

July 20, 2012

Developed at the May, 2012 Learning Health System Summit

Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS)

Preamble

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.

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.

Core Values

The design and operation of the national-scale LHS derive from its core values:

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.

Template of LHS *Core Values* Endorsement Letter

LETTERHEAD of Organization

<date>

Joshua C. Rubin
Executive Director
Joseph H. Kanter Family Foundation
901 North Pollard Street, #1107
Arlington, VA 22203

Dear Mr. Rubin:

Via this letter, <organization name> formally indicates its endorsement of the Learning Health System (LHS) *Core Values*, as expressed in the document of that name dated July 20, 2012.

<organization name> endorses these *Core Values* to express to its support for the concept of a national-scale LHS, and to express its belief that these values are foundational to a successful, multi-stakeholder process to advance the nation toward an LHS in pursuit of better health for all.

This endorsement does not commit <organization name> to participation in any specific activity, nor does it commit any resources on the part of <organization name>. This endorsement does authorize the inclusion of <organization name's> name on a public website that will list all organizations that have endorsed the *Core Values*, as well as in a one-time press release. Any other use of <organization name's> name in connection with this endorsement will require specific advance permission.

This endorsement may be withdrawn at any time.

SIGNATURE LINES

About the Joseph H. Kanter Family Foundation and Joe Kanter

Almost two decades ago, I founded the Joseph H. Kanter Family Foundation (KFF) with resources I accumulated over a long business career. KFF was born of the frustrations I faced as a prostate cancer patient unable to obtain scientific evidence about “what works best” in health care, based on the collective real-world experiences of other patients – evidence that would have helped me, and others like me, make better informed, life-or-death health decisions. The staff of KFF, my many colleagues in the public and private sectors, and I have been working tirelessly ever since to change that. What is today known as a Learning Health System, or LHS, will empower researchers, clinicians, and patients to learn from real-world health experiences of millions of patients as these experiences are increasingly recorded in electronic, computable form. Our nation’s fast march toward meaningful use of health IT will move us a giant step in the right direction by digitally capturing these health experiences as a byproduct of delivering care. However, much work still needs to be done to construct an LHS atop a foundation of meaningful use.

The LHS we aspire to build will be a gift that will touch the lives and health of those living today as well as future generations, including my five grandchildren. It is a gift I have been dreaming of giving to humanity for almost two decades. The work we are all doing will help transform this dream into a bold new reality – one in which we can all share.



From Left to Right: John Kanter (Son), Nancy Kanter (Spouse), Former Senator George Mitchell (D-ME), Joe Kanter, Hillary Kanter (Daughter), Former Senator Bob Dole (R-KS)

Contact Information

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

Executive Director

Joseph H. Kanter Family Foundation

+1.703.248.3142 Direct

+1.703.248.3231 Fax

+1.914.393.6740 Cell

Josh@JoshCRubin.com

www.KanterHealth.org

What will be YOUR Health Legacy?

