



For Immediate Release

January 23, 2009

News Release

Contact: Elaine Rubin (202) 265-9600

HIPAA Privacy Rule Limits America's Promise in Research

AAHC Report Recommends Reexamination and Revisions

WASHINGTON, Jan. 23 - The Privacy Rule of the Health Insurance Portability and Accountability Act (HIPAA) continues to have a significant negative impact on the scope, pace, and costs of research, according to [*The HIPAA Privacy Rule: Lacks Patient Benefit, Impedes Research Growth*](#), the latest report of the Association of Academic Health Centers (AAHC).

The report is based on findings from a questionnaire sent to vice presidents for research and principal investigators at academic health centers nationwide. The survey included questions on research administration and processes; multi-site research; research using specific data sources; and subject recruitment.

Findings from the report reveal that researchers have difficulty recruiting participants and that the Rule creates barriers to diversity in research studies. Such events are fundamentally changing the conduct of research and threatening the scientific credibility of future research.

To remedy this threat to research and the American people, a revision of the HIPAA Privacy Rule is imperative says the AAHC. Among its recommendations, the AAHC calls for biomedical research to be exempt from the HIPAA Privacy Rule and for the well-established Common Rule to be augmented with more explicit patient privacy protections.

"The government and the research community must quickly find constructive ways to resolve the problems related to the HIPAA Privacy Rule if the nation is to maintain its preeminence in research," said AAHC President Dr. Steven A. Wartman. "Ultimately, the nation needs a vigorous clinical research enterprise to ensure the delivery of the best evidence-based health care."

#

The AAHC is a national non-profit association dedicated to advancing health and well-being through leadership in health professions education, patient care, and research.

1400 16th Street, NW, Suite 720
Washington, DC 20036
P 202.265.9600 F 202.265.7514
www.aahcdc.org

Strengthen. Advocate. Lead.