



Strengthening the Learning Health System in Cardiovascular Disease Prevention: Time to Leverage Big Data and Digital Solutions

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Accepted: 11 February 2021 / Published online: 10 March 2021

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Abstract

Purpose of Review The past few decades have seen significant technologic innovation for the treatment and diagnosis of cardiovascular diseases. The subsequent growing complexity of modern medicine, however, is causing fundamental challenges in our healthcare system primarily in the spheres of patient involvement, data generation, and timely clinical implementation. The Institute of Medicine advocated for a learning health system (LHS) in which knowledge generation and patient care are inherently symbiotic. The purpose of this paper is to review how the advances in technology and big data have been used to further patient care and data generation and what future steps will need to occur to develop a LHS in cardiovascular disease.

Recent Findings Patient-centered care has progressed from technologic advances yielding resources like decision aids. LHS can also incorporate patient preferences by increasing and standardizing patient-reported information collection. Additionally, data generation can be optimized using big data analytics by developing large interoperable datasets from multiple sources to allow for real-time data feedback.

Summary Developing a LHS will require innovative technologic solutions with a patient-centered lens to facilitate symbiosis in data generation and clinical practice.

Keywords Learning health systems · Big data · Patient-centered · Shared decision-making · Patient-reported outcomes

This article is part of the Topical Collection on *Evidence-Based Medicine, Clinical Trials and Their Interpretations*

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Introduction

The US healthcare system has recently witnessed science and technology make great strides in treating and preventing cardiovascular disease (CVD). Meanwhile, there has been an associated accumulation of data and evidence from the results of these efforts. The culmination of these changes was expected to produce high-quality care in medicine, yet healthcare today displays notable shortcomings in healthcare delivery, knowledge utilization, and patient outcomes [1]. Despite the potential of our healthcare system, patients feel they lack the ability to be an active participant in their care, physicians yearn for better evidence-based guidance, and researchers want timely realization of their work [2, 3]. The US healthcare system is faced with fundamental challenges in the midst of increasing complexity of modern medicine.

The Institute of Medicine (IOM) released “Best Care at Lower Cost,” which examined the nation’s need for improved coordination between evidence generation and patient-centered medicine [4•]. The current system involves an evidence base that is poorly translated to clinical care as patient

perspective is not captured and they are largely left out of the equation. The report called for a learning health system (LHS) which was defined as a system “in which knowledge generation is so embedded into the core of the practice of medicine that it is a natural outgrowth and product of the healthcare delivery process and leads to continual improvement in care.” The primary goal of this review is to discuss how technology and data generation can help achieve the vision laid out by the IOM of a patient-centered LHS, particularly as it relates to CVD prevention.

Patient-Clinician Partnership in the LHS

Patient-centered medicine has been proposed as the future of medicine with growing appreciation for the centrality of patient involvement to enhance health [5, 6]. The IOM defined patient centeredness as “providing care that is respectful and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinician decisions” [7]. The Patient Protection and Affordable Care Act specifically endorses the development of decision aids, shared decision-making (SDM) programs, and metrics for the quality of decision-making for the purpose of incorporating patient preferences and values into the medical plan. Similarly, a core principal of the LHS is engaged and empowered patients who partner with clinicians for continuous improvement and innovation. This goal is sought in two main ways: incorporating patient preferences and increased collection of patient-reported outcomes (PROs) measurements.

Shared Decision-Making in the LHS

Many healthcare decisions have complex trade-offs of potential harms and benefits, yielding multiple reasonable decisions and professional equipoise. In these types of settings, SDM has been encouraged to be utilized [8]. SDM is the process by which patients and clinicians work together to ensure patient preferences are incorporated into medical decisions when there is not a clear option. A key principle of SDM is that both parties contribute, the clinician by offering medically reasonable diagnostic and treatment options, and the patient by exploring and communicating their personal goals, values, and preferences for their healthcare. This relationship is often described as patient and clinician partnership. SDM occurs over three steps. The first step involves knowledge transfer, ideally a symmetrical and bidirectional exchange of information between patient and clinician. The second step aims to critique the options with consideration placed on the patients’ preferences. The last step is reaching a consensus about which treatment strategy to implement.

In particular, cardiovascular diagnostic and therapeutic options exist on a wide continuum of risks and benefits with

relatively benign to potentially harmful options. Given the complexity of treatment options that confront patients as well as the potential life-changing benefits and harms, the importance of SDM in CVD prevention is vital. SDM has a role throughout clinical settings where multiple reasonable treatment options exist. SDM that occurs in the ambulatory setting has the capability of leveraging the longitudinal patient-clinician relationship and capability of being more thoughtful and more accurately reflecting patient preferences.

There have been multiple aids designed to assist in the SDM conversation. “Decision aids” are tools for both the clinician and patient that provide information about alternative options and outcomes to assist patients in clarifying personal goals [5]. These aids have taken the form of booklets, videos, and web-based systems to explain clinical decisions in an easily accessible manner and have been shown to increase the likelihood that clinicians engage patients in treatment decisions [9]. Numerous decision aids have been created for CVD prevention/management, including for hyperlipidemia, hypertension, atrial fibrillation, acute chest pain, statins, and coronary artery disease [10–14].

Indeed, core aspects of atrial fibrillation management call for SDM, including symptom management and thromboembolism prevention. A randomized clinical trial, Stroke Prevention in Atrial Fibrillation (SPAF) III, showed that an audio booklet decision aid empowered patients with knowledge about risks and benefits of particular treatment and helped them make an informed decision [15].

Another example of a decision aid is the Statin Choice aid, which was designed to assist patients and clinicians in discussing the pros and cons of statins. The tool leads the conversation through three steps: (1) patient’s cardiovascular risk without statins, (2) cardiovascular risk if taking a standard or high-dose statin, and (3) benefits versus downsides of initiating a statin according to patient personal health information. The decision aid was shown to lead to improvements in patient knowledge, reduced decisional conflict, and a trend towards improved adherence [14].

Another type of SDM aid is the “decision coach” which is a trained professional who assists patients in making medical decisions. The decision coach will frequently help patients prepare for the SDM visit by coaching and probing the patients to determine their values and goals. The Ottawa Personal Decision Guide is a worksheet that coaches can go through with patients to help facilitate these conversations [16].

SDM offers new opportunities to improve health outcomes and experiences. Although patients have been eager to incorporate SDM in the medical decision-making process, SDM and decision aids have not been widely adopted [17]. The barriers to widespread adoption of SDM are multifactorial and it is helpful to remember the involved constituents, namely, the patient (and his/her caregiver), clinician, and healthcare system. As each constituent has variable constraints, different

interventions should be appropriately targeted towards the patient, provider, or system. From a patient perspective, SDM requires baseline knowledge of their health condition. From a clinician perspective, there needs to be a culture change to emphasize and value SDM. Lastly, from a systems perspective, the healthcare system financially rewards clinicians for actions, not conversations, even though both activities are time-consuming and require clinician expertise. The Center for Medicare and Medicaid Innovations have funded grants to implement SDM including the Million Heart CVD Risk Reduction Model which encourages SDM as a tool to reduce absolute atherosclerotic cardiovascular disease risk [18]. Digital health intervention tools such as mobile applications provide a unique opportunity to intervene at all levels and allow SDM to be effectively incorporated in clinical care. This can be accomplished through empowering patients with knowledge about disease and treatment options. This will also reduce the burden on health systems and clinicians and will make encounter more efficient and meaningful. To create a true patient-centered LHS, value-based incentives must be implemented on a national level.

Patient-Reported Information

While patient engagement involves SDM, in a LHS, the aggregation and analysis of these patient-reported outcomes (PRO) are equally important to create a patient-centered LHS that can respond to patient preferences. PROs are an important and unique type of data in LHS as they are data elements collected directly from patients without clinician interpretation. Patient-centered outcomes, such as angina burden or functionality, are able to reflect outcomes that are most important to patients and provide a more comprehensive picture of a therapy. The American Heart Association (AHA) released a scientific statement defining patient-reported health status that includes three domains: symptom burden, functional status, and health-related quality of life. The statement further advocates for the inclusion of PROs as a measure of cardiovascular health [19]. There have been a variety of innovations to measure PRO including direct collection via surveys, biometric data, and mobile or web-based applications.

CVD-specific patient health surveys can quantify symptom burden, functional limitations, and HRQL related to a specific condition including CAD, atrial fibrillation, and heart failure [20–22]. These health status surveys score based on both the specific domain (symptom, physical function, and HRQL) and a summary score to reflect the overall health status of the patient. Recent articles have used PROs to identify discrepancies between clinician and patient assessment of disease including angina control [23]. The numerical scores of PROs also facilitate interpretation for use in research such as in the COURAGE (Clinical Outcomes Utilizing Revascularization and Aggressive Drug Evaluation) trial comparing PROs using the Seattle Angina Questionnaire for percutaneous coronary

intervention (PCI) with optimal medical therapy versus optimal medical therapy alone in patients with stable CAD [24]. The Seattle Angina Questionnaire asked patients about PRO such as physical limitations, angina stability, and treatment satisfaction. While implementation barriers largely hinder collection and utilization of PRO, there are strategies to fold these questionnaires into clinical workflow such as using tablets during clinic visits or direct outreach with phone calls [25].

Another promising area of development to generate patient-reported information is through biometric sensors. With advances in technology, these sensors can be integrated into wearable devices such as watches or phones and have the ability to accurately detect irregular rhythms, for example [26]. A prospective multicenter, randomized, controlled trial of 150 patients with atrial fibrillation is currently ongoing to evaluate the impact of the Apple Watch electrocardiography and irregular rhythm notification feature on PROs including the Atrial Fibrillation Effect on Quality-of-life (AFEQT) questionnaire global score [27]. In heart failure research, there have been innovative studies to trial remote cardiac pressure monitoring through implantable devices linked to a physician-directed patient self-management treatment system to guide medication dosing [28]. These new technologies have the ability to significantly increase the type and amount of usable data outside the conventional clinic setting.

An LHS's main objective is to improve healthcare over time by utilizing numerous and varied data types for continuous data feedback. PROs represent an important metric in patient-centered LHS as they directly incorporate the patient voice into clinical care and research. To optimize the amount of patient-generated data within a patient-centered LHS, it will be necessary to develop widespread collection of PROs as well as seamless integration of these data into clinical care and research. The former can be readily accomplished by collecting information using digital health technologies. Connecting with patients in communities and collecting real-life data outside the health system has a potential to bring patient at the center of healthcare. There is also much opportunity to further understand how to incorporate PROs into precision medicine within a LHS. As the health system develops a more streamlined approach to integrating PROs and SDM into clinical practice, there may be significant benefit in reducing unmet healthcare needs in the population.

Big Data in the LHS

A dominant paradigm in medical literature is currently the randomized controlled trial, wherein data is generated specifically for a singular research project. RCTs have been the foundation of clinical and biomedical research, yet with the rapid development of medical interventions, there remains a growing gap between current medical care and the evidence to support practices. Tricoci et al found that a large proportion of

recommendations in the American College of Cardiology/ AHA guidelines are based on lower levels of evidence or expert opinion, demonstrating the paucity of adequate evidence currently available [29]. While RCTs offer the strength of causal inference, the monetary, labor, and time burden required to carry out such a trial have limited the progression of healthcare research [30]. Charged with alleviating this problem, the health system is becoming more aware of the need for new approaches to knowledge generation.

The US IOM in a report entitled “*Best Care at Lower Cost*” implored the scientific community to develop “learning health systems” as the current system of scientific discovery is inefficient leading to missed opportunities, suboptimal patient care, and wasted finances [31•]. The report recommended a LHS where data informs care and care informs data to continuously capture clinical endpoints and care experiences to ultimately improve clinical decision-making.

In the era of near ubiquitous electronic health records (EHR) and exponential growth of data availability, there is now pressing need to understand how to effectively use this data. The path to achieving a LHS involves significant changes in both big data generation and application.

Data Sources

While lacking a formal definition, big data has been characterized as large volumes of high velocity and variable data that requires advanced techniques to store and analyze the information [32•]. The rapid adoption of digital health systems has led to the exponential growth of big data availability either from internal sources (e.g., electronic health record, imaging, genomics, clinical registries, administrative data), or external sources (e.g., web and social media sites, or biometric data) as seen in Fig. 1. Researchers have been working on harmonizing such information to complement traditional evidence-based methods, such as RCTs. The Food and Drug Administration (FDA), for example, has incorporated knowledge gained from these new data sources, termed real-world evidence, to improve the efficacy and speed of new medical product development and approval [33].

While the immense capacity of data generation discussed below presents new possibilities for a LHS, this future will not be realized until the data can be routinely incorporated into patient care. Rumsfeld et al. detailed eight areas of application of big data analytics to improve healthcare: (1) predictive modeling for risk and resource use; (2) population management; (3) drug and medical device safety surveillance; (4) disease and treatment heterogeneity; (5) precision medicine and clinical decision support; (6) quality of care and performance measurement; (7) public health; and (8) research applications [19•]. As outlined in Table 1 and discussed below, big data sources have unique characteristics; certain types of



Fig. 1 Types of big data sources

sources are better equipped for specific analytics than other sources.

Electronic Health Records

Internal sources have been the major source for observational knowledge generation thus far. EHR systems provide observational data collected from routine patient care. This data can include information such as patient demographics, clinical diagnoses, free text notes, and laboratory and imaging data that can enable advanced analytics and represent a diverse amount of data. In addition to patient data housed in the EHR, the amount of additional data from patient visits may include medication and treatment approaches, underlying genetics, and geographic variability. Transforming clinical data into knowledge to improve patient care has tremendous potential but the amount of additional EHR data requires computer-based methods to organize, interpret, and recognize patterns. Due to the nature of EHR's, however, a large proportion of this data is unstructured making extracting usable information difficult. Techniques such as natural language processing have been used to leverage massive amounts of unstructured data. The Congestive Heart Failure Information Extraction Framework (CHIEF) is a natural language processing application that was used to process free-text documents, extract ejection fraction measurements and medication lists, and measure the quality of heart failure patient care [34]. When compared to a human-annotated reference standard, the CHIEF application was able to accurately extract relevant medications with a recall of 97.8–99.7%. Other challenges specific to EHR utilization within a LHS include limitations

Table 1 Characteristics of big data sources

Data source	Example	Advantages	Disadvantages
Electronic health records	EPIC, PowerChart	Massive amount of information from each clinical visit Wide variety of types of data	Large variability in quality of data Much of the data is unstructured, decreasing utility
Administrative data	Medicare Part A	Large databases Diverse populations within the dataset Includes diagnosis and treatment coding	Inconsistent coding criteria across institutions Misclassification Missing data
Clinical Registry Data	Get with the guidelines	Multi-hospital datasets Can be linked to administrative data Can be used for benchmarking quality	Data generation is not linked to workflow Inconsistent coding criteria across institutions
mHealth	Apple Heart Study	Potential for large amounts of feedback Data generated outside of the healthcare environment Potential to advance precision medicine	Limited utilization currently

with interoperability, accuracy and completeness of records, security and privacy concerns, and inability to extract the needed information [35–38].

There is an opportunity to elevate the effectiveness of EHRs to provide more meaningful data for patient care. To develop a LHS where patient care and research inform each other in an iterative process, the field must move towards a national data model with data storage standards to decrease variability and increase utility of data between EHR systems. In order to maximize the amount of information gleaned from the health records, there needs to be system level changes, including less free text and more structured data to facilitate data mining. Structured data is more cumbersome within workflow and there are hesitations regarding mistakenly copy forwarding such data, so there needs to be considerable investment in informatics resources[39]. Additionally, as it is unlikely to move towards a fully structured EHR, innovations such as natural language processing are needed to categorize the remaining amount of free text seen in health records.

Administrative Data

Another source of health data is administrative data sources which are massive repositories of data collected in the course of providing and paying for care largely to record transactions [40]. These databases are often large and demographically diverse populations and may include diagnosis and procedure codes for clinical services, location of service, healthcare utilization, pharmacy, and amount billed and amount reimbursed. Given the high volume and systematic collection of data over time, administrative data provide a valuable variety of clinical and demographic information, particularly useful for epidemiological studies regarding prevalence and incidence of major diagnoses or diseases, and monitoring trends in utilization of specific services. Cardiology researchers have

already started using administrative data by using Medicare data linked to registry data to develop risk models [41].

The major limitations of administrative data include inconsistent coding criteria across institutions, lack of accuracy of data, changing criteria of diagnoses, diagnosis codes, and difficulties in merging different databases [42, 43].

Clinical Registry Data

Clinical registries are datasets that systematically and uniformly collect information from EHRs on all patients with a specific variable such as medication, diagnosis, or procedure. The registries aim to improve quality of care through benchmarking clinical outcomes, provide information on safety and efficacy of treatment, and assess healthcare utilization, among other functions. Cardiology has, in many ways, led the field in developing clinical specialty-focused databases. The AHA has developed the National Registries for a number of cardiovascular diseases, including stroke, atrial fibrillation, cardiac arrest, and more, known as “Get with the Guidelines” (GWTG) to allow participating hospitals to track the characteristics, treatments, and outcomes of patients with CVD and to inform effective quality improvement strategies.

In order to facilitate the use of clinical registries in a LHS, there needs to be a significant decrease in the time between care delivery and collection of data to improve timely insights to care. Currently, data collection is not linked to workflow causing the data collection to be collected at a later time either partially or completely by hand from the EHR leading to redundancy of work. Ideally, data are captured simultaneously and in real time using structured reporting and controlled vocabulary. Template-based documentation will also help reduce errors of omission [44]. Ultimately, many of the solutions to improve EHR data will also aid in data capture for clinical registries.

mHealth

A growing area of healthcare data includes data collected and/or stored outside of the healthcare system. With a growing pace of technologic innovations, the medical community has seen a recent surge in mobile health devices (e.g., wearables, mobile apps, and web-based platforms) known as mHealth. Through these devices, generation of physiologic data (digital biomarkers) and digital intervention outside of the clinic or hospital setting can be studied [45, 46]. The Apple Heart Study is one example of mHealth enabling big data collection outside of the healthcare system. This study utilized self-enrollment to study the ability for the Apple Watch to detect atrial fibrillation in 400,000 participants, which provided a foundation for large-scale studies via mHealth [26]. Another important virtual clinical trial in this space is an ongoing Heart Health Study Using Digital Technology to Investigate if Early AF Diagnosis Reduces the Risk of Thromboembolic Events Like Stroke IN the Real-world Environment (HEARTLINE). The goals of the trial include identification of patients with atrial fibrillation among study participants and evaluation of clinical outcomes [47]. Similar to the Apple Heart Study, the HEARTLINE study is utilizing self-enrollment to enroll a large number of patients (150,000). Big data and digital biomarkers from these types of trials have potential to transform healthcare into a more patient-centered system as we are tapping into the data that has been lacking from conventional clinical trials and is reflective of patients' everyday lives.

mHealth data are a natural source for a LHS as it incorporates large amounts of feedback on remote monitoring when a patient is in their own environment. For a LHS to utilize the full capability of mHealth, there will be a need to have a wider spread utilization to inform potential applications. mHealth can also aid in advancing precision medicine in a LHS to tailor medical therapies based on individual data.

Conclusion

The rapidly accelerating complexity of technologic innovation and therapies has offered opportunities to drastically improve the current healthcare system to produce a patient-centered LHS. Technologic tools have the capacity to refocus the conversation around patient involvement through shared decision-making tools and increased ability to generate patient-reported information. Additionally, with the growing cost, capabilities, and complexity of the healthcare system, big data sources have emerged as powerful tools to aid in the generation of evidence. Through these solutions, there may

come a system where patient care informs data and data informs care in a truly iterative cycle to ensure continued improvement.

Declarations

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

Conflict of Interest Khurram Nasir is on the Advisory Boards of Amgen, Novartis, and The Medicines Company, and his research is partly supported by the Jerold B. Katz Academy of Translational Research.

Seth Shay Martin reports personal fees from Amgen, AstraZeneca, Esperion, REGENXBIO, and 89bio; grants from Apple, Google, iHealth, Nokia, Maryland Innovation Initiative, American Heart Association, Aetna Foundation, PJ Schafer Memorial Fund, David and June Trone Family Foundation, Akcea Therapeutics,

and the National Institutes of Health; and is co-founder of Corrie Health, LLC. In addition, Dr. Martin has a pending patent on System of LDL-C Estimation.

The other authors declare no conflict of interest.

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