



Learning Health Systems Consensus Action Plan

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BACKGROUND

Almost 100 diverse stakeholders at the Second Learning Health System (LHS) Summit (sponsored by the Joseph H. Kanter Family Foundation) convened at conference space donated by the American Society of Clinical Oncology (ASCO) in Alexandria, Virginia on December 8-9, 2016. The multi-stakeholder consensus *LHS Core Values* (<http://www.learninghealth.org/corevalues/>) anchored the collaborative discussions. These discussions resulted in actionable recommendations for advancing Learning Health Systems (LHSs) at all levels of scale. What follows is a high-level summary of the output of those group discussions, with additional input incorporated after the Summit. These recommended action steps will be prioritized and implemented by leaders and contributors to the Learning Health Community and endorsers of the *LHS Core Values*.

I.) PROMOTE AND DISSEMINATE THE TRANSFORMATIVE VISION AND VALUE

1. Articulate the long-term business purpose and ultimate value proposition of LHSs across stakeholders
 - a. Identify the stakeholders, as well as their needs and priorities
 - b. Solicit input from the stakeholder identified; enlist their support and participation in developing innovative solutions to their key present and future challenges
 - c. Define the ultimate value proposition for each stakeholder group
 - d. Capture, develop, and communicate stories/narratives illustrating the life-changing value of functional LHSs through patient experiences; include specific benefits to individuals, patients, and families
 - e. Anchored in LHSs business cases (please see Section VI.), identify strategies to align incentives to drive LHSs to become standard practice
 - f. Articulate the clinical and scientific necessity of LHSs and develop models promoting cross-sector investments in the development of the science and learning to advance LHSs, including illuminating the consequences of not delivering on the promise of the LHS vision
2. Build a branding/messaging strategy and corresponding methods enabling diverse stakeholders to incorporate advantages of LHSs into their promotion activities
 - a. Embrace Institute of Medicine/National Academy of Medicine (IOM/NAM) and eventually international concepts around anchoring LHSs on patient needs and perspectives
 - b. Align with United States federal health IT strategic planning (including existing roadmaps embracing the *LHS Core Values*), as well as national initiatives in other nations globally
 - c. Develop the core content and templates for newsletters and presentations, as well as a corresponding concise LHS “elevator speech” that can be spread to diverse stakeholders to generate enthusiasm and participation

- d. Identify and catalogue existing stakeholder efforts; prioritize partnerships (e.g., United States Chamber of Commerce and Business Roundtable); and engage celebrities when possible
3. Initiate a small, action-oriented group or task force to engage and learn from outside perspectives and experiences, especially Internet and information/data brokers (e.g., Google, Amazon, Microsoft, Apple, Visa); understand their visioning, outreach and dissemination processes and how these may apply to LHSs

II.) DEFINE AND ASSEMBLE COMPONENTS TO FACILITATE IMPLEMENTATION

1. Survey existing LHS initiatives, endorsers, and key outside stakeholders to find out what is working well; develop models, define key characteristics and identify approaches to tracking and rapidly disseminating progress of such LHS initiatives
2. Develop a list of essential build components underpinning implementation and develop definitions and a common understanding of what they are; develop key features (pros/cons) regarding centralized vs. federated approaches
3. Name and vet a core set of standards (content, exchange, and terminology) for LHSs, utilizing and building upon existing standards wherever possible
4. Create an implementation guide for maturing LHSs of any scale (and scope)
5. Establish a maturity model covering structure, process, and outcomes for levels of implementation of essential elements toward realizing LHSs (e.g., similar to the HIMSS Analytics Electronic Medical Record Adoption Model EMRAM)
6. Develop readiness assessments, activities and metrics needed for monitoring progress
7. Create an assessment tool that could be used by organizations desiring to implement LHSs to identify gaps and assess organizational readiness
8. Develop linkages to other efforts aimed at transformations that are presently underway (e.g., National Patient Safety Foundation/Institute for Healthcare Improvement, the Society for Participatory Medicine, and the Global Alliance for Genomics and Health)
9. Create and host a collaborative repository of LHS best practices, using the maturity model (please see Section V.) and provide a corresponding “LHS Toolkit”

III.) CULTIVATE THE ORGANIZATIONAL CULTURE AND ECOSYSTEM TO DRIVE ADOPTION

1. Mobilize resources of organizations that will serve as test sites for evaluation of readiness, including information governance, technology, and evaluation teams
2. Create a Learning Collaborative Exchange Network among organizations specifically committed to advancing their LHS capabilities in collaboration with others; among other things, the network will share lessons learned in approaches to realizing LHSs as well as work to accelerate the collaborative development of core components
3. Invite other organizations at various scales to test the overarching model, readiness assessment tools (and corresponding metrics and certifications), security and trust-building approaches, and roadmaps
 - a. Collaboratively develop justifications for and incentives to pursue the metrics and certifications envisioned
 - b. Develop a corresponding public scorecard for technologies and institutions that are LHS enablers

4. Introduce “LHS Awards” (non-monetary) to provide recognition for early adopters of LHS approaches
 - a. Highlight those LHSs who “move the needle” (especially multi-stakeholder efforts)
 - b. Offer opportunities for inclusion in the process to as many stakeholders at various levels of development as possible
 - c. Communicate success stories broadly (per Section I)

IV.) ENGAGE ALL STAKEHOLDERS, ESPECIALLY INDIVIDUALS AND CONSUMERS

1. Identify early adopter LHSs/communities and how they empower individuals, patients, caregivers, and consumers to transform health through their shared experiences
2. Create a consumer engagement campaign anchored in an empowerment-driven definition (and vision) of consumer engagement that includes accountability and ownership of one’s own health (and embraces approaches to advancing health equity)
3. Support the goal of providing consumers with enhanced real-time, convenient access to their personal health data (and related applicable information and knowledge) in usable and actionable forms – enabling and empowering the exercising of existing rights to drive improvements in their health, the health of others, and the system overall
4. Facilitate strategic partnerships with key interested major (corporate) players across private industry as well the public sector, while ensuring that the effort is grounded in consumer needs and driven by actual consumers
5. Develop, validate, and disseminate a framework for a consumer-mediated learning health information ecosystem that includes the consumer-managed health record

V.) FORMALIZE BEST PRACTICES

1. Educate stakeholders on K2P (knowledge to practice/performance), on P2D (practice/performance/patient/physician to data), and on D2K (data to knowledge)
2. Produce a multi-stakeholder body of knowledge (e.g., a living, wiki-like document on the Learning Health Community website) on K2P/P2D/D2K best practices, including issues such as validity and provenance
3. Identify best practices around data quality standards and other enablers of sharing and collaboration to engender LHSs
4. Look at programs that worked to help patients find treatments and cures (e.g., YMCA)
5. Address through best practices the role of ELSI (ethical, legal, and social issues) in LHSs (e.g., partnerships with bioethics communities, hospital ethics communities, and IRBs) and foster research that informs issues around data access, protection, and sharing by leveraging existing documents on this topic
6. Highlight and provide input from multiple and diverse stakeholders to assist in developing and clarifying regulations and guidance affecting LHSs and the environment in which LHSs operate (e.g., explicit consent and approval for learning activities), and identify related best practices
7. Build “LHS thinking” into education, beginning in high school and possibly earlier, and extending through graduate and post-graduate programs plus continuing education

- a. Convene a prominent LHS education task force to facilitate formalizing LHS educational offerings as well as to serve as an advisory body for institutions seeking to integrate LHS educational components
- b. Create an LHS competency set and corresponding envisioned LHS workforce (spanning professions)
- c. Offer an LHS badge of recognition for curricula, as well as educational resources at undergraduate and graduate levels grounded in the maturity model (please see Section II.)
- d. Develop internship programs to promote practical hands-on exposure to LHS initiatives in real-world settings
- e. Create a website sharing common LHS educational resources to facilitate consistent quality and common messages across LHS educational experiences (please see Section III.)
- f. Incorporate LHS curricula into Continuing Medical Education (CME) and Continuing Nursing Education (CNE) programs
- g. Actively involve local government agencies in existing LHS prototype initiatives and emerging public-private initiatives (regional public health, community networks) and educate on these; identify coalitions to engage

VI.) FUND AND SUSTAIN THE MOVEMENT

1. Develop business plans, funding models, and lists of revenue sources for LHSs
2. Identify and encourage policy changes that support development of LHSs and alignment of incentives towards realizing successful LHSs
 - a. Clarify the relevant regulations and influence those that incur barriers to success of LHSs
 - b. Enable cost-effectiveness research (with economies of scale and scope)
3. Encourage disruptive or non-conventional organizational innovation in the health system
 - a. Support creating grant funding mechanisms aimed at enabling existing LHS initiatives to scale
 - b. Encourage academics; health economists (e.g., business and medical schools) to generate, publish, and disseminate evidence of the cost effectiveness and other benefits of LHSs
4. Stand up a trusted, neutral, multi-stakeholder, nonprofit organization aimed at accelerating progress toward realizing the national and global transformation of health anchored in the consensus *LHS Core Values*
 - a. Develop appropriate organizational documents including bylaws as well as statements of mission, vision, and strategy
 - b. Incorporate as an appropriate nonprofit legal entity
 - c. Develop business plans and identify paths to sustainability
 - d. Create a trust-engendering open, transparent, broadly representative, and inclusive accountability/governance structure
 - e. Ground the organization's work in the *LHS Core Values*; they should inform all decisions, and the vision they embody should serve as a beacon to guide all organizational actions