



Association of Academic Health Centers  
*Leading institutions that serve society*

**For Immediate Release**

June 16, 2008

# News Release

Contact: Elaine Rubin (202) 265-9600

## **HIPAA Privacy Rule Impedes Biomedical Research**

*AAHC Report Recommends Alternatives to Protect Privacy and Advance Healthcare*

WASHINGTON, June 16 - The privacy rule of the Health Insurance Portability and Accountability Act (HIPAA) is having a negative impact on the advance of biomedical research and the search for treatments that benefit society, says a newly-released report by the Association of Academic Health Centers (AAHC). [HIPAA Creating Barriers to Research and Discovery](#) describes the unintended disruptive consequences of the rule, including confusion for patients, misinterpretation by research participants, barriers to patient recruitment, and burdensome administrative procedures that increase research costs. It also offers specific recommendations to address these critical issues.

"The negative impact on participant recruitment was perceived to be one of the greatest threats that HIPAA poses to research," says Dr. Daniel Dorsa, vice president for research at Oregon Health & Science University and chairman of the AAHC vice presidents for research workgroup on HIPAA. In practice, HIPAA may not offer any greater protection than the longstanding regulations in the research arena, says the AAHC. More importantly, the rule's goal of protection through informed consent is undermined by the complexity of consent forms that are required of patients and participants, and which approach a level of incomprehensibility to average individuals.

"Protection of the patient and health information is always paramount when it comes to research conducted at academic health centers throughout the nation," says AAHC President Dr. Steven A. Wartman. "We now know that the privacy rule is having a serious and detrimental impact on research and ultimately patients. Solutions to problems generated by the privacy rule, as outlined in this report, should be pushed forward to protect privacy while ensuring the nation's biomedical research endeavors do not suffer in the near or long term."

The AAHC findings are based on focus group discussions of researchers and compliance personnel at five major academic health centers. Of particular significance to researchers, and often unrecognized by the public, is that HIPAA particularly affects access to stored tissue and genetic datasets, data warehouses and medical records, and community research. Community research, so vital in large collaborative research efforts is becoming increasingly difficult as community physicians are reluctant to engage in research due to the burdensome HIPAA requirements, according to the report.

The AAHC recommendations include: (1) the HIPAA Privacy Rule be revised to defer to the existing and well-established Common Rule—the existing federal policy for the protection of human subjects; (2) the U.S. Department of Health and Human Services should revise the rule through its Office of Civil Rights; and (3) Congress should implement a national genetic privacy act or include it in a revision of HIPAA to help resolve current conflicts between state privacy acts and HIPAA that now hamper tissue bank and genetic research.

# # # #

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.