Digital Infrastructure for the Learning Health System
The Foundation for Continuous Improvement in Health and Health Care
Summary of a Workshop Series

Health and health care are going digital. Enhanced use of web-based information, computerized medical records, online patient-clinician communication, and remote-site diagnosis and treatment are rapidly increasing as health tools for Americans and their clinicians. As seen in other industries, this transition presents enormous potential for increasing the efficiency, convenience, and effectiveness of health care. Digitalizing health care processes and information provides the foundation necessary for a continuously improving learning health system—one in which knowledge from the care experience is captured and used in real time to guide decisions.

This new report, Digital Infrastructure for the Learning Health System: The Foundation for Continuous Improvement in Health and Health Care, summarizes presentations and discussions from a series of workshops held to consider the digital infrastructure necessary to support a learning health system at the national level. In the learning health system, 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 health care.

The basis for such a system already is in place. Doctors’ offices and hospitals increasingly are shifting to electronic health records, private industry continues to develop more innovative technologies, and smartphones and wireless devices are revolutionizing information access. Using these tools, several organizations have already achieved impressive results at the local level. For example, by analyzing electronic health records of 1.4 million of its patients, Kaiser Permanente was able to identify heart attacks associated with the drug Vioxx, accelerating corrective action by the Food and Drug Administration and the manufacturer.
The series of workshops, convened by the Institute of Medicine (IOM) with the support of the Office of the National Coordinator for Health Information Technology, brought together researchers, computer scientists, privacy experts, clinicians, health care administrators, health IT professionals, representatives of patient advocacy groups, healthcare policymakers, and other stakeholders to identify the principles necessary to guide national efforts in developing the digital elements of a learning health system (see characteristics below).

The workshop included expert presentations, consideration of “out of the box” approaches and the use of examples from health and non-health fields to illustrate and test key needs and opportunities. Through small group sessions, participants identified and presented for discussion a number of strategic elements important to progress. These discussions focused on several key categories—including technical progress, knowledge generation and use, patient and population engagement, and governance—with the goal of identifying the most important principles to guide efforts in the establishment of a digital infrastructure that will support a learning health system at the national level. Themes most frequently cited by participants include the following:

- **Build a shared learning environment**: base decisions on input from all parties, including patients and the population at large.
- **Engage health and health care, population and patient**: think in terms of what happens beyond the doctor's office, to health decisions made in everyday life, and how these effect our health as a nation.
- **Leverage existing programs and policies**: build, whenever possible, on what we already have to accelerate progress and prevent waste.

### Learning Health System Characteristics

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<tr>
<th><strong>Culture</strong>: participatory, team-based, transparent, improving</th>
<th><strong>Knowledge</strong>: ongoing, seamless product of services and research</th>
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<tr>
<td><strong>Design and processes</strong>: patient-anchored and tested</td>
<td><strong>Digital technology</strong>: the engine for continuous improvement</td>
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<td><strong>Patients and public</strong>: fully and actively engaged</td>
<td><strong>Health information</strong>: a reliable, secure, and reusable resource</td>
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<td><strong>Decisions</strong>: informed, facilitated, shared, and coordinated</td>
<td><strong>Data utility</strong>: data stewarded and used for the common good</td>
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<td><strong>Care</strong>: starting with the best practice, every time</td>
<td><strong>Trust fabric</strong>: strong, protected, and actively nurtured</td>
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<td><strong>Outcomes and costs</strong>: transparent and constantly assessed</td>
<td><strong>Leadership</strong>: multi-focal, networked, and dynamic</td>
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• **Embed services and research in a continuous learning loop:** make processes easy to use, ensure that they don’t burden users unnecessarily, and continue to improve them.

• **Anchor in an ultra-large-scale systems approach:** base your approach on a set of technical and social principles that meet the current and future needs of a complex system.

• **Emphasize decentralization and specifications parsimony:** don’t over-prescribe, and encourage innovation to meet local needs.

• **Keep use barriers low and complexity incremental:** encourage maximum participation and let individuals determine how they want to use the system.

• **Foster a socio-technical perspective, focused on the population:** be cognizant of the social and cultural aspects, which can be more challenging than the technology.

• **Weave a strong and secure trust fabric among stakeholders:** create and nurture trust among system users.

• **Provide continuous evaluation and improvement:** continuously assess whether goals are being met and strive for improvement based on these results.

To advance the development of a system faithful to these principles, participants flagged priority areas to focus follow up activities. In several instances these involved seizing on the opportunities presented by ongoing efforts, and building upon them to include considerations or requirements specific to the learning capacity of the digital infrastructure. These priority action targets focused on the key areas of stakeholder engagement, technical progress, infrastructure use, and governance. Some of those most frequently noted include:

• **The case:** Conduct analyses to assess potential returns in terms of health and economics.

• **Involvement:** Begin initiatives to involve citizens, patients, and clinicians as active learning stakeholders.

• **Functionality standards:** Work toward consensus on standards for core functions of the digital infrastructure—care, quality, public health, and research.

• **Interoperability:** Continue efforts involving all stakeholders to accelerate exchange of health information and specifications for how to achieve greater interoperability.

• **Ultra-large-scale system test bed:** Identify opportunities to test and learn more about the implications of the taking an approach based on ULS principles.
• **Technical acceleration:** Create a collaborative vehicle for computational scientists and the health IT community to work together.

• **Quality measures:** Work toward consensus on quality measures that focus on outcomes and can be easily embedded in processes.

• **Clinical research:** Support a cooperative network to advance the distributed research capacity and the identification of core measures for use in research.

• **Identity resolution:** Establish a consortium to address the issue of consistent patient identification across the system.

• **Governance and coordination:** Work toward the determination and implementation of governing principles, priorities, system specifications, and cooperative strategies.

The possibilities, priorities, and vision for the digital infrastructure discussed by participants, and summarized in this report, hold the potential to transform the health and healthcare landscape in fundamental ways. However, the discussions also underscored that without successful efforts to create the conditions necessary for seamless interoperability, the development of protocols for knowledge generation, and the building of a culture of engagement and support, the potential will go unmet. Illustrated in the pages of this report are insights for achieving the continuously learning health system necessary—and possible—to ensure better health for all.

As a summary of the discussions, the report presents the views and ideas of workshop series participants and does not contain recommendations or position statements from the IOM. The summary can be downloaded at www.iom.edu/vsrt.