

# AN ASSESSMENT STRATEGY TO MEASURE PROGRESS TOWARDS REALIZING A NATIONWIDE LEARNING HEALTH SYSTEM

*Bryant Stephanie*

Indiana State University  
Terre Haute, Indiana

*E-mail: [s.bryant862@gmail.com](mailto:s.bryant862@gmail.com)*

## **Abstract**

Technology and digital communication system advances has made collection, storage and transmission of health information easier and faster. The US government has made electronic health information networks and health data systems a national priority by enacting legislation to develop a national health information infrastructure and encourage the meaningful use of electronic health records. Learning health systems seek to retrieve and analyze electronic health record data retrieved from nationally dispersed health information sources and develop new insights that will be useful to various stakeholder groups, including individuals, clinicians, researchers, and health policy makers. This effort seeks to determine how much progress has been made in using connected health data systems to learn from collected electronic health record data on a nationwide basis. The proposed assessment strategy seeks to examine progress toward realizing a national learning health system in terms of system operational concepts – system usage, data transformation capabilities, and sustainability; and progress measures in terms of system maturity, learning capabilities, and dissemination capabilities.

## **I. INTRODUCTION**

Technology and digital communication system advances has made collection, storage and transmission of health data easier and faster. Healthcare is a key nationwide industry that addresses both individual and population level health concerns. According to a Centers for

Medicare and Medicaid Services (CMS) report, in 2015 healthcare spending accounted for 17.8 percent of the US Gross Domestic Product (GDP), which measures the annual contribution of all goods and services of a country [1]. The US government has made electronic health information systems and networks a national priority by enacting legislation and creating a national health information technology office charged with establishing the foundations for a national health information infrastructure, as well as incentivizing the meaningful use of electronic health records.

Many stakeholders, including patients, clinicians, researchers, insurers, and policymakers are interested in health data collected in electronic health records (EHR). By analyzing EHR data, stakeholders can ascertain evidence-based implications of real life health issues, such as health outcomes and efficacies of treatment protocols, drugs, medical devices, and other health related topics. In a 2015 report, the Office of the National Coordinator (ONC), the federal organization charged with leading the digital conversion of health information and supporting health information infrastructure, reported that over 80% of doctors used an EHR system [2]. While electronic health record systems enable efficient collection, storage, and retrieval of health information, how can we develop insight from that electronic data on nationwide scale? A Learning Health System (LHS) integrates electronic health data networks with analytical components in order to analyze large sets of health data and develop evidence based insights of health topics supported by data from real patients.

A learning health system is envisioned as a system of systems that uses large scale (i.e., nationwide) health data networks to learn from collected electronic health data. This effort seeks to determine how much progress has been made in using connected health data networks to learn from collected electronic health record information on a nationwide scale. The proposed strategy examines the progress of selected early learning health system endorsers in extending their health data networks to include transformative capabilities that generate new knowledge or insights from existing electronic health data. The strategy also includes provisions to examine the experiences and variations of existing learning health system implementations and discover emerging patterns that may be applied in other organizations seeking to develop learning health system capabilities. The strategy seeks examine to progress toward realizing a national learning health system in terms of system operational concepts – system usage, data transformation capabilities, and sustainability; and progress measures in terms of system maturity, learning capabilities, and dissemination capabilities.

## **II. LEARNING HEALTH SYSTEM**

The Institute of Medicine (now the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine) recognizes the importance of health information and informatics. In 2007, the IOM developed a definition for a learning health system which represents a computational extension to existing health data networks [3]. A learning health system is an Informed decision making tool used for disseminating health knowledge generated from large and diverse health data sets and evidence based findings to clinicians, researchers, and other health stakeholder groups. The generated results are then used as input to next iteration of analysis in order to continuously learn from past information while incorporating new information. A learning health system's strength is achieving a continuous cycle of learning from existing and new information.

A nationwide learning health system requires the coordination and consensus of people and technology across local, regional and state boundaries. There are many challenges to realizing such an ultra large system. Some challenges can be categorized as governance, technology, and standards. Governance challenges include establishing general standards of operation, managing participation, codifying data use across multiple domains and organizations. Technology challenges include adoption of technology and processes, growing the system by interconnecting existing learning health system implementations, and integrating innovation. Standards challenges include gaining consensus on common system concepts of interoperability so that system can successfully exchange information in known formats.

Learning and analytical capabilities distinguishes a learning health system from health data system. Key activities in the knowledge generation or learning process of a learning health system consists of aggregation (gathering and prioritizing relevant data), analysis (mining data for patterns, and insights), and dissemination (transferring findings and insights to stakeholder groups for consideration). The stakeholder groups can be data generators as well as information users. The process forms a continuous loop of learning that benefits stakeholder groups by delivering timely evidence-based information.

As more organizations embrace the LHS vision, tracking progress toward realization of a nationwide inter-connection of learning health systems is important to understanding what work needs to be done in order to realize the vision of a nationwide learning health system. Sitting et al [4] constructed a framework of concepts to assess the progress of health information networks. The Learning Health Community developed a research agenda to identity relevant research questions pertaining to the development of a learning health system [5]. Morain, Kass, and Grossmann [6] studied challenges experienced by organizations in their transition to learning health care system and included recommendation for other

organizations considering a similar transition. This assessment strategy combines concepts and findings from these previous efforts in health data network operation and learning health systems to assess the progress towards a national learning health system. This proposed assessment strategy seeks measure national learning health system progress in terms system operational concepts and progress measures.

### **III. OPERATIONAL CONCEPTS**

System operational concepts focus on system usage, data transformation capabilities, and sustainability. The system availability and usability concepts seek to understand the essential health data network operation. System availability is the health data system's structure that enable users to access and interact with data over periods of time. Systems use addresses the frequency of system interaction by patient, provider, and other health information consumers.

The learning capability concepts address the learning health data networks ability to distill and transform health data in to information and insights. Nationwide health data transformation requires collection, analysis and sharing of information beyond the current organization, region, or legislative boundary. There varying degrees of data transformation, including aggregation, pattern finding, and insight development.

### **IV. PROGRESS MEASURES**

The proposed assessment strategy will be used a dissertation research effort. Data collected during research effort includes technology challenges, successful technology trends, and progress toward a nationwide (large scale) learning health system implementation. Assessment data will be gathered as part of semi-structured interviews with technologists familiar with an existing learning health system development and operation.

Measurement of progress is determined suing a set of measurement parameters supporting the assessment concepts. The author assigns each parameter a base line measure and progress is measure

as demonstrated capabilities beyond the baseline.

To achieve nationwide operation, learning health must be mature enough to support large scale and continuous operation. Technology Readiness Level (TRL) will be used to gauge system maturity. TRL, a technology assessment approach originating from the Department of Defense, used to report the overall development stage of a technology or system as one of nine levels from basic technology research (level 1) to mission operation (Level 9) (Azizian, et al, 2011). The baseline TRL level for an operating learning health system is level 6 – the prototype system has been tested in relevant environment.

The learning capability parameter is expressed as a discrete set of category options describing the data transformation and dissemination abilities of the LHS. The categories are “aggregate”, “reason”, and “disseminate”. Aggregate is the capacity to extract and filter relevant data from local and external systems into a set for automated analysis. Reasoning implies the incorporation of an analysis process to examine input data as a group and produce set-based results. Dissemination is capability to export the set-based results to local and external systems. This research effort assumes that the learning capability is beyond descriptive statistical analysis of the set, such histograms, averages, etc. The base level for the learning capability parameter is “aggregate”.

The system connectivity parameter is expressed as one of a discrete set of category options describing the capability of the target LHS to exchange information with external systems. The categories are “No external contact”, “Plan for external contact”, and “Executed external contact”. A plan for external contract could be the existence or establishment of a data sharing agreement between the target organization and an external organization under a separate governing structure. This strategy assumes that an LHS in a multi-site organization where each site is under the same governing control are considered a single LHS system. An external system must be separate for all internal sites. The base level for the system

connectivity parameter is “No external contact”.

Together the operational concepts and progress measures a target LHS address the system operational capability as health data system and extended capability necessary to operate as a learning health system and demonstrate some capability to participate in a large scale implementation of a learning health system.

## V. CONCLUSION

The proposed assessment strategy seeks to determine how much progress has been made in using connected health data systems to learn from collected electronic health record data on a nationwide basis. The strategy seeks to examine national learning health system progress in terms concepts operational concepts and progress measure: systems availability and usability, data transformation, system maturity, and sustainability, system connectivity. The strategy measures progress from an established base line chosen by the research in terms of system maturity, analysis capability, and external system contact for a set of target learning health system implementations.

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