Lightning Introduction Slides
Jonathan C. Silverstein, MD, FACMI
Chief Medical Informatics Officer

Share data securely for authorized purposes (and promote secure data liquidity).

learninghealth.org kanterhealth.org www.computationdoc.com tempus.com
Our organization, the Department of Learning Health Sciences at the University of Michigan, has begun building components of a scalable infrastructure that will be essential to a high-functioning LHS. The keystone to this effort is the “Knowledge Grid” that can support the “knowledge to practice” side of the learning cycle. We have also started a journal focused on LHS.

http://lhs.medicine.umich.edu/people/charles-p-friedman
http://lhs.medicine.umich.edu/
lhsjournal.com
Demonstrate concretely and openly how steps taken toward an LHS are contributing to the Triple Aim in healthcare and how taking the steps can fit the business model of organizations like yours.

www.linkedin.com/in/DarinHumphreys
Darin.Humphreys@imail.org
Joshua C. Rubin, JD, MBA, MPH, MPP
Vice President of the Board of Directors (Kanter Health Foundation)

Drive a consumer-mediated health information ecosystem by providing patients with real-time convenient access to their health data in usable and actionable forms.

http://www.kanterhealth.org/joshua-c-rubin
http://lhs.medicine.umich.edu/people/joshua-c-rubin
E: Josh@JoshCRubin.com
Lightning Introduction Slides
Your Name
Your Title

Your Photo

Your Organization’s Logo (or Your Organization’s Name)

Your Response to ONE of These Two Questions:

a) What one key thing has your organization done to advance our progress towards realizing a LHS? OR

b) What one key action step could all organizations like yours take to accelerate our progress towards realizing a LHS?

Links to Your Webpages and Contact Information
HIMSS demonstrates the Core Values of the LHS through our:
- Strategic Plan
- Interoperability Showcase
- Innovation Center
- Communities

And through the thought leadership of our 64,000 individual members, 640 corporate members, and over 450 non-profit organizational partners working to achieving an LHS.
Holt Anderson, AB
Principal

NCHICA, with support from its Board of Directors and Informatics & Analytics Roundtable, was an early endorser of the LHS Core Values and continues to promote the vision of achieving an operational LHS among its 300+ member organizations.

LHS@nchica.org
919-740-8697 (Mobile)
www.nchica.org
Juli A. Baker, PhD

Stewards of Change Institute – through thought leadership and hands-on collaboration with governments, industry and nonprofit organizations – has championed the understanding and use of interoperability and information-sharing to advance the social determinants of health and well-being across systems, thereby creating greater receptivity to LHS.

www.stewardsofchange.org
juli@stewardsofchange.com
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https://www.linkedin.com/in/michaelsbarr
Gary Bartholomew, BSc
Executive Chairman

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http://nhitunderserved.org/
Consulting organizations, including independent consultants, can maintain awareness of the bigger picture and keep the end in mind. Hopefully my work in Health IT can support incremental progress towards a LHS, connecting the dots between the work at hand and the larger goal.

https://www.linkedin.com/in/terrybequette
terrybeq@gmail.com  541.743.1680  PO Box 603, Hinesburg VT 05461
ANA continues to invite and engage all registered nurses, advanced practice registered nurses, colleagues, and other stakeholders in promoting health, wellness, safety, quality, standards, and robust healthcare consumer partnerships in all healthcare settings. Nurses contribute in so many ways to the advancement of the LHS values and integration of the vision into the reality of a pervasive Learning Health System.

www.nursingworld.org  carol.bickford@ana.org  301-628-5060
In order to create a strong ecosystem of health, that “efficiently and equitably serve[s] the learning needs of all participants” it is essential to make sure that diverse voices are not only heard, but their values and needs are acted upon.
We are developing an implementation of a LHS based on aggregated decedent data from multiple healthcare institutions.

http://kanterhealth.org
https://www.linkedin.com/in/eric-brown-2882993b
ecbrown@kanterhealth.org  847.757.0043
All organizations like mine should acknowledge, accept, and embrace the reality that a LHS will require organizations like mine to facilitate and support the research of others.

http://www.populationmedicine.org/node/209
https://www.linkedin.com/in/jeff-brown-dpm
www.popmednet.org
As an individual angel investor, member of the Mid-America Angels (Kansas City) and the national Angel Capital Assn., I am working on a solution to the following problem: the main obstacle to learning from the delivery of healthcare is the lack of sustainable economic incentives to collect research-quality, person-centered data and make it available to multiple prospective learners at reasonable cost. As a result, people don’t have health records. This problem is unchanged by the digitization of medical records.

https://www.linkedin.com/in/john-burch-720b0012
jlburch@mindspring.com
We have established the Center for Health Innovation and Delivery Science, whose goal is to rapidly translate research into practice. We evaluate those programs using a rigorous implementation science framework.

http://www.med.nyu.edu/pophealth/faculty/cantom01
michael.cantor@nyumc.org
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We assist AMGA members in improving population health, using comparative benchmarking to discover opportunities, and predictive analytics to identify high-risk patients. We drive discovery and sharing of best practices, and we help members translate them into practice, helping move data into action.
NLM HAS CONSISTENTLY BEEN A CHAMPION OF STANDARDS FOR HEALTH IT
Build momentum by raising awareness and gaining institutional support in our organizations so that we can:

1. Have capacity to engage and contribute to Learning Health System initiatives, projects, task forces
2. Identify others in our organizations who are interested; build coalitions in our organizations to help progress the Learning Health System
3. Inform our organizations’ strategies, initiatives and projects; prepare our organizations for an operational Learning Health System
King’s College London was an early adopter of the Learning Health System, through a series of projects, most notably EU TRANSFoRm. We are currently building on that work in the areas of clinical trials, decision support systems and data provenance, developing tooling and standards for specific domains.

W: https://sites.google.com/site/vasacurcin/
E: vasa.curcin@kcl.ac.uk
Lesley Curtis, PhD
Director, Center for Population Health Sciences

A key step institutions can take is to commit pilot funds to develop and rigorously test interventions aimed at improving healthcare delivery. Learnings from these pilots, in turn, can inform the development and evolution of a nimble, reusable infrastructure that supports rapid deployment and evaluation of interventions.
Develop a framework and approach to phased implementation of a LHS, integrated with commitments to the “3 - 4 Aims” and NQS as well as population health.

301 468 1166 / 301 832 2734 Cell
l.diamond@QHCAG.com
http://qhcag.com/
In response to a 2015 Institute of Medicine report on improving cardiac arrest survival in the United States, the American Heart Association committed to supporting a resuscitation learning health system to save an additional 50,000 lives/year. The AHA is working to drive the implementation of best practices while creating and capturing new knowledge as part of the patient care process.

http://circ.ahajournals.org/content/132/11/1049

https://www.linkedin.com/in/brianeigel
Thomas Foley, BSc, MPhil, MBBS
Principal Investigator

The Learning Healthcare Project has tried to link the literature, experts, clinicians, patients and policy makers. Highlighting the benefits and challenges of Learning Healthcare Systems to each group.

www.learninghealthcareproject.org
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Gregg Gilbert, DDS, MBA
Network Chair / Professor

Established a highly productive practice-based research/CQI network of several thousand dental offices nationally. In operation since 2005.

Web site: NationalDentalPBRN.org
Email: NationalDPBRN@uab.edu
My organization has funded, and continues to fund, health IT research in a variety of care settings that support measurement of rapid learning systems (monitoring safe use of health IT to order correct medications) and ways in which health IT can support the generation and application of evidence in healthcare settings (successful models for using patient-reported outcomes).

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3638184/
https://healthit.ahrq.gov/
Johanna.GoderreJones@ahrq.hhs.gov or 301-427-1453
AHRQ continues to be committed to the learning health system through its ongoing work to produce evidence to make health safer, higher quality, more accessible, equitable and affordable and using this evidence to drive improvement in the health care system.

The Leadership Consortium for a Value & Science-Driven Health System is comprised of senior leader and innovator members whose organizations work collaboratively through the National Academy of Medicine in advancing progress toward a continuously learning health system, care that is more efficient and effective, and better health for Americans.
HL7 International, the premier SDO, contributes a new standard, FHIR®, to enable interoperability for the data sharing and data transport that is critical for Learning Health.

Duke Health not only has a number of SMART-on-FHIR apps that contribute to LHS, but provides several learning opportunities in Learning Health.

www.hl7.org/fhir/
www.dchi.duke.edu
www.ctsi.duke.edu
william.hammond@duke.edu
We will get action when everyone is at the table.

That hasn’t happened yet. I hope through LHS we get there faster.

Until then, I will paint, speak, and write about the patient viewpoint in an effort to have those voices represented.

http://reginaholliday.blogspot.com/
https://twitter.com/ReginaHolliday
https://www.facebook.com/regina.holliday
ThotWave has created the Healthcare Analytics Competency Model that defines the skills, knowledge, and abilities that should be present within a healthcare organization so that data-driven insights can be discovered, socialized, operationalized, and their impact maintained. This model aligns to two other analytics certification bodies and uniquely incorporates competencies needed by those who support the analytics life cycle, such as product managers and business analysts.
Attempting to achieve Patient Centered Focus with Population Management and CPC+
Clifford Hudis, MD
Chief Executive Officer

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Applied registry data from patients with polycystic kidney disease to develop and validate a biomarker for use in trials to evaluate therapies for polycystic kidney disease.

https://c-path.org/programs/pkd/regulatory-successes/

LHudson@c-path.org https://c-path.org
Kanter Health Foundation: We are working toward realizing a health system in which every decision affecting health is informed by knowledge of “what works best”.

www.KanterHealth.org
www.unitedwestlabs.com
Kanter Health Foundation: We are working toward realizing a health system in which every decision affecting health is informed by knowledge of “what works best”.

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www.KanterHealth.org
Rebecca Kush, PhD
Founder and President

Develop global clinical research data, transport and interoperability standards (which work synergistically with those of other SDOs) that are housed in a curated electronic library (SHARE) from which the harmonized standards can be accessed electronically to automate processes to accelerate the LHS feedback loop, thus more rapidly bringing research results into care decisions and reducing research silos to unlock cures.

www.cdisc.org
www.unlockcures.org
What one key action step could all organizations like yours take to accelerate our progress towards realizing a LHS?

- Build and support robust research programs linked to clinical practice and health system operations
- Streamline administrative processes and remove barriers to publishing results of program evaluation, quality improvement, and rapid analyses so the broad community can learn from our experiences

[crn.cancer.gov](http://crn.cancer.gov)
[www.dor.kaiser.org](http://www.dor.kaiser.org)
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Links to Your Webpages and Contact Information
CancerLinQ has begun to accrue data from a wide variety of oncology settings (physician office, hospital, health system, cancer center) and now has 1.5 million unique patient records. We are feeding back information of quality metrics and plan to be able to extract new insights into cancer care starting next year.
Creating an organizational culture that cultivates learning and is capable of harnessing the value of data, information and analytics enabled by digital technology
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Links to Your Webpages and Contact Information
Key step:
Developing framework (cost, governance, measurement, etc.) that enables rapid testing/deployment of interventions followed by decision on whether to scrap, scale or maintain.

Most important - if scale or maintain, how to fund increased institutional support burden!

https://www.cincinnatichildrens.org/bio/m/keith-marsolo
keith.marsolo@cchmc.org
VA is committed to continuous improvement, and a palpable appreciation of the LHS imperative is occurring in both policy and practice, representing progression toward cultural alignment of leadership in research, education, and clinical operations.

https://www.va.gov/
David.Massaro@va.gov
John Mattison, MD
Chief Medical Information Officer

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The raw material of a Learning Health System is data – structured, machine-readable, patient-accessible data. Without it, a true LHS will never exist.

Allowing individuals to access their data for their own use in the platform of their choice isn’t just a policy need but a moral imperative.

www.galileoanalytics.com and www.stsiweb.org
Meryt McGindley
Vice President, Communications & Public Affairs

NATE is the only trust community focused exclusively on the enabling infrastructure required to enable consumers access to their health information. NATE operates the Blue Button for Consumers Trust Bundle and is collaborating with CMS and others on the TrustHarbor - a trust enabling mechanism for API based transactions.

www.nate-trust.org
meryt.mcgindley@nate-trust.org
310-345-1960
The Diary Corporation has maintained a focus on the collection of health data, personal and clinical, in a single place to cultivate better understanding of health for individuals, family members and the health community in which they choose to participate.
Study health data sharing preferences of consumers to understand public policy and legal implications for interoperability. Objective is meaningful inclusion of consumer voice in developing data governance structures and consent management mechanisms.

https://www.linkedin.com/in/lisa-moon-1a60b747
Since 2004 PatientsLikeMe (PLM) has advanced the value of patient reported and generated data as integral to achieving the promise of a continuously learning health system. With 90+ scientific publications and posters sourced from patient data PLM together with our members are thought leaders in the emerging science of patient centric engagement and empowerment in care, research and development.

sokun@patientslikeme.com | Twitter
http://www.patientslikeme.com | Twitter | Facebook | Blog
The Stanford University Research Compliance Office has taken an active, nuanced approach to differentiating activities of a learning healthcare system from traditional clinical investigations. Within that context, the Stanford University Clinical Informatics Fellows are encouraged to pursue systematic, data-driven, & rigorously evaluated informatics interventions to improve the quality of care and to share their results through publication.

http://systemsmedicine.stanford.edu/education/CI-Fellowship.html
npageler@stanford.edu
(650) 796-7167
Stewards of Change Institute – through thought leadership and hands-on collaboration with governments, industry and nonprofit organizations – has championed the understanding and use of interoperability and information-sharing to advance the social determinants of health and well-being across systems, thereby creating greater receptivity to LHS.

www.stewardsofchange.com
apertman@stewardsofchange.com
Joe Peterson, MD
CEO

SureTouch / Medical Tactile, Inc.

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http://suretouch.us/
http://medicaltactile.com/
For the last six years, MiHIN has fostered pervasive distribution of ADT message content and care summaries across the entire state of Michigan. More than 99% of statewide admissions (over 6,000,000 messages/week) are now routed through the MiHIN network, helping to improve healthcare quality, efficiency, and patient safety by promoting secure, electronic exchange of health information.

Email: pletcher@mihin.org
Web: www.mihin.org
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https://www.healthit.gov/newsroom/steven-posnack-ms-mhs
Casey Quinlan
The Mighty Mouth

My work is focused on open data, open science, and participatory medicine. As a journalist and content consultant, I advocate daily for inclusion of the patient perspective in quality improvement, clinical trial design, health literacy, care delivery, public health, and health/science journalism. Dedicated to embedding shared decision making in every clinical encounter, and making science accessible to just-plain-humans. And I wrote a comedy cancer memoir *Cancer for Christmas: Making the Most of a Daunting Gift*.

casey@mightycasey.com | Twitter | Facebook | LinkedIn

info@cancerforchristmas.com | Twitter | Facebook
Large employers and state governments are purchasing healthcare services for their employees without sufficient consideration of contractual terms that could accelerate the U.S. toward a learning health system. Organizations working in this space should engage purchasers wherever possible, educating on the value propositions of electronic data exchange and the possibilities of quality improvement with the availability of actionable data.

www.cedarbridgegroup.com
carol@cedarbridgegroup.com
503-477-8773
For stakeholders within commercial organizations, reframe the “business purpose” of efforts that are aligned with the tenets of LHS.
HIMSS is a global, cause-based, not-for-profit organization focused on better health through information technology (IT). HIMSS leads worldwide efforts to optimize health engagements and care outcomes using information technology and health IT thought leadership, education, events, market research, and advocacy. The scale, breadth and diversity of HIMSS affords us with a perspective unlike any other organization, and the ability to inform the evolution of the LHS.
Richard A. Rudick, MD
VP, Development Sciences, VBM

Biogen has supported a project called MS PATHS (Partners Advancing Technology for Health Solutions). MS PATHS is a demonstration project of a learning health system for Multiple Sclerosis.

Richard.Rudick@Biogen.com
Genentech’s Learning & Clinical Integration (LCI) team supports learning initiatives that accelerate the awareness and application of evidence-based medicine, in turn ensuring appropriate care for patients – both today, and tomorrow. Once the Medical Education & Research Grants team, LCI recognized the need to adapt toward a philosophy of improving the care experience for patients through systems-based lifelong learning that improved clinical quality while reducing the amount of time it takes for evidence to be fully integrated into practice. This challenge has required us to learn more about the Learning Health System so that we may champion it to educational stakeholders.
NATE is the only trust community focused exclusively on the enabling infrastructure required to enable consumers access to their health information. NATE operates the Blue Button for Consumers Trust Bundle and is collaborating with CMS and others on the TrustHarbor - a trust enabling mechanism for API based transactions.

www.nate-trust.org
aaron.seib@nate-trust.org
301-540-2311
We developed a visual analytics tool, EventFlow, to facilitate data cleaning & exploration for pattern discovery in Electronic Health Records.

http://hcil.umd.edu/EventFlow
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Since becoming an LHS endorser, TM Floyd & Company has:

- Been an active member of the LHS Policy and Governance Workgroup
- Conducted discussions with healthcare organizations to create greater awareness regarding the role of LHS in the healthcare of today and tomorrow
- Delivered consulting services to healthcare organizations to help them strategize, enhance, and integrate their technology systems and data for active participation in an operational LHS

jstarmack@tmfloyd.com
1301 Gervais Street | Suite 1700 | Columbia, SC 29201
803.227.1878
The University of Texas Dell Medical School has an explicit mandate to improve the health of central Texas and measure outcomes that matter to the community. We focus on improving capability, comfort, and calm of those in the embrace of care while also recognizing Health happens outside our brick and mortar facility. We seek to revolutionize how people get and stay healthy by creating a vital, inclusive, health ecosystem.

https://dellmedschool.utexas.edu/
Stewards of Change Institute – through thought leadership and hands-on collaboration with governments, industry and nonprofit organizations – has championed the understanding and use of interoperability and information-sharing to advance the social determinants of health and well-being across systems, thereby creating greater receptivity to LHS.

www.stewardsofchange.org
I have been getting the word out about LHS on podiums at HIMSS16 and the National Caregiving Conference -- where LHS was the focus of an exhibit table called “Healthcare Activism and YOU”.

Twitter: @SterlingHIT
Email: msterling@sterlinghealthit.com
Optum has continued to make themselves available to be part of the process. Identifying opportunities to participate and offer data expertise.
We are working to develop a multi-disciplinary field of *cyber-social learning systems* (CSLS). CSLS integrate physical, information, and human elements at scale. To achieve transformational improvements (such as a 10X reduction in mortality due to avoidable medical errors within 20 years), CSLS require new systems thinking, deeply integrating physical, computational, social, and domain science, engineering, and design. LHSs are a special cases of CSLS, major subjects of study for, and essential partners in this new discipline of CSLS.
Tannen, Richard
Emeritus Professor

I am on organizing committee, but PENN does not play a role in this process

U Penn

Tannen@mail.med.upenn.edu
Suggestion for academic institutions:
Design, implement and experiment with LHS prototypes in small subset domains as research/engineering theses and group capstone projects.

Wactlar@cmu.edu
https://www.cs.cmu.edu/~hdw/
In the fall of 2015, ONC released *A Shared Nationwide Interoperability Roadmap v.1.0*. The Roadmap, shaped by stakeholder input, lays out a clear path to catalyze the collaboration of stakeholders who are going to build and use the health IT infrastructure. The collaborative efforts of stakeholders is crucial to achieving the vision of a learning health system where individuals are at the center of their care; where providers have a seamless ability to securely access and use health information from different sources; an individual's health information is not limited to what is stored in electronic health records (EHRs), but includes information from many different sources and portrays a longitudinal picture of their health, not just episodes of care; and where public health agencies and researchers can rapidly learn, develop, and deliver cutting edge treatments.

https://www.healthit.gov
Twitter: @VindellW
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Links to Your Webpages and Contact Information
For 20 years, the last 13 within Anthem, one of the largest payers in the US, our organization has worked to mold the natural healthcare data environment derived from the normal course of healthcare delivery into a reliable system for real-world evidence development the designs of which include pragmatic clinical trials.

www.healthcore.com
Marcus Wilson, President, HealthCore| 123 Justison Str. Wilmington, Delaware | 302-230-2120
An Anthem Company
Marc Wine, MHA
Executive Strategic Lead, Clinical Informatics

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Extra Slides
Your Name
Your Title

Your Photo

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As the oldest asthma and allergy voluntary health organization in the U.S., the Asthma and Allergy Foundation of America (AAFA)’s mission is to improve the lives of people with asthma and allergies, through advocacy, research and education. AAFA supports the incorporation of patient perspectives, values, and outcomes (including patient generated and reported data) in patient care; research; public policies; innovation and discovery; and information dissemination. We believe that the LHS must encourage and support the conversion and translation of health and health care information into language understandable and usable by patients, families and caregivers.

mbloomrosen@aafa.org
Phone: 800.7.ASTHMA ext 223
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As a professional keynote speaker and business advisor I evangelize the IOM’s words in 2012: “A learning health care system is anchored in patient needs and perspectives.” Any provider who doesn’t know this is behind the times, and one who knows it and doesn’t agree is ignoring our most senior medical thinkers. :) 

Since 2015 I’ve been further evangelizing for creation of a new science of patient engagement, to formalize and rigorously develop what the IOM’s words should mean, in scientific terms and in evidence-based practice. Without this our efforts can’t be credible to scientists.

copyright 2016 e-Patient Dave LLC
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Links to Your Webpages and Contact Information
Jill Erickson, MPH, RD
Director, Independent medical Education & External Affairs

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ACP has consistently called on CMS and other relevant agencies to use the opportunities created via the Medicare Access and CHIP Reauthorization Act (MACRA), as well as other value-based payment approaches, to build a learning health and healthcare system. We believe this can be done by structuring measurement and reporting programs in such a way that they facilitate ongoing innovation and learning.

www.acponline.org
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Ahmed Ghouri, MD
CEO / Founder

Realize “a realtime interpreted ecosystem”:

E: Ahmed@interpreta.com
http://www.interpreta.com/
Kenneth Goodman, PhD
Director, University of Miami Institute for Bioethics and Health Policy

The University of Miami Miller School of Medicine Institute for Bioethics and Health Policy has tried to help ensure that ethical issues motivate, stimulate and guide the evolution of learning healthcare systems.

http://www.miami.edu/ethics
kgoodman@med.miami.edu
Your Response to ONE of These Two Questions:

a) What one key thing has your organization done to advance our progress towards realizing a LHS? OR

b) What one key action step could all organizations like yours take to accelerate our progress towards realizing a LHS?
Claudia Grossmann, PhD
Program Officer

Patient-Centered Outcomes Research Institute

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Links to Your Webpages and Contact Information
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Links to Your Webpages and Contact Information
Telehealth companies should ensure that any telehealth interactions - and associated data and images - are part of each person’s total health record. With a patient’s permission, telehealth consultants should have access to appropriate past health information from EHRs and HIEs as well as to context- and person-specific decision support tools that incorporate the latest health system knowledge to optimize each patient’s health and well-being.

www.vitelnet.com
robkolodner@vitelnet.com
Cell: (443) 864-2004
### Scalable Collaborative Infrastructure for a Learning Health System

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www.usfid.com
### Suniti Ponkshe
Sr. Vice President

UnitedHealth Group, Optum

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The National Network of Depression Centers is a nonprofit research consortium comprised of 25 leading academic medical depression centers around the country. The NNDC has a mission to transform the treatment of mood disorders and has invested years in LHS development and proof-of-concept testing to support that mission. The NNDC Mood Outcomes Program is transforming and improving patient care through the use of measurement-based care tools and quality improvement programs informed by patient care data at our centers.

Email: prinvelt@nndc.org
Web: www.nndc.org
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www.KanterHealth.org
www.unitedwestlabs.com
For better healthcare every consumer can have a secure, digital, lifetime health record that the consumer controls and can make available to any site of care and medical research they care about. Benefits include faster, more coordinated, less expensive care, better outcomes, improved consumer experience with doctors and hospitals, faster, less costly medical research, and greater health record security.

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