

Transforming the Future of Health Together: The *Learning Health Systems Consensus*

Action Plan

Revised DRAFT of: February 10, 2018

Authors:

Joshua C. Rubin, Jonathan C. Silverstein, Charles P. Friedman, Rebecca D. Kush, William H. Anderson, Allen S. Lichter, Darin J. Humphreys, Jeffrey Brown, Laura Crawford, James M. Walker, Richard L. Tannen, Kate Berry, Claudia Grossmann, Marianne Hamilton Lopez, Robert M. Kolodner, Janet M. Marchibroda, Frank W. Rockhold

Correspondence to:

Joshua C. Rubin, JD, MBA, MPH, MPP

President and CEO

Learning Health Community

Josh@JoshCRubin.com

Keywords:

Learning Health System, Learning Health Community, Empowerment, Multi-Stakeholder, Public Health, Chaordic, Interoperability

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as doi: [10.1002/lrh2.10055](https://doi.org/10.1002/lrh2.10055)

Abstract

The Learning Health Community is an emergent global multi-stakeholder grassroots incipient movement bonded together by a set of consensus *Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System* developed at the 2012 Learning Health System (LHS) Summit. The Learning Health Community's Second LHS Summit, convened on December 8-9, 2016, built upon LHS efforts taking shape, in order to achieve consensus on actions that, if taken, will advance Learning Health Systems (LHSs) and the LHS vision from what remain appealing concepts to a working reality for improving the health of individuals and populations globally. An iterative half-year collaborative revision process following the Second LHS Summit led to the development of the *Learning Health Systems Consensus Action Plan*.

From Moment to Incipient Movement: Birth of the Learning Health Community

In late 2011, a sixteen-member Planning Committee, including two former United States National Coordinators for Health IT (one appointed by a Republican President and one appointed by a Democrat President), formed to plan a multi-stakeholder invitational meeting with lofty aspirations.¹ Grounded in thought leadership vis-à-vis “Chaordic” organizations (organizations mixing elements of chaos and order, bonded together by shared principles),^{2,3} as well as networked models of emergent collaboration including the Internet,⁴ the envisioned Learning Health System (LHS) Summit⁵ aimed to “be to the

development of the LHS what the historic Dumbarton Oaks Conference was to the birth of the United Nations, which formed rapidly once consensus on principles was achieved.”⁶

The multi-stakeholder working meeting, sponsored by the Joseph H. Kanter Family Foundation,⁷ convened on May 17-18, 2012 at The National Press Club in Washington, D.C.⁸ Although most invitees came from the United States, leading individuals were invited from overseas as well; ultimately, European participants traveled across the Atlantic Ocean to participate in the LHS Summit, as well as joined in the planning process and in follow up activities (one formally joining the Interim Steering Committee for guiding efforts catalyzed by the LHS Summit). These organizers, and many others nationally and internationally, collectively recognized that, “Spiraling health care costs coupled to poor outcomes, the persistent latency between best practice knowledge and its actual application in practice, an inefficient public health infrastructure, and many other factors combine to make the LHS a national, and ultimately global, imperative. The urgency of the need was stressed at an August [2011] meeting of the Institute of Medicine’s new Digital Learning Collaborative. At the same time, many health organizations are establishing themselves as learning environments and the nation is moving toward Meaningful Use of health information technology. We have reached a propitious moment.”⁹

As a starting point, the organizers looked to a definition of a “Learning Health System” utilized by the Institute of Medicine (now the National Academy of Medicine) as an

integrated ecosystem “... in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health and healthcare.”¹⁰ They recognized the urgent need for continuous and rapid learning from experience to uniquely and invaluablely advance the Triple Aim of better quality care (and better patient and clinician experiences), better health of individuals and populations, and lower costs per capita.¹¹ Such an imperative affected health systems across the United States and around the world.

From there, the organizers looked to what they referred to as “tectonic activities” toward realizing the LHS vision at various levels of scale, nationally and internationally. Within the United States, there were myriad healthcare systems that were themselves working to become learning organizations (and networks), as well as leaders developing and improving key components. Further surveying the landscape, studying the history, assessing the challenges and opportunities, and underscoring the urgency, they also reviewed reports of the Institute of Medicine dating to 2007¹² (indeed, senior Institute of Medicine leadership served on the Planning Committee and presented at the LHS Summit), trends in the digitization of healthcare,¹³ other publications related to “rapid-learning” and “big data” in health,¹⁴ efforts of the Office of the National Coordinator for Health IT (ONC)

and other government agencies as well as other private and nonprofit organizations in the United States, emerging applications of analytics to improve health,¹⁵ and more.

Internationally, they looked to various European initiatives at the time including Electronic Health Records for Clinical Research (EHR4CR),¹⁶ the TRANSFoRm project (European LHS),¹⁷ the United Kingdom's National Information Governance Board,¹⁸ and others.

Beyond these initiatives, the promise of data sharing and collaboration between the United States and the European Union dating back to 2008 offered hope and potential for a trajectory toward a global LHS.¹⁹ However, to avoid scope creep, the LHS Summit focused specifically on the composition of a LHS at a nationwide scale (in the United States or any other nation on the planet), while recognizing the ultimate global vision and imperative as well as the “fractal” (any level of scale) characteristics of the vision and approach.

At the LHS Summit, over 80 individuals, representing diverse healthcare and health stakeholders, participated in this invitational working meeting; these included international speakers and participants.²⁰ The overarching deliverable, following iterative cycles of revision involving all participants for two months after the LHS Summit, was a set of multi-stakeholder consensus *Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System*.²¹ The *LHS Core Values Preamble* helps conceptualize the nationwide LHS vision and its *raison d'être* as follows, “The national-scale, person-

centered, continuous and rapid learning health system (LHS) will improve the health of individuals and populations. The LHS will accomplish this by generating information and knowledge from data captured and updated over time – as an ongoing and natural by-product of contributions by individuals, care delivery systems, public health programs, and clinical research – and sharing and disseminating what is learned in timely and actionable forms that directly enable individuals, clinicians, and public health entities to separately and collaboratively make informed health decisions.”²² More broadly, this vision is anchored in a shared cultural commitment to continually learn and improve as a by-product of every interaction, in order to protect and improve the health of individuals, communities, populations, the general public, and the system itself.

Further, as stated in the *LHS Core Values* Preamble, “The proximal goal of the LHS is to efficiently and equitably serve the learning needs of all participants, as well as the overall public good... The LHS will develop... by creating an environment that fosters collaboration and harmonization among all stakeholders... Ultimately recognizing that better health for all is a global imperative, the LHS aspires to embrace strategic approaches that facilitate harmonization with other nations in pursuit of a global system, as well as within the United States.”²³ Additionally, it is worth noting that these principles were intended from the outset to be leveraged by any entity or network at any level of scale striving to become a

LHS itself, as well as by any nation globally working to achieve the LHS vision at a nationwide scale. Please see TABLE 1 for a summary of the *LHS Core Values*.

TABLE 1: The Learning Health Community's *Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS)*, July 20, 2012

The *LHS Core Values* served to bond together a global multi-stakeholder grassroots incipient movement, ultimately called the Learning Health Community.²⁴ In turn, as will be discussed subsequently, the Learning Health Community, as a center for LHS intelligence, collaboration, and action, sought to mobilize, empower, and inspire diverse stakeholders to work together to transform healthcare and health by realizing the vision embodied by the *LHS Core Values*, through catalyzing multi-stakeholder initiatives aimed at engendering key components and collaboration needed to do so; the moment of consensus organically grew into a grassroots incipient movement. Organizations could make a public statement by formally endorsing the *LHS Core Values*. As of the time of submission of this manuscript, 115 organizations nationally and internationally have done so (please see TABLE 2).²⁵ These formal organizational endorsers of the *LHS Core Values* represent diverse stakeholder groups, spanning the public, private, nonprofit, and academic sectors (and several continents). They include organizations that compete vigorously with one another, as well as representatives of stakeholder types likely to mistrust one another or to be

motivated by divergent incentives, expressing a belief in common values and in a shared vision for the future of health.

TABLE 2: An Alphabetical List of the 115 Organizational Endorsers of the *Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS)*, as of October 30, 2017

Grassroots Collaboration Driving the Learning Health Community Incipient Movement

From the outset, it was recognized that, “The Learning Health Community’s approach is grounded in a collective recognition that the LHS represents an ultra-large-scale cyber-social system... Achieving this vision is a challenge too great for any one organization, stakeholder group, or even sector; it can only be achieved through multi-stakeholder, grassroots collaboration... By its grassroots nature, the community is a self-organizing coalition of the willing, whose work is driven by efforts of the participants that grow in the community’s fertile environment conducive to the multi-stakeholder collaboration essential to realizing the LHS as a movement.”²⁶

Further, “Consistent with the emergent characteristics of the LHS itself and the grassroots approach of the Learning Health Community, major steps toward realizing the LHS vision will be accomplished through self-organizing, multi-stakeholder, collaborative initiatives.

Each initiative will be hosted by a trusted neutral convener... Like any grassroots endeavor, the Learning Health Community and the initiatives it spawns will become what the members of this community make it into.”²⁷

Learning Health Community initiatives²⁸ aimed at achieving consensus on an essential set of standards and structures to enable learning (ESTEL), and at convening a national dialogue around a governance and policy framework for a nationwide LHS, have been launched; diverse stakeholders have traveled across the United States and around the world to participate, generally on their own time and at their own expense. The Learning Health Community’s website notes, “Consistent with the emergent characteristics of the LHS itself and the grassroots approach of the Community, major steps toward realizing the LHS vision are accomplished through self-organizing, multi-stakeholder, collaborative initiatives... Each initiative is hosted by a trusted neutral convener... All initiatives will be designed to ensure that grassroots collaborative efforts result in sustained action and engagement as well as continued and meaningful impact.”²⁹

The Learning Health Community has also aimed to grow the incipient movement it embodies, to educate and evangelize about (and safeguard) the vision embodied in the *LHS Core Values* and to make the LHS vision a destination on the map. Its mailing list includes over 2,000 individuals expressing interest in the incipient movement. Community activists

have presented at conferences spanning the health IT, clinical medicine, nursing, biomedical research, public health, health law and policy, patient empowerment, and many other arenas, nationally and globally. Endorsers of the *LHS Core Values* have donated to support Learning Health Community efforts, have publicized and promoted their involvement, have published papers on their efforts, have incorporated the *LHS Core Values* into their own organizational mission statements as well as projects and investments, and more. Federal health IT nationwide strategic planning in the United States prominently references the Preamble to the *LHS Core Values*, with a nationwide LHS as the end goal,³⁰ and other nations and organizations globally have followed suit. Organizations in Europe and Asia have formally endorsed the *LHS Core Values*; individuals and organizations from these continents and other continents have not only initiated LHS initiatives of their own, but have traveled to the United States to participate in Learning Health Community initiatives, as well as collaborated with participants in the Learning Health Community incipient movement to amplify their respective impacts.

As LHS visionary Joseph H. Kanter noted in early 2016, “Together, we have moved the LHS from impossible to imperative to inevitable. A future of health that involves big data and analytics will happen; it is already happening. What I believe we’re really fighting for is the soul of this future.”³¹ Elaborating on what this notion means, he stated, “In 2020, there’s likely to be 50 times as much health data as there is today. Medical knowledge that took 50

years to double 50 years ago, will be doubling every 73 days. The questions we're seeking to answer are whether the power that comes with all that will be concentrated in the hands of the few, or will it democratize health and serve the public good in the hands of the many? Will the knowledge generated be trustworthy (and shared widely and rapidly), or self-serving for powerful interests? Will the system be inclusive and flexible and adaptable, or will it be locked into something proprietary? Will these efforts make the practice of medicine more rewarding to doctors and nurses, or will it try to turn them into cogs in the machine? Will patients be more empowered over their lives, their health, and their data? Will those least well-served now be further left out of this future, inequitably distributing benefits, or will we ensure this rising tide lifts all boats?... We all know what the right answer to all of these questions is. Our job is to work together to make the best possible vision of this future into the one our grandchildren and their grandchildren get to live in and build upon."³² Indeed, the *LHS Core Values* and the incipient movement they bond together play an invaluable role in guiding us toward such "right answers to all of these questions".

The Second Learning Health System Summit: December 8-9, 2016³³

By 2015, diverse stakeholders had bought into the LHS concept. They were actively working toward realizing Learning Health Systems (LHSs) on their own, as well as

Author Manuscript

harmonizing them into the cohesive LHS vision; what was needed next was an action plan to accelerate and coalesce progress.

The Learning Healthcare Project in the United Kingdom captured many of these developments taking shape around the world.³⁴ Its research was shaped in no small part through interviews with experts that included many members of the Interim Steering Committee of the Learning Health Community as well as participants in Learning Health Community initiatives.^{35,36} Ultimately, the Learning Healthcare Project came to include the Learning Health Community website as its top suggested link/resource and vice versa.³⁷

Recognizing these developments, initially, the Interim Steering Committee of the Learning Health Community³⁸ (which since 2012 had included at least one international member) collaborated with leadership of the Collaboration for Open Data Alignment (CODA) to organize a consensus meeting to create a “Declaration of Interdependence issued from the Second Learning Health System Summit... a concrete commitment to action.”³⁹ With the sudden passing of CODA’s founder Hunt Blair in September, 2015,⁴⁰ the planning process changed, but efforts to honor Blair’s vision and legacy were interwoven into the planning. Throughout 2016, the Learning Health Community’s Interim Steering Committee (please see EXHIBIT 1) met virtually and in-person to plan a multi-stakeholder invitational meeting to “build on the first [LHS Summit] by achieving consensus on a list of specific actions that,

if taken, will advance the LHS from what remains an appealing concept to a working reality for improving the health of individuals and populations. Following the Second LHS Summit and building on this further consensus, participants will collaboratively develop guidance for what organizations can do individually and collectively to advance the LHS, as well as ways to measure and recognize actions taken to realize the vision.”⁴¹

EXHIBIT 1: Second Learning Health System Summit: Planning Committee Members
(September 14, 2016)

Although published shortly following the Second LHS Summit, a “keynote” paper authored by three presenters at the Second LHS Summit illuminates the extent to which national and international developments informed this planning process.⁴² This paper noted (citations deleted) that, “The concept of LHS was first advanced by the U.S. Institute of Medicine (now the National Academy of Medicine) in 2007. In the ensuing 10 years, the concept has gained increasing attention, initially in the U.S., but currently and progressively around the world... In the U.S., several recent developments point to increasing interest in and development of LHSs... The literature reveals a panoply of reports of individual organizations seeking to achieve the capabilities associated with LHSs... Interest in LHSs has spread across the globe. Specifically, in the European Community, the TRANSFoRm

project has addressed some of the challenges of achieving a robust infrastructure for LHSs. The European Institute for Innovation through Health Data seeks ‘to tackle areas of challenge in the successful scaling up of innovations that critically rely on high-quality and interoperable health data’. In the U.K., the LHS concept has become a beacon for health improvement. The Swiss government has recently announced a national LHS initiative; and in Asia, collaborative efforts joining Japan to Taiwan have resulted in an incipient Consortium for Asia Pacific Learning Health Systems.”⁴³

With these developments, and the individuals and organizations shaping them in mind, as well as a sense of the history to date of the Learning Health Community incipient movement, the Second LHS Summit Invitees included: current representatives of organizations endorsing the *LHS Core Values*, past representatives of organizational endorsers who had moved onto roles in other organizations, additional representatives from stakeholder groups, recognized thought leaders, and those who had demonstrated their commitment to the incipient movement through their participation in Learning Health Community initiatives and other efforts to advance LHSs (please see EXHIBIT 2).

EXHIBIT 2: Second Learning Health System Summit: Participant List (Handout from the Second Learning Health System Summit, December 8-9, 2016)

With support from the Joseph H. Kanter Family Foundation, the Second LHS Summit was convened, with 98 participants,⁴⁴ on December 8-9, 2016, at conference space generously provided by the American Society of Clinical Oncology (ASCO) just outside of Washington, D.C.⁴⁵ Prior to the working meeting, all participants were asked to respond to two questions: “a.) What one key thing has your organization done to advance our progress towards realizing a LHS? b.) What one key action step could all organizations like yours take to accelerate our progress towards realizing a LHS?” (please see LINK 1).⁴⁶ Such data was synthesized to generate a preliminary list of potential actions that was discussed, organized, and further synthesized during the two-day meeting. On the first day, six random and heterogeneous breakout groups formed to prioritize previously listed action items and to add in essential missing ones.⁴⁷ Results of the work of these groups was synthesized and printed overnight. On day two, different breakout groups convened based on categories of actions, and worked to coalesce their respective efforts into a cohesive preliminary draft action plan by the end of the day; although the wording ultimately changed slightly, such categories that formed the basis of organizing the second day’s breakout groups ultimately aligned quite closely with the categories of action in the final consensus deliverable.⁴⁸

LINK 1: Lightning Introduction Slides Created by Participants in the Second Learning Health System Summit, as of December 9, 2016, are available at:

<http://www.learninghealth.org/s/Second-LHS-Summit-Lightning-Introduction-Slides-12-2016-V-12092016-9PM.pdf>

As an aside, it is worth noting that commitment to action aimed at protecting and improving the health of people and the public was baked into the planning process and the character of the event from the outset, as illustrated by the following several examples. Recognizing the nature of environmental impacts upon human health, more than nine months prior to the event, the organizers implemented efforts to reduce the environmental impact of the meeting itself, as well as to more than offset its estimated carbon footprint. At the same time, recognizing the foundational nature of nutrition and nourishment to health, while acknowledging that most participants in the Second LHS Summit were not personally worried about where their next meal would come from, the organizers made donations to provide more than twice as many meals to school children facing hunger (nationally and globally) as the estimated total number of meals to be provided to all Second LHS Summit participants. Along a similar vein, at the outset of the planning process, the organizers reached out for guidance to organizations working to ensure patient inclusion in such conferences. On a related note, in the spirit of recognizing diverse people who have contributed to protecting and improving health pursuant to the vision embodied by the *LHS Core Values*, a “Learning Health Heroes” portion of the meeting was

planned. Such actions helped set a tone for a working meeting whose core themes interwove collaboration and action to advance LHSs.

The *Learning Health Systems Consensus Action Plan*⁴⁹

Following the Second LHS Summit, a process comprising a series of collaborative iterative revisions to drafts of the *Learning Health Systems Consensus Action Plan* took place until June, 2017. Iterative feedback was solicited in multiple cycles from all participants in the Second LHS Summit, from those invitees who could not participate but expressed a strong interest, from additional federal officials, from participants at various health conferences in which highlights of preliminary drafts were shared, and from other participants in Learning Health Community initiatives.^{50,51} Please see TABLE 3 for an overview of the categories of action envisioned.

TABLE 3: A List of Categories of Multi-Stakeholder Action from the Learning Health Community's *Learning Health Systems Consensus Action Plan*

In releasing the *Learning Health Systems Consensus Action Plan*,⁵² it was acknowledged that, “Unlike the timeless multi-stakeholder consensus *LHS Core Values*, the consensus action plan will be a living document that will change and adapt over time.”⁵³ Next steps envisioned include disseminating the plan, working to solicit volunteers to facilitate efforts

and take responsibility for components of the plan, and publishing the plan. They also entail transforming “the Learning Health Community movement, already a center (and catalyst) for multi-stakeholder collaboration and action, into a more formal nonprofit organization... together, we will accelerate progress toward the transformation of health anchored in the consensus *LHS Core Values*.”^{54,55} Please see EXHIBIT 3.

Shaping the future of the Learning Health Community, the final element of the *Learning Health Systems Consensus Action Plan*, under the category of “Fund and Sustain the Movement”, is to “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*.”⁵⁶ Doing so involves the following four key steps, among others: 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; and D.) Create a trust-engendering open, transparent, broadly representative, and inclusive accountability/governance structure.”⁵⁷ Most importantly, though, is our collective calling to, “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.”⁵⁸ Indeed, through grounding our shared efforts

and vision in these multi-stakeholder consensus *LHS Core Values*, we will transform the future of health together.

EXHIBIT 3: The Learning Health Community's *Learning Health Systems Consensus Action Plan* (Last Updated: June 27, 2017)

Acknowledgement:

The authors of this manuscript wish to acknowledge Joseph H. Kanter and the Joseph H. Kanter Family Foundation. The generosity of the Joseph H. Kanter Family Foundation made both the 2012 Learning Health System Summit and the 2016 Second Learning Health System Summit possible. Mr. Kanter (94 years old at the time of publication), was among the first to envision a health system in which every clinician and (especially) every patient (and every other stakeholder making decisions affecting health) are empowered by knowledge of “what works best”. Mr. Kanter’s personal crusade to realize this transformative vision – spanning over a quarter century – continues to inspire and to catalyze action among the authors as well as myriad participants in (and beyond) the global Learning Health Community incipient movement.

References:

- ¹ Joseph H. Kanter Family Foundation. Press Release: Joseph H. Kanter Family Foundation Convenes Historic Learning Health System Summit; Stakeholders Collaboratively Work Toward Realizing a National-Scale Learning Health System. *PR Newswire*. May 23, 2012; 2012. <http://www.prnewswire.com/news-releases/joseph-h-kanter-family-foundation-convenes-historic-learning-health-system-summit-stakeholders-collaboratively-work-toward-realizing-a-national-scale-learning-health-system-153255845.html>
- ² Hock D. *Birth of the Chaordic Age*. Berrett-Koehler Publishers; 1999. https://books.google.com/books/?id=osgYgo_lHp4C
- ³ Holliday R. The word of the day is “chaordic”. *Regina Holliday's Medical Advocacy Blog*. May 18, 2012; 2012. <http://reginaholliday.blogspot.com/2012/05/word-of-day-is.html>
- ⁴ Leiner BM, Cerf VG, Clark DD, Kahn RE, Kleinrock L, Lynch DC, Postel J, Roberts LG, Wolff S. Brief History of the Internet. Origins of the Internet. *Internet Society*. 1997. <http://www.internetsociety.org/internet/what-internet/history-internet/brief-history-internet#Origins>
- ⁵ Learning Health Community. 2012 National Learning Health System Summit. May 17-18, 2012; 2012. <http://www.learninghealth.org/kanter-summit/>
- ⁶ Friedman CP. Email: “Personal Invitation to the Learning Health System Summit”. February 29, 2012; 2012.
- ⁷ Learning Health Community. 2012 National Learning Health System Summit. May 17-18, 2012; 2012. <http://www.learninghealth.org/kanter-summit/>
- ⁸ Joseph H. Kanter Family Foundation. Press Release: Joseph H. Kanter Family Foundation Convenes Historic Learning Health System Summit; Stakeholders Collaboratively Work Toward Realizing a National-Scale Learning Health System. *PR Newswire*. May 23, 2012; 2012. <http://www.prnewswire.com/news-releases/joseph-h-kanter-family-foundation-convenes-historic-learning-health-system-summit-stakeholders-collaboratively-work-toward-realizing-a-national-scale-learning-health-system-153255845.html>
- ⁹ Friedman CP. Email: “Invitation to the Planning Committee for the Kanter Foundation Learning Health System Summit”. October 30, 2011; 2011.
- ¹⁰ McGinnis JM, Powers B, Grossmann C, editors. Digital infrastructure for the learning health system: the foundation for continuous improvement in health and health care: workshop series summary. National Academies Press; October 21, 2011; 2011. <http://nationalacademies.org/hmd/reports/2011/digital-infrastructure-for-a-learning-health-system.aspx>
- ¹¹ Berwick, Donald M., Thomas W. Nolan, and John Whittington. “The triple aim: care, health, and cost.” *Health affairs* 27.3 (2008): 759-769. <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.27.3.759>
- ¹² McGinnis JM, Aisner D, Olsen L, editors. The learning healthcare system: workshop summary. National Academies Press; June 1, 2007; 2007. <http://www.nationalacademies.org/hmd/reports/2007/the-learning-healthcare-system-workshop-summary.aspx>
- ¹³ Kanter JH. *Your Life, Your Health: Share Your Health Data Electronically—It May Save Your Life*. Los Angeles, CA: Joseph H. Kanter Family Foundation; 2012. https://books.google.com/books/about/Your_Life_Your_Health_Share_Your_Health.html?id=KgueMQEACAAI
- ¹⁴ Etheredge LM. A rapid-learning health system. *Health Affairs*. March 2007;26(2):w107-18. <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.26.2.w107>
- ¹⁵ Roberts DW. Improving care and practice through learning health systems. *Nursing Management*. April 1, 2013;44(4):19-22. https://journals.lww.com/nursingmanagement/fulltext/2013/04000/Improving_care_and_practice_through_learning.5.aspx

-
- ¹⁶ Sundgren M. The EHR4CR Project 2011-2015. EHR4CR (EU). 2011. <http://www.ehr4cr.eu/views/about/index.cfm>
- ¹⁷ Delaney BC. TRANSFoRm: translational medicine and patient safety in Europe. Digital Infrastructure for the Learning Health System. 198. September 21, 2011; 2011. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4619923/>
- ¹⁸ Cayton H. Information Governance in the National Health Service (UK). Digital Infrastructure for the Learning Health System. 180. September 21, 2011; 2011. https://www.ncbi.nlm.nih.gov/books/NBK83569/pdf/Bookshelf_NBK83569.pdf#page=206
- ¹⁹ McGinnis JM, Powers B, Grossmann C, editors. Digital infrastructure for the learning health system: the foundation for continuous improvement in health and health care: workshop series summary. National Academies Press; October 21, 2011; 2011. <http://nationalacademies.org/hmd/reports/2011/digital-infrastructure-for-a-learning-health-system.aspx>
- ²⁰ Learning Health Community. 2012 National Learning Health System Summit. May 17-18, 2012; 2012. <http://www.learninghealth.org/kanter-summit/>
- ²¹ Learning Health Community. Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS). July 20, 2012; 2012. <http://www.learninghealth.org/corevalues/>
- ²² Learning Health Community. Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS). July 20, 2012; 2012. <http://www.learninghealth.org/corevalues/>
- ²³ Learning Health Community. Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS). July 20, 2012; 2012. <http://www.learninghealth.org/corevalues/>
- ²⁴ Learning Health Community. What is a Learning Health System?. 2017. <http://www.learninghealth.org/>
- ²⁵ Learning Health Community. Endorsers. October 30, 2017; 2017. <http://www.learninghealth.org/endorsers/>
- ²⁶ Rubin JC, Friedman CP. Weaving together a healthcare improvement tapestry: Learning health system brings together health it data stakeholders to share knowledge and improve health. *J AHIMA*. 2014;85(5):38-43. <http://library.ahima.org/doc?oid=300438#WXywcKEm7Zs> PubMed: <https://www.ncbi.nlm.nih.gov/pubmed/24938034>
- ²⁷ Rubin JC, Friedman CP. Weaving together a healthcare improvement tapestry: Learning health system brings together health it data stakeholders to share knowledge and improve health. *J AHIMA*. 2014;85(5):38-43. <http://library.ahima.org/doc?oid=300438#WXywcKEm7Zs> PubMed: <https://www.ncbi.nlm.nih.gov/pubmed/24938034>
- ²⁸ Learning Health Community. Community Initiatives. 2017. <http://www.learninghealth.org/sample-initiative-1/>
- ²⁹ Learning Health Community. Community Initiatives. 2017. <http://www.learninghealth.org/sample-initiative-1/>
- ³⁰ Office of the National Coordinator for Health Information Technology. Connecting health and care for the nation: a shared nationwide interoperability roadmap FINAL version 1.0; 2015. <https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide-interoperability-roadmap-final-version-1.0.pdf>
- ³¹ Joseph H. Kanter Family Foundation. 2016 Kanter Health Annual Meeting. March 24-25, 2016; 2016. <https://kanterhealthorg.wordpress.com/events/2016-kanter-health-annual-meeting-march-24-25-2016-miami-florida/>
- ³² Joseph H. Kanter Family Foundation. 2016 Kanter Health Annual Meeting. March 24-25, 2016; 2016. <https://kanterhealthorg.wordpress.com/events/2016-kanter-health-annual-meeting-march-24-25-2016-miami-florida/>
- ³³ Learning Health Community. Second Learning Health System (LHS) Summit. December 8-9, 2016; 2016. <http://www.learninghealth.org/2016-second-lhs-summit/>

-
- ³⁴ Foley T. Mapped: Learning Health System Projects. The Learning Healthcare Project (UK). 2016. http://www.learninghealthcareproject.org/location_map.php
- ³⁵ Foley T. Publications and Interviews. The Learning Healthcare Project (UK). 2016. <http://www.learninghealthcareproject.org/publications>
- ³⁶ Learning Health Community. Second Learning Health System Summit: Planning Committee Members. September 14, 2016; 2016. <http://www.learninghealth.org/s/S2-LHC-Planning-Committee-09-14-2016-V1.pdf>
- ³⁷ Foley T. International LHS Organisations. The Learning Healthcare Project (UK). 2016. <http://www.learninghealthcareproject.org/links.php>
- ³⁸ Learning Health Community. Second Learning Health System Summit: Planning Committee Members. September 14, 2016; 2016. <http://www.learninghealth.org/s/S2-LHC-Planning-Committee-09-14-2016-V1.pdf>
- ³⁹ Rubin JC, Blair HH. CODA Blog: Guest Post from 2nd Summit Collaborator, Josh Rubin. Collaborate or Fail: Building the Digital Infrastructure of the Learning Health System. *Collaboration for Open Data Alignment (CODA) Blog*. June 30, 2015; 2015. <http://collaborationforlhs.blogspot.com/2015/06/guest-post-from-2nd-lhs-summit.html>
- ⁴⁰ Robinson C. In Memoriam: Hunt Blair. A call to action: Let us honor the life and bold vision championed by a true interoperability guru. *Healthcare IT News. HIMSS Media*. September 10, 2015; 2015. <http://www.healthcareitnews.com/blog/memoraim-hunt-blair>
- ⁴¹ Learning Health Community. Second Learning Health System (LHS) Summit. December 8-9, 2016; 2016. <http://www.learninghealth.org/2016-second-lhs-summit/>
- ⁴² Friedman CP, Rubin JC, Sullivan KJ. Toward an Information Infrastructure for Global Health Improvement. *Yearbook of Medical Informatics*. International Medical Informatics Association (IMIA). August, 2017;26(01):16-23. <https://www.thieme-connect.de/products/ejournals/pdf/10.15265/IY-2017-004.pdf>
- ⁴³ Friedman CP, Rubin JC, Sullivan KJ. Toward an Information Infrastructure for Global Health Improvement. *Yearbook of Medical Informatics*. International Medical Informatics Association (IMIA). August, 2017;26(01):16-23. <https://www.thieme-connect.de/products/ejournals/pdf/10.15265/IY-2017-004.pdf>
- ⁴⁴ Learning Health Community. Second Learning Health System Summit: Participant List. December 8-9, 2016; 2016. <http://www.learninghealth.org/s/Participant-List-Merged.pdf>
- ⁴⁵ Learning Health Community. Second Learning Health System Summit: Agenda. December 8-9, 2016; 2016. http://www.learninghealth.org/s/2016LHSSummitAgenda12022016V11_Print.pdf
- ⁴⁶ Learning Health Community. Second Learning Health System Summit: Lightning Introduction Slides. December 8-9, 2016; 2016. <http://www.learninghealth.org/s/Second-LHS-Summit-Lightning-Introduction-Slides-12-2016-V-12092016-9PM.pdf>
- ⁴⁷ Friedman CP. Breakout Groups Process Overview (Day One). Learning Health Community. Presented at the Second Learning Health System (LHS) Summit. December 8, 2016; 2016. <http://www.learninghealth.org/s/Friedman-Summit-Group-Process-Slides-ver-127.pdf>
- ⁴⁸ Friedman CP. Breakout Groups Process Overview (Day Two). Learning Health Community. Presented at the Second Learning Health System (LHS) Summit. December 9, 2016; 2016. <http://www.learninghealth.org/s/Friedman-Summit-Group-Process-Slides-ver-129.pdf>
- ⁴⁹ Learning Health Community. Learning Health Systems Consensus Action Plan, Last Updated: 27 June 2017. June 27, 2017; 2017. http://www.learninghealth.org/s/LHS_Consensus_Action_Plan_06-27-2017_V10.pdf
- ⁵⁰ Silverstein JC, Friedman CP, Rubin JC. "FEEDBACK REQUESTED: Draft LHS Consensus Action Plan". Learning Health Community. March 7, 2017; 2017. http://www.learninghealth.org/s/S2_Action_Items_Feedback_Outreach_Cover_Letter_03072017_V10.pdf

⁵¹ Silverstein JC, Friedman CP, Anderson WH, Kush RD, Rubin JC. "FEEDBACK REQUESTED: Preparing the LHS Consensus Action Plan for Publication". Learning Health Community. May 4, 2017; 2017. http://www.learninghealth.org/s/S2_Action_Items_Next_Outreach_Cover_Letter_05042017_V10.pdf

⁵² Learning Health Community. Learning Health Systems Consensus Action Plan, Last Updated: 27 June 2017. June 27, 2017; 2017. http://www.learninghealth.org/s/LHS_Consensus_Action_Plan_06-27-2017_V10.pdf

⁵³ Silverstein JC, Friedman CP, Anderson WH, Kush RD, Rubin JC. "Learning Health Systems Consensus Action Plan and Key Next Steps". Learning Health Community. July 12, 2017; 2017. http://www.learninghealth.org/s/S2_Action_Items_Outreach_Letter_07122017_V10.pdf

⁵⁴ Silverstein JC, Friedman CP, Anderson WH, Kush RD, Rubin JC. "Learning Health Systems Consensus Action Plan and Key Next Steps". Learning Health Community. July 12, 2017; 2017. http://www.learninghealth.org/s/S2_Action_Items_Outreach_Letter_07122017_V10.pdf

⁵⁵ Learning Health Community. Learning Health Systems Consensus Action Plan, Last Updated: 27 June 2017. June 27, 2017; 2017. http://www.learninghealth.org/s/LHS_Consensus_Action_Plan_06-27-2017_V10.pdf

⁵⁶ Learning Health Community. Learning Health Systems Consensus Action Plan, Last Updated: 27 June 2017. June 27, 2017; 2017. http://www.learninghealth.org/s/LHS_Consensus_Action_Plan_06-27-2017_V10.pdf

⁵⁷ Learning Health Community. Learning Health Systems Consensus Action Plan, Last Updated: 27 June 2017. June 27, 2017; 2017. http://www.learninghealth.org/s/LHS_Consensus_Action_Plan_06-27-2017_V10.pdf

⁵⁸ Learning Health Community. Learning Health Systems Consensus Action Plan, Last Updated: 27 June 2017. June 27, 2017; 2017. http://www.learninghealth.org/s/LHS_Consensus_Action_Plan_06-27-2017_V10.pdf

<u>The Learning Health Community's Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS), July 20, 2012</u>		
H.)	Hyperlink	http://www.learninghealth.org/corevalues/
P.)	Preamble	<p>The national-scale, person-centered, continuous and rapid learning health system (LHS) will improve the health of individuals and populations. The LHS will accomplish this by generating information and knowledge from data captured and updated over time--as an ongoing and natural by-product of contributions by individuals, care delivery systems, public health programs, and clinical research--and sharing and disseminating what is learned in timely and actionable forms that directly enable individuals, clinicians, and public health entities to separately and collaboratively make informed health decisions. The proximal goal of the LHS is to efficiently and equitably serve the learning needs of all participants, as well as the overall public good. The LHS offers an important opportunity to facilitate sharing of data in order to serve this goal, aiming to surmount obstacles to such sharing.</p> <p>The LHS will develop as a synergy of initiatives already underway, as well as new ones that will be launched, by creating an environment that fosters collaboration and harmonization among all stakeholders. It is anticipated that the LHS, in its operation, will leverage a data federation rather than a centralized national database. The LHS will build upon enablers already taking shape, including the national pursuit of Meaningful Use of electronic health records, personal health records, and other health information technologies. Ultimately recognizing that better health for all is a global imperative, the LHS aspires to embrace strategic approaches that facilitate harmonization with other nations in pursuit of a global system, as well as within the United States.</p>

1.)	Person-Focused	The LHS will protect and improve the health of individuals by informing choices about health and healthcare. The LHS will do this by enabling strategies that engage individuals, families, groups, communities, and the general population, as well as the United States healthcare system as a whole.
2.)	Privacy	The LHS will protect the privacy, confidentiality, and security of all data to enable responsible sharing of data, information, and knowledge, as well as to build trust among all stakeholders.
3.)	Inclusiveness	Every individual and organization committed to improving the health of individuals, communities, and diverse populations, who abides by the governance of the LHS, is invited and encouraged to participate.
4.)	Transparency	With a commitment to integrity, all aspects of LHS operations will be open and transparent to safeguard and deepen the trust of all stakeholders in the system, as well as to foster accountability.
5.)	Accessibility	All should benefit from the public good derived from the LHS. Therefore, the LHS should be available and should deliver value to all, while encouraging and incentivizing broad and sustained participation.
6.)	Adaptability	The LHS will be designed to enable iterative, rapid adaptation and incremental evolution to meet current and future needs of stakeholders.
7.)	Governance	The LHS will have that governance which is necessary to support its sustainable operation, to set required standards, to build and maintain trust on the part of all stakeholders, and to stimulate ongoing innovation.
8.)	Cooperative and Participatory Leadership	The leadership of the LHS will be a multi-stakeholder collaboration across the public and private sectors including patients, consumers, caregivers, and families, in addition to other stakeholders. Diverse communities and populations will be represented. Bold leadership and strong user participation are essential keys to unlocking the potential of the LHS.
9.)	Scientific Integrity	The LHS and its participants will share a commitment to the most rigorous application of science to ensure the validity and credibility of findings, and the open sharing and integration of new knowledge in a timely and responsible manner.
10.)	Value	The LHS will support learning activities that can serve to optimize both the quality and affordability of healthcare. The LHS will be efficient and seek to minimize financial, logistical, and other burdens associated with participation.

An Alphabetical List of the 115 Organizational Endorsers of the *Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS)* (As of October 30, 2017)

For updates, please see: <http://www.learninghealth.org/endorsers>

2311, LLC
Advanced Health Institute

Alabama One Health Record
Alaska eHealth Network (AeHN)
Alliance for Nursing Informatics (ANI)
Altarum Institute
American Academy of Pediatrics (AAP)
American College of Physicians
American Health Information Management Association (AHIMA)
American Medical Informatics Association (AMIA)
American Nurses Association
American Society of Clinical Oncology (ASCO)
AMGA
AZZLY
Betterpath Technologies, Inc.
Billings Clinic
Biovista
Booz Allen Hamilton
Boston Children's Hospital Informatics Program
California Association of Health Information Exchanges (CAHIE)
CedarBridge Group
Cerner Corporation
Clinical Data Interchange Standards Consortium (CDISC)
Collaboration for Open Data Alignment (CODA)
Consortium for Oral Health Research and Informatics (COHRI)
Critical Path Institute
Dana-Farber Cancer Institute
Department of Primary Care and Public Health at Imperial College London
Diogenec Group LLP
e-Patient Dave
eHealth Initiative (eHI)
Eli Lilly and Company
Elligo Health Research
Epic
FACE Recording & Measurement Systems Ltd. UK
Farr Institute of Health Informatics Research
Galileo Analytics
GE Healthcare IT
Geisinger Health System
Genetic Alliance
GlaxoSmithKline
Global Patient Identifiers, Inc.
Harvard Pilgrim Health Care Institute
Health Catalyst

Health e-Research Centre (HeRC)
Health Record Banking Alliance (HRBA)
Healthcare Information and Management Systems Society (HIMSS)
HealthCore/WellPoint
HL7 International
Indiana University Health
Inland Northwest Health Services (INHS)
Intermountain Healthcare
Internet2
Interpreta Inc.
Johns Hopkins Medicine
Joseph H. Kanter Family Foundation
Kani Consulting Group LLC
Keep Livin
King's College London Division of Health and Social Care Research
Lambda Solutions, Inc.
Lewin and Associates LLC
MedDATA Foundation
Medical Advocacy Mural Project
Memorial Sloan-Kettering Cancer Center
Michigan Health Information Network Shared Services (MiHIN)
Minnesota Department of Health and Minnesota e-Health Initiative
Mosaica Partners
NantHealth
National Association for Trusted Exchange (NATE)
National Dental Practice-Based Research Network
National eHealth Collaborative (NeHC)
National Network of Depression Centers (NNDC)
North Carolina Healthcare Information and Communications Alliance (NCHICA)
NorthShore University HealthSystem
Oncology Nursing Society (ONS)
Open Health Tools (OHT)
Open mHealth
Open Source Health
Our Health Data Cooperative (OHDC)
OZ Systems
Patient Planet
PatientsLikeMe
Premier, Inc.
Quality Health Care Advisory Group, LLC (QHCAG)
Quantia, Inc.
Rhode Island Quality Institute

RightCare Solutions
Sanofi
SAS Institute Inc.
Scalable Collaborative Infrastructure for a Learning Health System (SCILHS)
SecureHealthHub, LLC
Siemens Health Services
Stanford Children's Health
Stewards of Change Institute
Tempus
Texas e-Health Alliance
The CDI Group
The Center for Learning Health at the Duke Clinical Research Institute
The Dairy Corporation
Thinkwise Health
ThotWave Technologies
TM Floyd & Company (TMF)
Truven Health Analytics
UC San Diego Health
University of Manchester
University of Miami Miller School of Medicine
University of Michigan
University of Pittsburgh (School of Dental Medicine, Center for Dental Informatics)
University of San Francisco Program in Health Informatics and School of Nursing and Health Professions (SONHP)
Ursus Technologies (SDVOSB)
Veterans Health Administration (VHA) Office of Informatics & Analytics (OIA)
vitaphone e-health solutions
vitaTrackr, Inc.
Vlasic & Roth LLC
WEGO Health

Categories of Multi-Stakeholder Action: The Learning Health Community's <i>Learning Health Systems Consensus Action Plan</i>	
Last Updated: June 27, 2017	
Hyperlink: http://www.learninghealth.org/2016-second-lhs-summit/	
I.)	PROMOTE AND DISSEMINATE THE TRANSFORMATIVE VISION AND VALUE
II.)	DEFINE AND ASSEMBLE COMPONENTS TO FACILITATE IMPLEMENTATION
III.)	CULTIVATE THE ORGANIZATIONAL CULTURE AND ECOSYSTEM TO DRIVE ADOPTION
IV.)	ENGAGE ALL STAKEHOLDERS, ESPECIALLY INDIVIDUALS AND CONSUMERS
V.)	FORMALIZE BEST PRACTICES
VI.)	FUND AND SUSTAIN THE MOVEMENT