Digital Data Improvement Priorities for Continuous Learning in Health and Health Care

Digital health data are the lifeblood of a continuous learning health system. A steady flow of reliable data is necessary to coordinate and monitor patient care, analyze and improve systems of care, conduct research to develop new products and approaches, assess the effectiveness of medical interventions, and advance population health. The totality of available health data is a crucial resource that should be considered an invaluable public asset in the pursuit of better care, improved health, and lower health care costs.

This publication, Digital Data Improvement Priorities for Continuous Learning in Health and Health Care, summarizes discussions at the March 2012 Institute of Medicine (IOM) workshop to identify and characterize the current deficiencies in the reliability, availability, and usability of digital health data and consider strategies, priorities, and responsibilities to address such deficiencies. This workshop built on a body of work done by the Roundtable on the centrality of a clinical data utility to support continuous learning and improvement in health and health care.

The applications of digital health data in a learning system are multiple, including care coordination; management of patient populations; associated care and business processes; outcome, quality, and value assessments; generation of clinical evidence, including clinical trials, clinical effectiveness, and genomic studies; surveillance and trend detection, including medical products safety, syndromic and actionable surveillance, and hypothesis generation; and public health program management. These differing uses vary in their requirements for data quality and characteristics, but all share common challenges related to data access, liquidity, interoperability, and the development of innovative methods for analysis. These issues formed the foundation for the presentations and discussions at the workshop and were followed by a final session during which individual participants reflected on the day’s presenta-
tions and discussed actions they felt were important to progress forward. These priority action targets and accompanying strategies covered six broad thematic areas:

### Thematic Areas and Associated Strategies

1. **Improve awareness and gap assessment of existing data sources**: Work toward a better understanding of what data sources exist, their characteristics, their relationships to each other, and the implications of these details on the uses of the data. Strategies discussed included:
   - Map digital health resources.
   - Map high-priority questions and issues to existing sources and methods.

2. **Improve the quality, patient orientation, and utility of data input**: Make data collection more responsive to the needs of patients, clinicians, and other data users. Strategies discussed included:
   - Collect and provide information patients care about.
   - Improve usability of health and biomedical information technology.
   - Implementation of contextual tagging.
   - Development of core digital health data elements.

3. **Improve the access, tools and capacity for data analysis**: Improve the analytic tools and capacity necessary for learning. Strategies discussed included:
   - Create more inclusive toolsets.
   - Continuously curate data sources.
   - Integration of data.

4. **Ramp up the involvement and engagement of the patients and the public for improved clinical data**: Successfully engage stakeholders to fully realize the learning and improvement potential of digital health data. Strategies discussed included:
   - Build capacity for direct patient engagement.
   - Build trust among stakeholders.
   - Develop mutual understandings of expectations for confidentiality, privacy, and security.
   - Increase use of user-appropriate data presentation techniques
   - Account for disparate health literacy levels.
   - Empower the public for a culture of participation.

5. **Build a clinical data learning utility**: Harness the potential for learning from the digital health data utility. Strategies discussed included:
   - Develop innovative methods to use data for multiple purposes.
   - Implement distributed approaches.
   - Engage bias and its implications.