



## STATEMENT FOR THE RECORD

House Energy and Commerce Committee, Subcommittee on Health:  
*"Legislative Hearing on 21st Century Cures"*

April 30, 2015

Dear Chairman Upton, Representative DeGette, Ranking Member Pallone, Chairman Pitts, and Representative Green:

The Healthcare Leadership Council (HLC), a coalition of chief executives of the nation's leading healthcare companies and organizations, appreciates your efforts and the bipartisan work toward the release of the second draft of the "21st Century Cures Act" by the House Energy and Commerce Committee.

HLC strongly supports the effort to modernize the discovery, development and delivery of innovative treatments and cures to patients nationwide and is pleased to see this effort led on a bipartisan basis by Energy and Commerce Committee Chairman Fred Upton (R-MI), Oversight and Investigations Subcommittee Ranking Member Diana DeGette (D-CO), full committee Ranking Member Frank Pallone, Jr. (D-NJ), Health Subcommittee Chairman Joe Pitts (R-PA), and Health Subcommittee Ranking Member Gene Green (D-TX). HLC and its members have actively worked to support many sections of this draft legislation.

For example, HLC is pleased by the inclusion of provisions designed to speed the clinical trial process and reduce unnecessary administrative burdens. While the provisions on expanding the sharing of data generated through NIH-funded research are important, HLC strongly believes that any effort to accelerate treatments and cures must include robust data sharing from the Centers for Medicare and Medicaid Services (CMS), as well.

In testimony before the House Energy and Commerce health subcommittee last summer, on existing barriers to developing and communicating medical evidence, HLC testified that in order to advance health system improvements and medical research, health data held by the federal government should be shared more freely with organizations working to treat patients and develop new treatments and cures. Any

standard that restricts access to critical federally-held data is detrimental to our shared goals for medical and human progress. We hope future drafts include provisions encouraging greater data sharing with the private sector by federal agencies.

HLC is pleased to see the Energy and Commerce Committee address modernization of research restrictions related to the Health Insurance Portability and Accountability Act (HIPAA). We believe that medical privacy laws are serving the public well, but minor updates are necessary to enabling optimal use of today's health databases. HLC's testimony to Congress encouraged members to keep in mind that HIPAA was created at a time in which policymakers weren't thinking about the knowledge that could be gained by accessing data residing in large databases and the technological ability to process that data very rapidly. It is appropriate to adjust the authorization components of HIPAA to ensure that data can be used effectively for research.

Throughout the 21<sup>st</sup> Century Cures Initiative process, HLC has emphasized the importance of telehealth and electronic health record interoperability for inclusion in the draft legislation. We strongly support the Energy and Commerce Committee's continued work on these sections for inclusion in the final legislation.

HLC CEO members, who are leaders in every healthcare field, have agreed on the need for an interoperable health IT infrastructure constructed in a way that is both beneficial to consumers and realistic and sustainable for industry. In a September 2014 statement (attached), all HLC members endorsed a role for policymakers in encouraging the exchange of material and meaningful health data and in decertifying electronic health record products that knowingly block information. We will continue to work with Congress to finalize draft language addressing these critical issues in the 21st Century Cures Act.

We look forward to seeing the provisions on telehealth, and are pleased that work continues on a bipartisan basis. Telemedicine legislation is essential to equip healthcare providers with the tools needed to ensure they can meet the demands of an innovative healthcare system, dramatically changing patient demographics, and engaging patients in the prevention and management of their chronic diseases. HLC's multisector, consensus principles on workforce identify telehealth as a top priority, and stress the importance of significantly addressing the current restrictive reimbursement, licensure, and other regulatory barriers that make it challenging to employ telehealth effectively.

Thank you for your continued leadership on issues critical to millions of Americans. We appreciate the opportunity to work with you as you continue to develop this legislation.

The opportunity to accelerate cures and treatments for those most in need is one we all must embrace and advance.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary R. Grealy". The signature is written in a cursive style with a large, prominent initial "M".

Mary R. Grealy  
President

Attachment



## STATEMENT ON INTEROPERABILITY AND EXCHANGE OF PATIENT INFORMATION

*The Healthcare Leadership Council (HLC) has long served as the innovative voice of healthcare in the United States. HLC members recognize the increasing importance of efficient, timely transfer of patient information throughout the healthcare system, enabling care to be delivered to the patient more quickly and guided by meaningful data. We believe in a future in which health organizations work not as “silos” of information, but as an interoperating health system using shared data to accelerate progress in medicines, technologies, and healthcare delivery.*

*HLC CEOs, who are leaders in every healthcare field, have agreed upon the need for an interoperable health IT infrastructure that takes shape in a way that is both beneficial to consumers and workable for industry. It is our hope that these recommendations support the work of Congress, the administration, and other organizations working to create the health system of the future.*

- We believe that policymakers should **encourage exchange of material and meaningful health data** through the use of technologies and applications that enable bidirectional and real-time exchange of health data currently residing in electronic health record (EHR) systems (e.g., open and secure API technology).
- Policymakers should also use appropriate authority to **certify only those EHR technology products that do not block or otherwise inhibit health information exchange**. The HHS Office of the National Coordinator should decertify “Meaningful Use” products that intentionally block the sharing of information, or that create structural, technical, or financial impediments or disincentives to the sharing of information.
- The federal government, in collaboration with the private sector, should **build on current and emerging best practices in patient identification and matching** to identify solutions to ensure the accuracy of every patient’s identity, and the availability and accessibility of their information, absent lengthy and costly efforts, wherever and whenever care is needed.
- Any interoperability **requirements or incentives should be “technology neutral” and focused on outcomes**—active interoperation between and among systems—rather than on adoption or use of specified technologies. It is critical that future policies do not stifle potential innovations in health system connectivity.

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*(Alphabetized by Company)*



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