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President’s Council of Advisors on Science and Technology Releases Report on Health Information Technology

Calls for Adoption of Universal Exchange Language to Mobilize Data, Improve Healthcare, Enhance Privacy, and Cut Costs

Information technology has the potential to revolutionize healthcare in the United States by increasing quality of care and reducing costs, and the Federal government has made good progress laying the foundation for widespread adoption of electronic health records, according to a report released today by the President’s Council of Advisors on Science and Technology (PCAST), a group of presidentially appointed experts from academia, non-governmental organizations, and industry.

But achieving the full potential of health information technology will require the development and adoption of a robust information-sharing infrastructure to facilitate the exchange of data among institutions, the report concludes. Unlike conventional electronic health records, which are effectively digital versions of paper charts that are trapped in the offices where they are created, such a system would allow health data to follow patients wherever they are, with appropriate privacy protection and patient control, while giving patients’ various doctors a more complete picture of those patients’ medical conditions and needs.

The report, “Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: The Path Forward,” calls upon the Federal government to facilitate the widespread adoption of a “universal exchange language” that allows for the transfer of relevant pieces of health data while maximizing privacy. Reflecting input from industry and IT experts, privacy groups, healthcare professionals, and others, the report provides specific recommendations for cultivating an information technology (IT) ecosystem that facilitates the real-time exchange of patient information in order to modernize diagnosis and treatment, improve public health, enhance the privacy and security of personal data, and create new high-technology markets and jobs while catalyzing healthcare-related economic reforms needed to address our Nation’s long-term fiscal challenges.

“The United States spends more on healthcare as a fraction of gross domestic product than any other industrialized nation, yet we lag on critical measures such as life expectancy and infant mortality,” said Eric Lander, Co-chair of PCAST. “Information technology has the potential to vastly improve patient care and create new markets based on health care innovation—but only if we make wise decisions now. This report outlines a path to achieving these aims.”
The report finds that the technology for creating the necessary infrastructure and exchange language is already proven and available. But since the development of those systems is not likely to be a profitable venture in itself, the Federal government should facilitate their creation and then leave the private sector to develop products that build on them.

Specifically, PCAST recommends that the Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Medicare and Medicaid Services (CMS) within the Department of Health and Human Services develop guidelines to spur adoption of an exchange language for use by health information technology systems. That would facilitate a transition from traditional electronic health records—whose usefulness is largely limited to a single physician’s office—to a more medically useful and secure system in which individual bits of healthcare data are tagged with privacy and security specifications.

Importantly, implementation of PCAST’s recommendation to designate a universal exchange language for health information would not require physicians to replace their existing electronic health records systems, virtually all of which could be made compatible through “apps” and other “middleware.”

“Health information technology can allow clinicians to have real-time access to complete patient data and help them make the best possible decisions,” said PCAST member Christine Cassel. “It can help patients become more involved in their own care, which is especially important in managing chronic conditions like diabetes, asthma, or heart disease. It can help public health officials detect developing epidemics, health risks in the environment, or unexpected side effects caused by medications. It can streamline processes and reduce overhead, as it has in other industries, and lead to innovations to advance patient-centered care.”

The report finds that the best way to manage and store data for advanced data-analytical techniques is to break them down into the smallest individual pieces that make sense to exchange or aggregate. These individual pieces are called “tagged data elements,” because each unit of data is accompanied by a mandatory “metadata tag” that describes the attributes, provenance, and required security and privacy protections of the data. Universal exchange languages for metadata description, called “extensible markup languages,” are widely and successfully used.

A key advantage of the tagged data element approach is that it allows a more sophisticated privacy model—one in which privacy rules, policies, and applicable patient preferences are innately bound to each separate tagged data element and are enforced both by technology and by law. For example, a patient with diabetes may decide that her blood sugar information should be available to any of her doctors and to emergency physicians requesting that information should she have a problem while traveling in another state—but that details about her past treatment for cancer should remain private and not be shared.

Also addressing a widespread privacy concern, such a system would not require the creation or assignment of universal patient identifiers, nor would it require the creation of any centralized Federal database of patients’ health information.

The report calls upon ONC and CMS to move rapidly to implement its recommendations by creating appropriate definitions in its “meaningful use” standards for health information technology, which under law must be achieved in stages by 2013 and 2015. It also calls upon CMS to accelerate the modernization and restructuring of its IT platforms and staff expertise.

For more about PCAST, and to view the full report, please visit: www.whitehouse.gov/ostp/pcast

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