



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Secretary's Advisory Committee on
Genetics, Health, and Society
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February 8, 2006

The Honorable Michael O. Leavitt
Secretary of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Leavitt:

I am writing on behalf of the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) to commend you for your leadership in advancing our Nation's health information infrastructure. As your advisory committee charged with addressing key issues and challenges to the integration of genetic and genomic technologies into clinical practice, we are aware of the important role that the National Health Information Infrastructure (NHII) can play in enhancing the quality of health care for the American people. As such, we take this opportunity to bring several issues to your attention.

We were briefed last year about the efforts of the Office of the National Coordinator for Health Information Technology (ONCHIT) to advance the NHII. We were pleased to learn that the Consolidated Health Informatics initiative is moving forward in the development of standard health vocabularies and that one such standard, the Human Gene Nomenclature (HUGN), has been adopted to assign names and symbols to genes. The adoption of standards such as HUGN is a very good start. As the infrastructure progresses, we urge you to ensure that new standards reflect the full complexity of the rapidly evolving fields of genetics and genomics and are capable of supporting their use in both clinical and research settings.

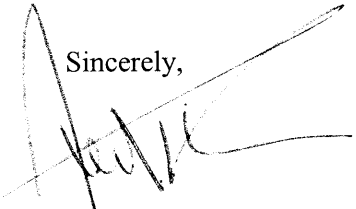
In addition, given the importance of family history information to clinical care, we also urge that you use your influence to support the incorporation of family history information into the next generation of electronic health records standards. The U.S. Surgeon General's Family Health Initiative, a coordinated effort of a number of HHS agencies, has developed an impressive family history tool for consumers and has actively promoted it to assist families in compiling health histories that include familial risk factors for common diseases. The tool represents an excellent foundation for the development of a family history standard. Ideally, the family history tool could be combined with relevant clinical guidelines such as those developed by the U.S. Preventive Services Task Force to develop health information technology products that more precisely identify individuals at increased risk for disease.

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Finally, through our public forums, we have learned that the security and privacy of genetic information, including family history information, is of great importance and concern to the American people. Therefore, we note with interest your charge to the American Health Information Community to provide input and recommendations on privacy and security of health information. The Committee is also encouraged that the Certification Commission for Healthcare Information Technology is incorporating criteria for security into its standards. If we can be of assistance to you in supporting or communicating the results of these efforts, please do not hesitate to call on us.

The Committee applauds you for your leadership on this issue and we are appreciative of the input we have received from the HHS agencies that are *ex officio* to our Committee. We are convinced that, if aggressively implemented, the NHII and the initiatives noted above will lead to facilitated integration of genetics and genomics into health care and will aid in the determination of the health impact of new genetic tests and applications. We look forward to working with you to accomplish these objectives.

Sincerely,



Reed V. Tuckson, MD, FACP
SACGHS Chair

cc: David J. Brailer, MD, PhD, National Coordinator for Health Information Technology