships with data curators and experts will ease some of the burden placed on health system staff who face a steep learning curve to maximizing their data's evidence potential.

Within the present study, health systems noted the benefit of partnering with businesses and systems that operate in tandem with or adjacent to health systems, including pharmacies and dialysis centers. Partnerships with these organizations provided expanded opportunities to get comprehensive and timely insights into patients' health care status (e.g., compliance with medication), and health-related social needs. Respondents also noted expanded opportunities to leverage these partnerships to improve patient outcomes by coordinating care services with partners. For example, by partnering with a local pharmacy, one health system was able to coordinate with the pharmacy team to

print reminders for recommended preventative care services and primary care appointments on the documents patients received with their medications. These proactive measures spotlight

the potential benefits associated with seamlessly integrating health care delivery across the health delivery landscape.

Payment models that support robust data collection

LHSs rely on data to function. If robust data are not available, systems will have a harder time making timely, meaningful, and accurate decisions. Therefore, systems must collect robust data on patient visits in the EHR as well as in any parallel data workflows. As noted above, a key element to achieving robust data collection is a well-designed, easy to use data infrastructure that reduces/mitigates provider administrative burden. Another issue revolves around the lack of payment models that support robust data collection. Some ACOs are successfully incorporating learning health approaches by including incentives to participating providers based on performance metrics.³⁰ Additional efforts are needed to inform and create payment and care models that iterate on these successful approaches. Relatedly, further consideration should be given to incentivizing the collection of data elements related to social determinants of health, as the inclusion of this information into LHS approaches will assist with facilitating more equitable allocation of resources and the prioritization of health issues most impacting served communities.

Literature has pointed out that economic disincentives have the propensity to hinder the widespread adoption of LHS principles.³¹ While these concerns were not explicitly reported in

this study, they bear consideration. EHR vendors, stakeholders whose technology upon which LHSs depend, may not have reason to coordinate with competitors. Creating interoperable products promotes market sharing, which is less economically enticing than aiming for market dominance. Similarly, the current regulatory and business landscape incentivizes health systems to make their data scarce and sell it to third parties. Individual organizations can ensure profit through monetizing data, but freely sharing their data to facilitate long-term learning does not offer the same prospects. LHS proponents must be able to counter the existing disincentives—especially for health system leadership who make strategic decisions.

One studied health system was able to detail how applying LHS principles contributed to better, well-recorded outcomes, which led to organizational savings from CMS. The health system further detailed how providers are galvanized to use LHS principles to achieve cost-saving metrics. By fostering outcome competition within the health system and implementing shared savings programs for providers whose outcomes metrics generate savings, providers are driven to help save the organization money. Achieving financial through these programs can provide alternative incentives for how health systems use and share their RWD.

Informed consent in LHSs

As more health data is created and leveraged for a wider range of decision making, it is important that patients know how their data is being used. As learning health concepts proliferate, health systems have an obligation to share enough information for patients to make informed

decisions, even in circumstances where informed consent might not be required. Patient navigators or additional educational resources should be present to facilitate educating patients and their caregivers about how their data is used within a health system to make decisions that

might impact care, particularly beyond the visit in question. Data infrastructure should be set up to allow easy implementation of opt-out preferences.

Even with these pieces in place, ethical questions remain about how to obtain informed consent ethically and adequately from patients, especially when many data and technology companies that are driving the advancement of RWD are not

always subject to the same regulations and best practices as organizations directly providing health care. While gray areas will always exist, leaving ethical discussions around RWD sharing and use unresolved will further discourage participation among patients/caregivers.³² Therefore, addressing their concerns is vital to achieve continual LHS feedback and improvement.

Training support and workforce development

As uses of real-world data and evidence become more complex and integrated, training for current and new staff will have to adapt. As noted through our interviews, many providers and health system staff do not receive in-depth training on implementation science, systems operations, statistics, health applications of artificial intelligence, and other disciplines that will drive the increased use of LHS principles. This lack of training means new approaches are slowly and insufficiently adopted limiting the potential expansion of LHS concepts. While deep expertise in these disciplines is unnecessary and overly burdensome to achieve, provider and support staff education and training should adapt to

cover vital core concepts within these areas for the advancement of LHS principles, including in undergraduate health-related programs all the way to graduate and medical school training.

Though much of the burden for workforce development will fall on training and degree program curricula, the National Institutes of Health and other federal funding agencies could support training grants built around increasing competency in these core concepts and provide a model for other training opportunities. Continuing education programs likewise should provide opportunities for in-depth training to advance LHS adoption.

Building a Culture of Learning

Health systems seeking to support a culture of learning therein must consider present burdens and stressors experienced among providers and other patient caregivers, administrators, and staff supporting health system operations. Entering data into EHRs in a robust and complete manner can be a time-consuming task. Placing that burden on providers without providing additional support will cripple efforts to advance LHSs before they can truly begin by leaving systems with data that is of insufficient quality to drive decision making. Health systems, and those that might fund or provide support to them, should consider opportunities to incentivize data collection by providers as well as offer assistance whether through support staff or new digital tools driven

by artificial intelligence. Such tools present their own challenges, which must be carefully considered before adoption.

Furthermore, as our findings noted, learning health principles that are established must include a cultural reset within health care systems. LHS cultures should embody a clear mission and vision championed by all health system stakeholders and driven by leadership to deliver evidence-informed care that achieves sustainable practices toward patient wellness and health system operations. This culture should include, at minimum, addressing burnout among health care providers using evidence-generating and -based solutions (see **Table 2**).

Table 2: Current Health System Challenges and Potential Solutions to Support a Culture of Learning

Current Health System Challenge	Potential Strategies to Support a Culture of Learning Collaboratively with Health Systems
Siloed data within health systems and lack of interoperability between internal health system data platforms.	<ul style="list-style-type: none"> • Begin with the EHRs. Evaluate each EHR's individual interoperability and customization capabilities and look to maturity models, such as EMRAM, to guide interoperability development. • Revise and/or create system-wide methods and standards for collecting and storing data.
Siloed data and lack of interoperability across health systems—low compliance with new data transferability mandates.	<ul style="list-style-type: none"> • Engage with government programs (e.g., Medicare Promoting Interoperability Program) to incentivize and benefit from interoperability compliance. • Design more intuitive patient portals that allow patients to easily and independently access and transfer their data.
Insufficient sample size and completeness of patient data—specifically regarding demographics.	<ul style="list-style-type: none"> • Link external, local health care registries that track socioeconomic and social determinants of health data. • Apply to participate in funded research (e.g., government grants) that helps build data collection infrastructure and connects health systems to other data repositories.
Low patient buy-in and participation in evidence generation.	<ul style="list-style-type: none"> • Incorporate patient voices and perspectives from the beginning of LHS development. • Ensure patients understand which of their data is being collected, for which purposes, and what is the governance/ownership structure.
Low provider engagement in efforts to leverage RWE to support health system decision-making.	<ul style="list-style-type: none"> • Collect comprehensive patient-reported outcomes for departments that may lack either internal or external data linkages to show impact. • Foster competition by rewarding better patient outcomes with increased shared savings bonuses.
Low patient engagement in obtaining health goods and services with external providers (e.g., pharmacy).	<ul style="list-style-type: none"> • Partner with external organizations to continuously link specific data on patient health status (e.g., link pharmacy refill schedules across patient, pharmacy, and prescriber).
Lack of staff with data informatics expertise to make use of the RWD collected.	<ul style="list-style-type: none"> • Partner with data curating firms, academic systems, and consortia that inform and train new and veteran staff in new principles and have participating staff educate their health system colleagues in turn. • Incorporate LHS principles and data analytics into curricula to educate students who will become care providers and health care administrators.
Administrative and time burden on providers entering data into EHRs.	<ul style="list-style-type: none"> • Support sustainable uses of infrastructure and digital tools, including wearable devices, to enable easier collection of patient data. • Hire support staff or incorporate new digital tools to manage provider burnout while still collecting complete data.

Conclusion

Efforts remain underway to support the notion and practice of leveraging RWE to achieve a culture of learning within and across health systems. Though many health systems are making efforts to become learning systems, our landscape assessment of health system practices shows that specific organizational, interpersonal, and structural elements are critical to achieve this goal. Such elements include a robust data infrastructure built on internal and external interoperability, a culture that prioritizes research and learning, and incentives that encourage sustainability. Federal agencies, policymakers, and other RWE policy stakeholders must strive to meet health systems where they are in their LHS journey to support these efforts.

Appendix A: Duke-Margolis RWE Collaborative 2022 Advisory Group Members

This paper was informed by the expert collaborators in the Duke-Margolis Real-World Evidence Collaborative Advisory Group. We thank the members of the Advisory Group, especially those from the 2022 cohort, for informing the development of this paper. The following list reflects the 2022 Advisory Group roster, which advised on the initial development of this work stream.

Listed 2022 member affiliations may not reflect current affiliations. For a current roster of the Duke Margolis Real-World Evidence Collaborative's Advisory Group, please visit the RWE Collaborative [page](#) on the Duke-Margolis Center for Health Policy [website](#).

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Appendix C: Learning Health Care Systems Survey

Section 1: Learning Health Care Systems

Learning health systems (LHS) are health systems that use sustained data collection and analytic methods to generate knowledge, engage relevant stakeholders, and implement changes that improve system sustainability and patient outcomes. To better understand how health systems are integrating the principles of a LHS into clinical practice, the Duke Margolis Real-World Evidence Collaborative's Learning Health Care Systems (RWECLHS) workstream is distributing this survey to representatives across health systems. Responses from the survey will inform a maturity model that outlines essential components of an LHS, provide a benchmark for evaluating and guiding health systems that want to incorporate core LHS principles, and inform key policy recommendations. We ask that you answer these questions to the best of your knowledge. The survey is

1) Please select the U.S. territories that your health system operates in. (Select all that apply.)

- | | | | |
|---|--|---|---|
| <input type="checkbox"/> Alabama | <input type="checkbox"/> Indiana | <input type="checkbox"/> Nevada | <input type="checkbox"/> South Dakota |
| <input type="checkbox"/> Alaska | <input type="checkbox"/> Iowa | <input type="checkbox"/> New Hampshire | <input type="checkbox"/> Tennessee |
| <input type="checkbox"/> Arizona | <input type="checkbox"/> Kansas | <input type="checkbox"/> New Jersey | <input type="checkbox"/> Texas |
| <input type="checkbox"/> Arkansas | <input type="checkbox"/> Kentucky | <input type="checkbox"/> New Mexico | <input type="checkbox"/> Utah |
| <input type="checkbox"/> California | <input type="checkbox"/> Louisiana | <input type="checkbox"/> New York | <input type="checkbox"/> Vermont |
| <input type="checkbox"/> Colorado | <input type="checkbox"/> Maine | <input type="checkbox"/> North Carolina | <input type="checkbox"/> Virginia |
| <input type="checkbox"/> Connecticut | <input type="checkbox"/> Maryland | <input type="checkbox"/> North Dakota | <input type="checkbox"/> Washington |
| <input type="checkbox"/> Delaware | <input type="checkbox"/> Massachusetts | <input type="checkbox"/> Ohio | <input type="checkbox"/> West Virginia |
| <input type="checkbox"/> District of Columbia | <input type="checkbox"/> Michigan | <input type="checkbox"/> Oklahoma | <input type="checkbox"/> Wisconsin |
| <input type="checkbox"/> Florida | <input type="checkbox"/> Minnesota | <input type="checkbox"/> Oregon | <input type="checkbox"/> Wyoming |
| <input type="checkbox"/> Georgia | <input type="checkbox"/> Mississippi | <input type="checkbox"/> Pennsylvania | <input type="checkbox"/> Other US subdivision |
| <input type="checkbox"/> Hawaii | <input type="checkbox"/> Missouri | <input type="checkbox"/> Puerto Rico | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> Idaho | <input type="checkbox"/> Montana | <input type="checkbox"/> Rhode Island | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Illinois | <input type="checkbox"/> Nebraska | <input type="checkbox"/> South Carolina | |

2) Which of the following describes the tax filing status for your health system?

- Non-profit 501(c)3
- For-profit (publicly traded or private)
- Unsure
- Prefer not to say

3) Which of the following care setting(s) are currently represented within your health system? (Select all that apply.)

- | | |
|--|---|
| <input type="checkbox"/> Inpatient care clinic(s) | <input type="checkbox"/> Community-based clinic(s) |
| <input type="checkbox"/> Outpatient care clinic(s) | <input type="checkbox"/> Private practice clinic(s) |
| <input type="checkbox"/> Residential or home-based care service(s) | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Mobile health clinic(s) | <input type="checkbox"/> Other [free text] |

4) How long have you worked within your health system?

- | | |
|---|--|
| <input type="checkbox"/> Less than 1 year | <input type="checkbox"/> 16 to 20 years |
| <input type="checkbox"/> 1 to 5 years | <input type="checkbox"/> 21 years or more |
| <input type="checkbox"/> 6 to 10 years | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> 11 to 15 years | <input type="checkbox"/> Prefer not to say |

5) Please select the item that best reflects your work setting within your health system.

- | | |
|--|--|
| <input type="checkbox"/> Academic medical center | <input type="checkbox"/> Other |
| <input type="checkbox"/> Federally qualified health center | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> Community health center | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Health clinic | |

6) Please select the item(s) that best reflect(s) your current role(s) within your health system.

- | | |
|---|---|
| <input type="checkbox"/> Researcher | <input type="checkbox"/> Informatician (e.g., data manager, data administrator, etc.) |
| <input type="checkbox"/> Health care provider | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Administrator | |

7) How long have you worked in your current role?

- | | |
|---|---|
| <input type="checkbox"/> Less than 1 year | <input type="checkbox"/> 11 to 15 years |
| <input type="checkbox"/> 1 to 5 years | <input type="checkbox"/> 16 to 20 years |
| <input type="checkbox"/> 6 to 10 years | <input type="checkbox"/> 21 years or more |

8) Which departments or units are associated with your current work duties? (Select all that apply.)

- | | |
|---|--|
| <input type="checkbox"/> Acute care (inpatient) | <input type="checkbox"/> Pediatrics |
| <input type="checkbox"/> Long term care | <input type="checkbox"/> Emergency department |
| <input type="checkbox"/> Assisted living | <input type="checkbox"/> Psychiatry/Behavioral Health |
| <input type="checkbox"/> Clinic (outpatient) | <input type="checkbox"/> Telemetry / Intensive care unit |
| <input type="checkbox"/> Med / Surg | <input type="checkbox"/> Other, please specify: _____ |
| <input type="checkbox"/> Obstetrics | |

Section 1a: Health System Characteristics

9) Please indicate your level of agreement with the following statements:

	1 Strongly Agree	2 Agree	3 Neutral	4 Disagree	5 Strongly Disagree	9 Don't know	10 Prefer not to say
My health system collects a wide range of data and information about the quality of care and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health system uses a wide range of data and information about the quality of care and services to improve system functioning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health system employees are actively involved in determining what data are collected for the purpose of improving the quality of care and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health system compares its data on the quality of care and service with data from other health systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section 1b: Leadership Characteristics

10) Please indicate your level of agreement with the following statements:

	1 Strongly Agree	2 Agree	3 Neutral	4 Disagree	5 Strongly Disagree	9 Don't know	10 Prefer not to say
The health care provider (e.g., physician) leadership is personally involved in quality improvement efforts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senior executives seek information on needs and suggestions for quality improvement directly from external customers (e.g., patients, families).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The senior executives have articulated a clear vision for improving the quality of care and services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section 1c: Quality Improvement

11) Please indicate your level of agreement with the following statements:

	1 Strongly Agree	2 Agree	3 Neutral	4 Disagree	5 Strongly Disagree	9 Don't know	10 Prefer not to say
Patients' complaints are studied to identify patterns and prevent the same problems from recurring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Data on patient satisfaction are widely communicated to hospital staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health system uses data on customer expectations and/or satisfaction when modifying current services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health system uses data on customer expectations and/or satisfaction when modifying current services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section 2: EHR System Features

12) Does your health system use an electronic health record (EHR) system?

- Yes
 No
 Unsure
 Prefer not to say

(Respondents that select 'yes' on question 12 will complete the follow-up questions below.)

12a) Does your health system use an electronic health record (EHR) system?

- | | | |
|---|--|--|
| <input type="checkbox"/> Cerner | <input type="checkbox"/> Praxis | <input type="checkbox"/> Medhost |
| <input type="checkbox"/> Epic | <input type="checkbox"/> GE Healthcare | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> Nextech | <input type="checkbox"/> MEDITECH | <input type="checkbox"/> Other [Free text] |
| <input type="checkbox"/> EClinicalWorks | <input type="checkbox"/> EClinicalWorks | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Allscripts | <input type="checkbox"/> Evident, a CPSI company | |
| <input type="checkbox"/> athenahealth | <input type="checkbox"/> Netsmart Technology | |

(Respondents that select more than one EHR system on question 12a will complete the follow-up question below.)

12b) Are the EHR systems you selected linked across one or more clinics or care delivery settings?

- Yes
 No
 Unsure
 Prefer not to say

13) Does your health system use EHR data to inform patient care delivery?

- Yes
 No
 Unsure
 Prefer not to say

(Respondents that select 'yes' on question 13 will complete the follow-up questions below.)

13a) To your knowledge, how is EHR data used for patient care within your health system?

(Select all that apply.)

- | | |
|---|--|
| <input type="checkbox"/> Accessing and documenting patient information in a centralized location (e.g., x-rays, labs, clinic notes) | <input type="checkbox"/> Using clinical support tools |
| <input type="checkbox"/> Communicating with colleagues about issues related to patient care | <input type="checkbox"/> Distributing or obtaining questionnaires or measures to/from patients |
| <input type="checkbox"/> Searching the medical or nursing literature | <input type="checkbox"/> Obtaining feedback about care experiences from patients |
| <input type="checkbox"/> Supporting diagnostic and therapeutic decision making | <input type="checkbox"/> Accessing or creating aggregated information about patient outcomes |
| <input type="checkbox"/> Prescribing treatments & follow-up regimens | <input type="checkbox"/> Other, please specify: _____ |
| <input type="checkbox"/> Providing clinical alerts and reminders to patients | _____ |

14) To your knowledge, does your health system use EHR data for purposes beyond delivering patient care? (e.g., research, quality improvement.)

- Yes
 No
 Unsure
 Prefer not to say

(Respondents that select 'yes' on question 14 will complete the follow-up question below).

14a) From your experience, which of the following items are most reflective of the frequency in which EHR data is currently used for clinical research, quality improvement, and/or financial and operational management purposes within your health system?

Clinical Research	Quality Improvement (e.g., modifications to care processes or procedures to improve patient care)	Financial and Operational Management (e.g., billing)
<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Often <input type="checkbox"/> Always	<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Often <input type="checkbox"/> Always	<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Often <input type="checkbox"/> Always

14b) To your knowledge, how likely is your health system to expand the use of EHR data across clinical research, quality improvement, and financial and operational management domains within the next year?

Clinical Research	Quality Improvement (e.g., modifications to care processes or procedures to improve patient care)	Financial and Operational Management (e.g., billing)
<input type="checkbox"/> Very Likely <input type="checkbox"/> Likely <input type="checkbox"/> Neutral <input type="checkbox"/> Unlikely <input type="checkbox"/> Very Unlikely	<input type="checkbox"/> Very Likely <input type="checkbox"/> Likely <input type="checkbox"/> Neutral <input type="checkbox"/> Unlikely <input type="checkbox"/> Very Unlikely	<input type="checkbox"/> Very Likely <input type="checkbox"/> Likely <input type="checkbox"/> Neutral <input type="checkbox"/> Unlikely <input type="checkbox"/> Very Unlikely

Participants that select 'likely' or 'very likely' in any of the domains in 14b will answer question 15.

15) Please describe how you presently anticipate uses of EHR data expanding within your health system in the next year.

15a) If there are additional detail(s) you would like to share about how EHR data is currently being used by your health system, please include it in the box below.

Section 4: Claims Data

16) How is claims data obtained by your health system? (Select all that apply.)

- Private health insurance companies (e.g., Anthem, UnitedHealth Group, Atena)
- Medicare
- Medicaid
- Other private health insurance program(s) (e.g., nonprofit or charity programs)
- Other federal or state health insurance program(s) (e.g., Veterans affairs, Tricare, CHIP)
- Unsure
- Prefer not to say

Section 5: Claims Data Considerations and Use

17) Does your health system use claims data to inform patient care delivery?

- Yes
- No
- Unsure
- Prefer not to say

(Respondents that select 'yes' on question 17 will complete the follow-up questions below.)

17a) To your knowledge, how is claims data used to inform patient care within your health system? (Select all that apply.)

- In the form of predictive analytics
- To evaluate the quality of care provided by providers within the system (e.g., determining whether providers are following nationally recommended medical protocols for treating patients diagnosed with specific medical conditions)
- Evaluate the quality of care provided by the health system as a whole
- Examining patient outcomes (e.g., reviewing readmissions)

18) Does your health system use claims data for purposes beyond delivering patient care (e.g., research, quality improvement, financial and operational management)?

- Yes
- No
- Unsure
- Prefer not to say

(Respondents that select 'yes' on question 18 will complete the follow-up question below.)

18a) From your experience, which of the following items is most reflective of how frequently claims data is currently used for clinical research, quality improvement, and/or financial and operational management purposes within your health system.

Clinical Research	Quality Improvement (e.g., modifications to care processes or procedures to improve patient care)	Financial and Operational Management (e.g., billing)
<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Often <input type="checkbox"/> Always	<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Often <input type="checkbox"/> Always	<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Often <input type="checkbox"/> Always

Participants that select 'likely' or 'very likely' in any of the domains in 18a will answer question 19.

19) Please describe how you presently anticipate uses of claims data expanding within your health system in the next year.

19a) If there are additional detail(s) you would like to share about how claims data is currently being used by your health system, please include it in the box below

Section 6: Additional Data Sources: Considerations and Use

20) To your knowledge, does your health system collect or acquire data that is not extracted from EHRs or medical claims (e.g., registries, medical devices, etc.)?

- | | |
|------------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to say |

(Respondents that select 'yes' on question 20 will complete the follow-up questions below.)

20a) To your knowledge, which of the following options is representative of additional sources of data that are currently collected or acquired by your health system? (Select all that apply.)

- Registry data
- Laboratory data (e.g., special lab data, sequencing, etc.)
- Patient-reported outcomes data (e.g., self-report surveys)
- Patient-generated health data from devices (e.g., smartphones, fitness trackers, medical devices, etc.)
- Consumer-generated data (e.g., emails, text messages, purchase history, social media, web-browsing data, posts from patient forums, etc.)
- Retail prescription history data
- Genetic, genomic, and/or any "omics" data
- Insurance claims data
- None of the above
- Unsure
- Other _____

(Respondents that select any option besides 'None of the above' on question 20.a will complete the follow-up questions below,)

21) Does your health system use any of the additional data sources you previously selected to inform patient care delivery?

- | | |
|------------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to say |

(Respondents that select 'yes' question 21 will complete the follow-up questions below)

21a) To your knowledge, which of the following additional data sources you previously selected used to inform patient care delivery?

- Registry data
- Laboratory data (e.g., special lab data, sequencing, etc.)
- Patient-reported outcomes data (e.g., self-report surveys)
- Patient-generated health data from devices (e.g., smartphones, fitness trackers, medical devices, etc.)
- Consumer-generated data (e.g., emails, text messages, purchase history, social media, web-browsing data, posts from patient forums, etc.)
- Retail prescription history data
- Genetic, genomic, and/or any "omics" data
- Insurance claims data
- None of the above
- Unsure
- Other _____

21b) To your knowledge, how are the additional data sources you previously selected used to inform patient care delivery within your health system?

22) Does your health system use the additional data sources you previously selected for purposes beyond delivering patient care?

- Yes
- Unsure
- No
- Prefer not to say

(Respondents that select 'yes' question 22 will complete the follow-up questions below.)

23) Please indicate the frequency in which the additional data sources you previously selected are currently used for clinical research, quality improvement, and/or financial and operational management purposes within your health system

Clinical Research	Quality Improvement (e.g., modifications to care processes or procedures to improve patient care)	Financial and Operational Management (e.g., billing)
<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never
<input type="checkbox"/> Rarely	<input type="checkbox"/> Rarely	<input type="checkbox"/> Rarely
<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes
<input type="checkbox"/> Often	<input type="checkbox"/> Often	<input type="checkbox"/> Often
<input type="checkbox"/> Always	<input type="checkbox"/> Always	<input type="checkbox"/> Always

24) Does your health system have plans to expand the use of any of the additional data sources you previously selected within the next year?

Yes

Unsure

No

Prefer not to say

(Respondents that select 'yes' question 24 will complete the follow-up questions below.)

25) Please describe how you presently anticipate uses of the additional data sources you previously selected expanding within your health system in the next year.

25a) If there are additional detail(s) you would like to share about how the additional data sources you previously selected are currently being used by your health system, please include it in the box below.

Section 7: Survey Conclusion

If there are individuals in your network that would be interested in participating in this survey, please enter their email addresses below. Please notify the individual(s) you list below within 24 hours.

Thank you for participating in the survey. The responses you provided will help to improve our understanding of the essential components of a LHS. As a token of our appreciation, we would like to share a summary of the responses obtained from the survey at the culmination of the data collection period.

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