

*Joint Policy Committee
Societies of Epidemiology*

July 27, 2009

Office for Civil Rights
Office of the Secretary
Department of Health & Human Services
Washington, DC 20201

Dear Dr. Frohboese:

Thank you very much for your June 29, 2009 response to our letter to Secretary Sebelius. We are glad to hear that your office recognizes the importance of the issues related to the HIPAA Privacy Rule and its impact on clinical research given the myriad of issues the Secretary has to address. As members of the research community, we are particularly interested in your work with others in the research community to improve the quality and effectiveness of research while still providing research participants with the privacy protections they need and deserve.

We would greatly appreciate hearing more about the specific activities members of your office are involved with in this regard and offer the service of our members representing several major national and international professional organizations of epidemiologists and other health scientists. As you know, these privacy issues affect us both personally and professionally, and can have both negative and positive impacts on the population-based health research we conduct. We feel it is both an obligation and an opportunity for us to help inform and develop effective ways of protecting privacy while not impeding research. We seek your guidance as to how we can best assist your office in addressing these issues.

We look forward to hearing from you. Please contact Dr. Roberta Ness (Dean, University of Texas School of Public Health, Houston, TX; 713 500 9052; roberta.b.ness@uth.tmc.edu).

Sincerely yours,

Joint Policy Committee of the Societies of Epidemiology

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