Commentary

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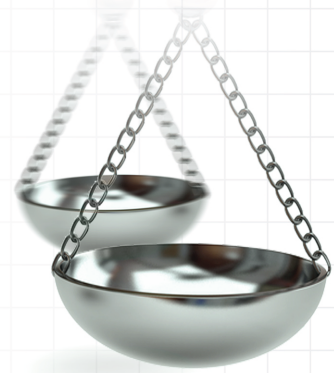

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Expanding the learning health system model to be health literate

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> "if gaps in health literacy persist, there will always be groups that do not achieve the care they need, as certain groups are more likely to experience limited health literacy (e.g., adults over 65, racial and ethnic groups other than White, recent refugees and immigrants, people with less than a high school degree or equivalent, non-native speakers of English and people with incomes at or below poverty levels). Improving health literacy is on the critical path to health equity."

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Nearly nine out of ten adults struggle to understand and use personal and public health information [1]. Low health literacy is an economic burden for the USA, costing US$238 billion or more annually and representing between 7% and 17% of all personal healthcare expenditures [2]. In 2012, the National Academy of Medicine identified ten attributes that exemplify a health-literate healthcare organization, meaning an environment that enables people to understand, access and benefit optimally from the range of healthcare services [3]. Almost 10 years later, few, if any, healthcare organizations embody these key attributes. We can no longer focus on individuals' aptitudes but must recognize and address the "*health literacy-related demands and complexities of our healthcare organizations*" [3]. More recently, Healthy People 2030, the nation's 10-year plan to improve the health of all Americans, featured, for the first time, health literacy in its framework. Further, it expanded health literacy to include a new organizational component, recognizing the essential role healthcare organizations play in improving health literacy. If the demands of healthcare organizations can better align with an individual's literacy skills and abilities, language and culture, we can address many of the persistent obstacles to achieving health equity.

Achieving health literacy aligns with other proposals to create learning health systems (LHSs). Most recently, Bodenheimer and Sinsky expanded Don Berwick's Triple Aim of improving the care experience and the health of populations and reducing costs by adding a fourth aim, "*improving the work life of healthcare clinicians and staff . . . in order to succeed in improving population health*" [4]. In doing so, they proposed that the Triple Aim should become the Quadruple Aim. As the nation grapples with advancing health equity and the underlying issues required to improve the health of all subpopulations, we believe it is time to address health literacy as the next leap forward in improving population health and advancing health equity and justice. Including health literacy as an objective in the LHS approach would transform the Quadruple Aim to a Quintuple Aim. The concept of a Quintuple Aim has been described in an Agency for Healthcare Research and Quality white paper, on redefining primary care, in which the fifth aim focuses on equity [5]. We posit that applying the ten attributes of a health-literate organization will address health disparities and social determinants of health and, therefore, is part of the path to achieving the Quintuple Aim. If health equity is an aim, however, we recognize that health literacy is a necessary but insufficient condition for achieving the Quintuple Aim. Nonetheless, if gaps in health literacy persist, there will always be

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Table 1. Health-literate learning healthcare system model.

Ten attributes of health-literate organization	Leading practices for health literacy-focused learning health system	Agency for Healthcare Research and Quality learning health system principles					
							
1. Has leadership that makes health literacy integral to its mission, structure and operations	Leadership must make health literacy a priority and create the mindset and values of continuous improvement to health literacy improvement.	X					
	Measure impact of health literacy efforts using the Quadruple Aim to align with broader organizational goals.		X		X	X	
2. Integrates health literacy into planning, evaluation measures, patient safety and quality improvement	Leaders in safety and quality from across the organization develop a common model for health literacy to support coordinated integration into operations.	X					
	Integrate evidence-based guidance and resources for promoting health literacy into patient portals and other patient-facing information technology systems, as well as into the electronic medical records to support clinicians.			X	X		
	Integrate patients and community members into organizational planning in different ways (e.g., patient and family advisory councils).				X	X	
	Create and use a health literacy dashboard.					X	
	Apply structured quality improvement methodologies to health literacy measures.						X
3. Prepares the workforce to be health literate and monitors progress	Assess workforce health literacy competencies and provide ongoing, personalized development.	X	X				
	Provide just-in-time support to reinforce established health literacy practices and to disseminate new ones.			X			
	Establish a regular cycle of training needs analysis, gap identification and ongoing workforce learning and development around health literacy promotion.						X
4. Includes populations served in the design, implementation and evaluation of health information and services.	Integrate patients and community members as valued team members and collaborators in developing and managing information and services.				X		
	Capture patient experiences with health information and services in a way that informs ongoing development and refinement of offerings.					X	
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization	Incorporate information about health literacy into clinical encounters and use them to guide patient interactions and aggregate findings to understand broader trends.		X				
	Ensure patients and community members with a range of health literacy skills are involved in improvement efforts.				X	X	
	Incorporate assessments of stigmatization/stigmatizing language in the structure of quality improvement processes.						X
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact	Encourage the patient to be an active participant in all communications.	X			X		
	Use patient data to drive choice of engagement strategies most likely to be effective at different phases of care.		X				
7. Provides easy access to health information and services and navigation assistance	Provide tools for healthcare workers to facilitate access to information.			X			
	Foster inclusion of patients on the healthcare team through ease of access to information.			X	X		
8. Designs and distributes print, audiovisual and social media content that is easy to understand and act on	Ensure access to content and alignment of messages between electronic and in-person communication.			X			
	Track use and usability of media developed for patients and the community.					X	

 : Have leaders who are committed to a culture of continuous learning and improvement.

 : Systematically gather and apply evidence in real time to guide care.

 : Employ information technology methods to share new evidence with clinicians to improve decision-making.

 : Promote the inclusion of patients as vital members of the learning team.

 : Capture and analyze data and care experiences to improve care.

 : Continually assess outcomes AND refine processes and training to create a feedback cycle for learning and improvement.

Table 1. Health-literate learning healthcare system model (cont.).

Ten attributes of health-literate organization	Leading practices for health literacy-focused learning health system	Agency for Healthcare Research and Quality learning health system principles					
							
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines	Ensure patient involvement during high-risk situations using methods most appropriate for the patient.				X		
	Develop and use a common framework for health literacy-related events across key sources of information (e.g., patient safety event systems, patient complaints, claims data).					X	
	Include health literacy as an explicit dimension in retrospective (e.g., root cause analyses) and prospective (e.g., failure mode and effects analyses) risk identification efforts.	X					
10. Communicates clearly what health plans cover and what individuals will have to pay for services	Ensure fully informed and shared decision-making of costs (particularly out-of-pocket) and benefits of diagnostic and treatment options.			X			

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groups that do not achieve the care they need, as certain groups are more likely to experience limited health literacy (e.g., adults over 65, racial and ethnic groups other than White, recent refugees and immigrants, people with less than a high school degree or equivalent, non-native speakers of English and people with incomes at or below poverty levels). Improving health literacy is on the critical path to health equity.

We propose that as the aims for improving healthcare have evolved, so also must the scope and focus of LHSs. The Agency for Healthcare Research and Quality LHS framework aligns with the ten principles described by the National Academy of Medicine for health-literate healthcare organizations. This alignment provides an opportunity to advance health equity and justice and continue maturing LHS capabilities. As detailed in Table 1, integrating these approaches yields an initial set of 25 leading practices for implementing a health-literate learning healthcare system. These practices are proposals, rooted in conceptual linkages between the attributes of a health-literate healthcare organization and the LHS principles. They illustrate how an LHS approach can amplify and mature efforts to build health-literate organizations.

The LHS model applied to the principles of building a health-literate healthcare organization can be transformative – capitalizing on the infrastructure already in place after a decade of LHS maturity and harnessing its tools to meet the challenges for the rising priorities of health equity and justice. However, realizing this vision requires addressing three needs.

First, there is a need to diversify the pool of LHSs. To date, LHS models have taken root in academic medical centers and large healthcare systems with the technological and human resources needed to implement rapid, data-driven transformation. However, smaller, nonacademic hospitals often have deeper connections in the communities they serve and, consequently, are vital drivers of change and progress in health literacy. This is particularly true for healthcare organizations serving marginalized or disenfranchised communities. Existing LHSs seek to serve diverse patient populations, but little attention has been paid to implementing the LHS model in a broader range of healthcare organizations. Progress requires concerted efforts to spread the LHS model to the full range of healthcare organizations. Furthermore, diversity and representation of the workforce within LHS will be key to continued maturation of the LHS model, particularly with respect to health literacy objectives. This creates the opportunity for partnerships between existing LHSs with sophisticated technical approaches to data-driven improvement and aspiring LHSs with strong relationships with the communities they serve. These partnerships can be mutually beneficial, as the adaptive or relational expertise of community-engaged organizations can help accelerate improvement in organizations lacking that capacity.

Box 1. Practical pathways to building a learning health system to improve health literacy to achieve equity and inclusion.

Employ universal precautions in health literacy to create understanding and personalized approaches to build trust and belief.

- Healthcare organizations must meet the basic standards of providing information accessible for all.
- Influencing behaviors requires more than ensuring patients receive and understand information. Patients must trust the source and believe in the message. This is particularly important in the new (mis- and dis-) information ecosystem, where truthful messages must compete with a high volume of counternarratives.
- Trust in institutions and professions is eroding across all aspects of modern life. This increases the importance of individual relationships between healthcare workers and patients as well as the healthcare organization and the communities it serves.

Assess the ability of the system and individual to act on information.

- Even if understanding, trust and belief in information have been achieved, healthcare decisions and health behaviors may not align with recommendations for very practical reasons.
- What administrative and financial burdens are placed on patients pursuing recommended actions? What can be done to lower them?

Do not conflate decisions counter to care recommendations with low health literacy.

- Fully health-literate patients may make choices that differ from those advocated by the care team, but this does not mean that information is not understood.
- Seek to understand individual (e.g., needle-phobic person being prescribed insulin) and cultural (e.g., blood transfusions) drivers of decisions contrary to care team recommendations and engage in shared decision-making processes.

Second, there is a need for meaningful (valid, practical and actionable) metrics of health literacy capable of driving broader engagement and activation of patients and the healthcare workforce. Data are central to the LHS approach and while many measurement tools are available, much innovation is needed across a range of measurement types (e.g., patient experiences, care process, outcomes) and sources (e.g., self-report, electronic health record-based) to increase timely access to data and reduce the burden of data collection. Advances in measurement are needed to drive diagnostic tools for LHSs that can be used to find opportunities to improve health literacy, contextualized for different patient populations. Ideally, these diagnostic tools would link care outcomes, processes and health literacy in a logical causal model. For example, do we have subpopulations at higher risk for bad outcomes for care they access in our system? Are those differences in outcomes due to differences in care decisions and processes? Are any differences in care decisions due to lack of effective communication for understanding? A data-driven LHS model can apply this type of rigor to self-assessment, the improvement of health literacy and its impact on a wide range of patient safety, quality and equity issues (e.g., access to preventative services, management of chronic conditions, reduction of unnecessary hospital visits and readmissions, medication errors).

Third, there is a need to evaluate barriers and enablers of old and new interventions for driving change. Learning at the organizational level is a change management problem, which is notoriously difficult. Individual change solutions and broader learning processes must be implemented within a complex social and technical system that is resource constrained and struggling to meet many, often competing priorities. Implementation and organizational sciences provide rich frameworks and evidence bases from which to draw guidance, but a contextual understanding of how and when different strategies work will be needed. An analysis of barriers and enablers should be inclusive of healthcare workers seeking to communicate and engage in shared decision-making as well as patients seeking to act on information. If patient choices diverge from recommendations, the organization should consider other explanations than low health literacy (e.g., are their practical constraints experienced by the system or patients, or are recommendations inconsistent with personal or cultural values?). All healthcare organizations experience external pressure to improve safety, quality and equity while under increasing resource constraints (e.g., workforce shortages). However, improving health literacy should not be viewed as an additional burden but a means to managing the multiplying metrics organizations are held accountable to. By integrating health literacy within existing operational LHS structures and processes, the capacity should be augmented with a more engaged and informed patient population.

The LHS framework can also help mature and strengthen our approach to managing health literacy. Experiences during the pandemic have made salient the challenges of mis- and disinformation in health. Existing health literacy frameworks do not address these issues, as they focus on communicating to build understanding. While

understanding is certainly critical, the current health information space requires attention to building the belief in the truth of the information and the trust in the health system that drive behaviors. Box 1 provides tangible and practical pathways that LHSs can focus on to improve health literacy by building shared understanding, belief and trust and understanding of what is driving care decisions.

The pandemic heightened the salience of the gaps in health literacy and made the need for accelerated learning processes clear. The journey toward health equity and justice will no doubt be long, and there are many lessons to learn along the way. The burden of that journey can be eased with the adaptation and adoption of a decade of innovation in LHS implementation [6]. Health literacy is on the critical path to equity and justice and a health-literate learning healthcare organization offers a structural approach to address health inequity.

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