COMMENTARY

Transforming the future of health together: The Learning Health Systems Consensus Action Plan

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Abstract
The Learning Health Community is an emergent global multistakeholder 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 was convened on December 8 to 9, 2016 building upon LHS efforts taking shape in order to achieve consensus on actions that, if taken, will advance 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 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 health 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, the organizers also reviewed reports of the Institute of Medicine dating\(^{10}\) to 2007 (indeed, senior Institute of Medicine leadership served on the Planning Committee and presented at the LHS Summit), trends in the digitization of health care,\(^{11}\) other publications related to "rapid-learning" and "big data" in health,\(^{12}\) 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,\(^{13}\) and more.

Internationally, the organizers looked to various European initiatives at the time including Electronic Health Records for Clinical Research (EHR4CR),\(^{14}\) the TRANSFoRm project (European LHS),\(^{15}\) the United Kingdom's National Information Governance Board,\(^{16}\) and others. Behind 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.\(^{6}\) 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 LHS vision and approach.

At the LHS Summit, over 80 individuals, representing diverse health care and health stakeholders, participated in this invitational working meeting; these included international speakers and participants.\(^{5}\) The overarching deliverable, following iterative cycles of revision engaging all participants for 2 months after the LHS Summit, was a set of multistakeholder consensus Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System.\(^{17}\) 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.\(^{17}\) More broadly, this democratizing vision for health 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.” 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.

The LHS Core Values served to bond together a global multistakeholder grassroots incipient movement, ultimately called the Learning Health Community. 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 health care and health by realizing the vision embodied by the LHS Core Values, through catalyzing multistakeholder 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). These formal organizational endorsers of the LHS Core Values represent diverse stakeholder groups, spanning the public, private, nonprofit, and academic sectors (and spanning several countries).
### 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

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. | Quantia, Inc. |
| Quality Health Care Advisory Group, LLC (QHCAG) | 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 | The Center for Learning Health at the Duke Clinical Research Institute |
| Texas e-Health Alliance | (Continues) |
| The CDI Group | (Continues) |

(Continues)
TABLE 2 (Continued)

| Organization                      |
|-----------------------------------|
| The Diary 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                       |

continents). They include organizations that compete vigorously with one another, as well as representatives of stakeholder types likely to inherently mistrust one another or to be motivated by divergent incentives, all expressing a belief in common values and in a shared vision for the future of health.

2 | 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."20

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 ... Like any grassroots endeavor, the Learning Health Community and the initiatives it spawns will become what the members of this community make it into.”20

Learning Health Community initiatives21 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, “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.”21

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 2000 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 ultimate end goal,22 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 also 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.”23 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.”23

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.”

3 | THE SECOND LHS SUMMIT24: DECEMBER 8 TO 9, 2016

By 2015, diverse stakeholders had bought into the LHS concept. They were actively working toward realizing LHSs on their own, as well as harmonizing them into the cohesive LHS vision; what was needed next was an action plan to accelerate and coalesce progress, to democratize health together.

The Learning Healthcare Project in the United Kingdom captured many of these developments taking shape around the world. 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.26,27 Ultimately, the Learning Healthcare Project came to include the Learning Health Community website as its top suggested link/resource and vice versa.28

Recognizing these developments, initially, the Interim Steering Committee of the Learning Health Community27 (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.”29 With the sudden passing of CODA’s founder Hunt Blair30 in September, 2015, 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 S1) met virtually and in-person to plan a multistakeholder 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.”31

A paper authored by three presenters at the Second LHS Summit illuminates the extent to which national and international developments informed this planning process.31 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.”32

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 S2).

With support from the Joseph H. Kanter Family Foundation, the Second LHS Summit was convened, with 98 participants,32 on December 8 to 9, 2016, at conference space generously provided by the American Society of Clinical Oncology (ASCO) just outside of Washington, D.C.33 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).34 Such data were synthesized to generate a preliminary list of potential actions that was discussed, organized, and further synthesized during the 2-day meeting. On the first day, 6 random and heterogeneous breakout groups formed to prioritize previously listed action items and to add in essential missing ones.35 Results of the work of these groups were synthesized and printed overnight. On day 2, 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.36

- Link 1: Lightning Introduction Slides Created by Participants in the Second LHS 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 9 months prior to the event, the organizers implemented efforts to reduce the environmental impact of the meeting itself, as
of health anchored in the consensus
on
holder collaboration and action, into a more formal nonprofit organiza-

tion
Community movement, already a center (and catalyst) for multi

drafts were shared, and from other participants in Learning

participants at various health conferences in which highlights of prelimi-

backs was solicited in multiple cycles from all participants in the Second

systems Consensus Action Plan

Following the Second LHS Summit, a process comprising a series of

iterative iterative revisions to drafts of the Learning Health Systems

Consortium for Learning Health Systems

and the 2016 Second LHS 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, as well

as every other stakeholder making decisions affecting health, are

engaged. 

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 transfor-
mation of health anchored in the consensus LHS Core Values.”

Doing so involves the following 4 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 accountabil-

ity/governance structure.”

Most importantly, though, is our collec-
tive calling to unwaveringly, “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.” Indeed, through grounding our shared efforts and vision in

these multistakeholder consensus LHS Core Values, we will trans-

form the future of health together.

ACKNOWLEDGMENT

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 LHS Summit

and the Joseph H. Kanter Family Foundation. The generosity of the

LHS Core Values

and the Joseph H. Kanter Family Foundation.

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

intervowe collaboration and action to advance LHSs.

4 | THE LEARNING HEALTH SYSTEMS

CONSENSUS ACTION PLAN

Following the Second LHS Summit, a process comprising a series of

collaborative iterative revisions to drafts of the Learning Health Sys-

tems Consensus Action Plan took place until June 2017. Iterative feed-
b ack 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 par-
cipants at various health conferences in which highlights of prelimi-
nary drafts were shared, and from other participants in Learning

Health Community initiatives. Please see Table 3 for an overview

of the categories of action envisioned.

In releasing the Learning Health Systems Consensus Action Plan, it

was acknowledged that, “Unlike the timeless multi-stakeholder con-
sensus LHS Core Values, the consensus action plan will be a living doc-
ument that will change and adapt over time.” Next steps envisioned

include disseminating the plan, working to solicit volunteers to facil-
tate 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-stake-
holder collaboration and action, into a more formal nonprofit organiza-
tion... together, we will accelerate progress toward the transformation

of health anchored in the consensus LHS Core Values.” Please see

Exhibit S3.

TABLE 3 A list of categories of multistakeholder action from the Learning Health Community’s Learning Health Systems Consensus Action Plan

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 |

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SUPPORTING INFORMATION
Additional Supporting Information may be found online in the supporting information tab for this article.