

Patient Empowerment and the Learning Health System

Guest Editor:

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Introduction

“He rests his hand on a tree of knowledge as he points to a city in the distance. Here is the city on a high hill for all to see. This is a symbol of the Learning Health System... [The] patient is the great unknown variable as we climb the hill. He has not yet been activated and could do so much good... I guess [it] is kinda frightening trying something new. It is sort of chaordic. But that is the energy that we need to crest this hill.” – Patient Activist and Artist Regina Holliday, 2012¹(“Health Care’s Rosa Parks”²)

Welcome to Issue 3 of *Learning Health Systems*, focused on “Patient Empowerment and the Learning Health System.” As Guest Editor for this theme issue, I find this topic near and dear to my heart, as it would be to the hearts of anyone who ever has been or will be a

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patient or caregiver. We all stand poised to benefit from a health system in which opportunities for learning engender empowerment of everyone.

The contributing authors share perspectives from diverse backgrounds. Almost all of them are motivated in part by some personal experience as a patient or caregiver when they learned something about themselves, about others, or about the health system that touched and changed their lives. Their efforts are driven by partnerships between patients themselves and other stakeholders, recognizing the paramount importance of putting people at the center of their collaborative work to protect and improve health, often driven through processes of learning.

The papers illuminate how patient (as well as family and community) participation advances the vision for a Learning Health System (LHS) – and in turn how a LHS supports patient-empowering initiatives. Indeed, the National Academy of Medicine (NAM) sees “engaged, empowered patients” as a key characteristic of a LHS,³ and the multi-stakeholder consensus *Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System* (endorsed by over 100 organizations globally⁴ and referenced in United States federal health IT strategic planning⁵) begins with “Person-Focused” as the first shared *LHS Core Value*.⁶ The papers in this theme issue bring a participatory LHS vision to life and paint vivid pictures of what it could look like and be like. The distinct person-

centered approach to transforming health embodied in each paper manifests itself as a use case for a LHS sociotechnical infrastructure. Many authors illuminate how a LHS will advance or transform their work.

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TABLE 1

<i>Table 1: The Learning Health Community's Core Values Underlying a National-Scale Person-Centered Continuous Learning Health System (LHS), July 20, 2012</i>		
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.

About the Authors

When *Learning Health Systems* issued a general call for papers, we received an overwhelming response from individuals and organizations spanning the health spectrum, and sharing their interest in patient empowerment through learning. Several papers in this issue bring years or decades of being a patient or caregiver as their expertise. Others bring professional training in varied professions that must collaborate to realize a person-centered LHS. Some have made careers as patient and caregiver activists. Others have built nonprofit organizations and for-profit startups aimed at advancing patient empowerment. Still others serve as leaders within federal government regulatory agencies, public health organizations, health IT organizations, advocacy organizations, patient communities, and academia. All of these authors are extraordinary communicators; all have compelling research to share or powerful stories to tell. We are grateful they chose to share them with the world through our open access online journal.

Whether explicit or implicit, the underlying motivations for the work showcased in the papers in this theme issue often emanate from the authors' deeply personal interactions as patients and caregivers. For example, one author, who is a registered nurse, is a leader at a patient community digital platform founded by two brothers when their third brother was diagnosed with amyotrophic lateral sclerosis (ALS). Yet another author, exasperated by seeing firsthand how factors such as skin color, gender, zip code, and socioeconomic status (as well as myriad social determinants of health outside the doctor's office) too often

predict health outcomes, proposes a novel framework for integrating equity into a LHS, recognizing that health equity is embedded in the *LHS Core Values* and the grassroots movement bonded together by them.⁷ In this paper, the author proposes a framework leveraging the power of patients and the LHS vision to address what Rev. Dr. Martin Luther King, Jr. recognized over half a century ago: “Of all the forms of inequality, injustice in health is the most shocking and inhuman.”⁸ From seemingly unlikely places, such as a federal regulatory agency, a nonprofit association with many of large health IT vendors as members, and a global pharmaceutical/life-sciences company, other authors exude comparable passion for empowering patients to protect and improve their health and the health of others.

A Science of Empowerment

Recognized patient activist “e-Patient Dave” deBronkart, citing the half-century-old *The Structure of Scientific Revolutions* by Dr. Thomas Kuhn, has been among the earliest advocates for envisioning a new science of patient engagement.⁹ His thinking on the subject points to a natural complementarity with the science of learning systems when one considers his proposed definition for empowerment. Referencing a 2002 World Bank definition, deBronkart states, “Empowerment is increasing the capacity of individuals and groups to make choices and transform those choices into effective actions and outcomes.”¹⁰

Consider the apparent synergy between an area of science anchored in increasing the capacity of individuals and groups to make decisions and a hallmark of a LHS that “health-related decisions by individual members of society, care providers, and managers and planners of health services” are themselves underpinned by timely, actionable, trustworthy, and routinely updated best practice knowledge of what works best gleaned from the study of “every patient’s characteristics and experiences...”.¹¹ In realizing a LHS at a nationwide or at an international scale, the importance of this science of empowerment becomes even more paramount when one recognizes that a LHS is not only “human intensive” but also that, “The system as a whole – not just the digital infrastructure, but also networks of people and institutions – will have to be understood not just as users of a technological infrastructure, but also as parts of the information system itself.”¹²

The Patient Empowerment Imperative

Dr. Charles Safran, who has served as a leader at national and international medical informatics associations, recognizes the patient empowerment imperative; Dr. Tom Ferguson’s 2007 *e-patients* whitepaper¹³ leads off with a quote by Safran: “... [When patients] participate more actively in the process of medical care, we can create a new healthcare system with higher quality services, better outcomes, lower costs, fewer medical

mistakes, and happier, healthier patients. We must make this the new gold standard of healthcare quality and the ultimate goal of all our improvement efforts: Not better hospitals. Not better physician practices. Not more sophisticated electronic medical systems. Happier, healthier patients.”¹³

In Issue 1 of *Learning Health Systems*, an allusion to the four system-level requirements of a LHS (including that a LHS be “trusted and valued by all stakeholders”) by Editor-in-Chief Dr. Charles P. Friedman suggests that “Transcendent research challenges... may require new methods and new modes of thinking that evolve naturally from the admixture of (diverse social and technical sciences) disciplines.”¹¹ In this issue, we evidence the importance of including among these research challenges those associated with the study and advancement of empowerment of patients, caregivers, families, communities, and other stakeholders, in part through learning. These papers show how the emerging research methodologies they share can and must contribute to the (sociotechnical) science of learning systems.

There is a saying in policy circles that if one is not at the table, he/she is likely on the menu. Patient activist Sharon Terry of the Genetic Alliance (and PCORnet’s Executive Committee) gave a speech on participant-driven research using a similar phrase in its title last year.¹⁴ Further investment in the development of the envisioned scientific components will

contribute invaluablely to giving a seat at the table and a powerful voice in the dialogue shaping the future of health to patients, families, and those who advocate for and benefit from patient empowerment. It will prepare us for a paradigm shift in which, as Dr. Eric Topol writes (to patients), “The Future of Medicine is in Your Hands”.¹⁵ It will form the foundation underpinning a people-powered transformation of healthcare and health,¹⁶ and perhaps even a corresponding patient-driven health information economy.¹⁷

The envisioned participation becomes especially invaluable when one considers the emergent nature of a LHS and the extent to which individuals play a role in shaping it. The scientists envisioning “An Ultra-Large-Scale Systems Approach to National-Scale Health Information Systems”¹⁸ recognized: “A web server is designed and engineered. The internet protocol, IP, and HTTP were designed and engineered. The World Wide Web (WWW) was not. Rather, it emerged from the decentralized and locally autonomous actions of many independent actors acting within the framework of the WWW architecture. A building is designed and engineered. A city is planned and governed, but it emerges largely outside the direct control of a designer or engineer. A garden plan is designed, but the garden emerges, without either the control or the need for actions by the gardener.”¹⁸

As an ultra-large scale (cyber-social) system, a LHS, especially at a nationwide scale, will have the emergent characteristics of the aforementioned WWW and city (and garden).

Realizing it in a way that engenders the qualities desired will require that patients, consumers, and individual citizens be a part of the system and invaluable contributors to it, not merely passive recipients of its envisioned benefits, however benevolent. Patient empowerment will be an outcome of a LHS, but also an important engine propelling it.

Just as a LHS cannot simply be built from a blueprint,¹¹ a LHS cannot simply be built by others for patients; it must be built with and by patients (and all other stakeholders).

While the papers in this theme issue generally highlight positive paths to addressing challenges and advancing empowerment, there are myriad studies (and individuals and organizations) that highlight present failings in our healthcare system to empower patients. Hence, the papers in this issue also provide guidance toward a course correction.

As the future of healthcare and health moves in the LHS direction, the importance of patients shaping the design of the system becomes paramount. Think for a moment, outside of healthcare, about your interactions as a consumer in any system that (often in the name of efficiency) was designed without considering the needs of (or input from) consumers and workers, rendering them cogs in a machine. One example would be a service experience where a person serving a consumer must use a tool or application that constrains any ability to utilize their own skill and judgment, necessitating a process that stands in the way of a human interaction with the consumer. To an observer, it appears

that the worker serves the commands of the device he/she uses and that the consumer is merely a passenger lacking autonomy and “along for the ride”. Another example would be where both the consumer and the local worker must engage in a process involving another worker at a national call center; by design, the national worker lacks the local knowledge or engagement with the consumer to help meaningfully, the local worker lacks the authority to help, the consumer (and both workers) are disempowered, and knowledge fragmentation in the system results in a process lacking empathy. A key hallmark of any person-centered system is empathy: i.e., knowing what it is like to stand in the consumer’s shoes based on personalized relevant data about that consumer and knowledge derived from the experiences of others.

In these aforementioned examples, the key participants in the systems (consumers and workers) were very likely not involved in designing or shaping the systems, and best practices from the science of human-centered design principles were likely not applied. Beyond putting the patient in the driver’s seat of his/her own health, empowering patients to shape the transformative future of health anchored in a LHS will be essential to realizing a LHS that embodies the *LHS Core Values* and delivers on the promise of the LHS vision.

Patient Empowerment: Shaping the Character of the Future of Health

In a 2016 speech titled “Power to Patients”¹⁹ (that coincidentally fell on the 50th anniversary of the previously referenced quote by Rev. Dr. Martin Luther King, Jr. regarding inequality and injustice in health⁸), LHS visionary and patient empowerment activist Sir Joseph H. Kanter noted: “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.”¹⁹

While our open access journal is anchored in a science underpinning “both the cyber-social and ultra-large-scale systemic character of the LHS”,¹¹ this theme issues serves to remind us that there is something distinctive about health. At that time of this issue’s release in July 2017, many Americans will have already celebrated the anniversary of the adoption of the Declaration of Independence which is grounded in the notion that all people are endowed with certain unalienable rights including rights to life, liberty, and the pursuit of happiness.²⁰ A principle underpinning the United States legal system is that, in theory, when a threat to one’s exercise of these unalienable rights is triggered, an individual is afforded rights (and sometimes tools and capabilities) to vigorously advocate to protect these paramount human rights. It is easy to see how an individual’s health is central to his/her ability to exercise his/her fundamental human rights to life, liberty, and the pursuit of happiness. Yet when disease threatens a person’s liberty or life today, he/she is not regularly told that he/she has rights to the information and tools he/she needs to

vigorously advocate to protect his/her health; in certain ways, a person-centered LHS takes important steps toward changing that dynamic by empowering people through learning.

The papers in this theme issue showcase select mechanisms by which a LHS can empower patients – with information, health literacy, personalized tools, connections to communities, and more – to be, in collaboration with their caregivers and care teams (and other stakeholders), strong advocates and activists to leverage learning to protect and promote their health as well as the health of others. *Learning Health Systems* serves as a gathering point (and perhaps an infrastructure component) for the community interested in the science of cyber-social learning systems as applied to health. It can also be a catalyst for advancing the science that will be foundational in driving this change in the way individuals and society relate to safeguarding and advancing health. Hence, these themes are interwoven into people's exercising of their human rights.

Many of the authors in this issue have not only been engaged in conducting rigorous research and in pioneering initiatives, but they have also fought courageously and sacrificed greatly to advance patient empowerment. Some have accumulated scars on their extensive journeys championing patient empowerment and the LHS. I hope that the thoughts I have shared with you in this commentary and especially the papers featured in this first theme issue of *Learning Health Systems* will help to illuminate how and why these

contributors were so willing to work steadfastly to advance this urgently important cause, endeavoring to disruptively transform the future of health.

Closing: Honoring and Learning from Jerry Matczak

I wish to close by recognizing the late Jerry Matczak, a co-author of the paper entitled “Patient-centered drug development and the Learning Health System,” who passed away earlier this year. A champion of patient empowerment who worked as a social media guru and leader of a Clinical Open Innovation team at a global pharmaceutical/life-sciences company, Jerry was widely lauded for actively listening to and communicating with patients, to advance clinical research and drug development.²¹ A vocal advocate for open sharing to advance human health, he was personally recognized for sharing his “unique perspective among geek-minded people,” harnessing humanity to draw the types of connections in science that will be at the heart of advancing the science of learning systems.²²

Jerry Matczak’s commitment to open innovation and community provides a powerful lens from which to view the papers in this issue as well as the emerging science that will underpin the development and advancement of the fabric weaving together a patient-empowering LHS. With motivation stemming from deeply personal family health

experience, Jerry stated in a 2012 interview: “[By] acting openly, with honesty, transparency and integrity we intend to foster a community that will make a difference in people’s lives. When you think about it that way, it’s easy to commit.”²²

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