



June 5, 2015

The Honorable John Boehner
Speaker
U.S. House of Representatives
H-232, The Capitol
Washington, D.C. 20515

The Honorable Nancy Pelosi
Minority Leader
U.S. House of Representatives
H-204, The Capitol
Washington D.C. 20515

RE: 21st Century Cures Act (H.R. 6)

Dear Speaker Boehner and Minority Leader Pelosi:

The undersigned members of the Physician Clinical Registry Coalition (the Coalition) strongly encourage the House of Representatives to pass H.R. 6, the 21st Century Cures Act, approved by the House Energy & Commerce Committee (the Committee) on May 21, 2015. The Coalition applauds the Committee for its leadership in drafting and passing the bill. The Coalition particularly appreciates the provisions that would allow clinical data registries better access to health information to be used for research purposes under the Health Insurance Portability and Accountability Act of 1996 implementing regulations (HIPAA rules) and those that would improve the interoperability of health information technology.

The Coalition is a group of more than 20 organizations that sponsor clinical data registries that collect identifiable patient information for quality improvement purposes so as to help participating providers monitor clinical outcomes among their patients. We are committed to advocating for policies that enable the development of clinical data registries and enhance their ability to improve quality of care through the analysis and reporting of clinical outcomes.

H.R. 6 promotes and advances medical research by revising and clarifying the HIPAA rules on the use and disclosure of protected health information for research purposes. The proposed language, which eliminates the need for patient authorization or a privacy board waiver for

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research purposes in certain circumstances, would reduce some of the current hurdles faced by registries in using and sharing data for medical research—helping to save lives now and in the future.

In addition, the bill includes provisions that would require the Secretary to develop interoperability standards for health information technology, which will improve clinical data registries' ability to securely exchange health information with providers "without special effort." These provisions would help reduce the number of practical and functional barriers that currently make it difficult for clinical data registries to access health information for the purpose of tracking clinical outcomes and improving quality of care. We believe it is implicit that these new standards will not allow vendors of health information technology to pass the costs of enhanced interoperability on to physicians and other health care providers. We would strongly support additional bill language or at least report language to clarify this point. The bill also seeks to prevent information blocking or the practice of interfering with the availability, exchange, and use of electronic health information. Eliminating these practices will help clinical data registries access patient health information and therefore increase registries' ability to analyze this information to improve quality of care.

The undersigned members of the Coalition thank the House Energy & Commerce Committee for developing the 21st Century Cures Act and urge the House to pass the bill with its much needed improvements to the accessibility of health information for research and quality improvement purposes.

Respectfully submitted,

AMERICAN ACADEMY OF DERMATOLOGY ASSOCIATION
AMERICAN ACADEMY OF NEUROLOGY
AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS
AMERICAN ACADEMY OF OPHTHALMOLOGY
AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION
AMERICAN JOINT REPLACEMENT REGISTRY
AMERICAN COLLEGE OF EMERGENCY PHYSICIANS
AMERICAN COLLEGE OF SURGEONS
AMERICAN GASTROENTEROLOGICAL ASSOCIATION
ANESTHESIA QUALITY INSTITUTE/AMERICAN SOCIETY OF ANESTHESIOLOGISTS
AMERICAN SOCIETY OF CLINICAL ONCOLOGY
AMERICAN SOCIETY OF NUCLEAR CARDIOLOGY
AMERICAN SOCIETY OF PLASTIC SURGEONS

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AMERICAN UROLOGICAL ASSOCIATION
GIQUIC/ AMERICAN COLLEGE OF GASTROENTEROLOGY
NATIONAL ASSOCIATION OF SPINE SPECIALISTS
SOCIETY OF INTERVENTIONAL RADIOLOGY
SOCIETY OF NEUROINTERVENTIONAL SURGERY
SOCIETY FOR VASCULAR SURGERY

cc: The Honorable Fred Upton, Chairman, House Energy & Commerce Committee
The Honorable Frank Pallone, Ranking Member, House Energy & Commerce Committee
The Honorable Paul Ryan, Chairman, House Ways & Means Committee
The Honorable Sander Levin, Ranking Member, House Ways & Means Committee
Members of House Energy & Commerce Committee
Members of House Ways & Means Committee