

# Subcommittee on Privacy, Confidentiality and Security

The Way Forward to the Next  
Decade

June 17, 2010



With many thanks to chairs and  
staff from 2000-2008

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# Accomplishments this Decade

- **February 7, 2000** Recommendations on the notice of proposed rule-making for standards for privacy of individually identifiable health information
- **October 1, 2001** Letter to the Secretary on Consent Requirements and Minimum Necessary Provisions as it relates to the new Privacy Rule
- **November 21, 2001** Letter to the Secretary on Research recommendations as it relates to the new Privacy Rule
- **March 1, 2002** Letter to the Secretary - Privacy and Confidentiality Recommendations on Marketing and Fundraising
- **April 25, 2002** Letter to the Secretary - Privacy and Confidentiality Additional Recommendations and Response to NPRM
- **September 27, 2002** Letter to the Secretary - Comments on Preparations for Implementation of Privacy and Confidentiality regulations
- **November 25, 2002** Letter to the Secretary - regarding comments on the implementation of Privacy & Confidentiality regulations



# Accomplishments this Decade

- **June 25, 2003** Letter to the Secretary: Program to measure the effects of the Privacy Rule
- **March 5, 2004** Letter to the Secretary - Recommendation on the effect of the Privacy Rule
- **June 17, 2004** Letter to the Secretary - Recommendations on the Effect of the Privacy Rule in Banking
- **June 17, 2004** Letter to the Secretary - Recommendations on the Effect of the Privacy Rule in Law Enforcement
- **June 17, 2004** Letter to the Secretary - Recommendations on the Effect of the Privacy Rule in Schools
- **September 1, 2004** Letter to the Secretary - Implementation of the Privacy Rule's marketing provisions
- **September 1, 2004** Letter to the Secretary - Privacy Advocate



# Accomplishments this Decade

- **September 2, 2004** Letter to the Secretary - Findings and Recommendations on the Impact of the Privacy Rule on Fundraising
- **June 22, 2006** Letter to the Secretary - Recommendations regarding Privacy and Confidentiality in the Nationwide Health Information Network
- **June 21, 2007** Letter to the Secretary - Update to privacy laws and regulations required to accommodate NHIN data sharing practices
- **June 21, 2007** Letter to the Secretary - Improving the interaction of FERPA and the HIPAA Privacy Rule with regard to school health records
- **February 20, 2008** Letter to the Secretary - Individual control of sensitive health information accessible via the Nationwide Health Information Network for purposes of treatment
- **July 1, 2009** Report to the Secretary - Recommendations on Privacy and Confidentiality, 2006-2008
- **September 28, 2009** Letter to the Secretary - Protection of the Privacy and Security of Individual Health Information in Personal Health Records



# Challenges for the Next Decade: An Overview

With the increasing adoption of interoperable electronic health records technology, along with the move toward global access to health data and emerging new uses of data, methods of access and information availability raise significant new and unique privacy and security concerns.

Appropriate privacy, confidentiality, and security protections; data stewardship; governance; fair information practices and an understanding of shared responsibility for the proper collection, management, sharing, and use of health data are critical to addressing these concerns.



# Challenges for the Next Decade




- Protecting individual rights
- Respecting the needs of society.
- Establishing an appropriate privacy, confidentiality and security framework is essential.
- Ensuring that privacy laws do not inappropriately impede the efficient and effective delivery of healthcare.







# Challenges for the Next Decade: the Rapid Evolution of the World of Health Data




## **New data types**

-  New types of genetic information
-  Increased use of structured data
-  Web search patterns

## **New structures of data**

-  EMRs, HIEs, NHIN
-  PHRs, Health 2.0

## **New data flows**

-  Between EMRs to PHRs
-  Between EMRs to HIEs, NHIN
-  From HIEs, NHIN to public health, research, state and federal government



# Challenges for the Next Decade: Respecting Many Values

- Appropriate security, privacy, and confidentiality protections to:
  - maintain public trust
  - protect individual rights and choices
- Access to and use of data are critical to:
  - Improve healthcare
  - Contain healthcare costs
  - Improve tools for public health and bio-surveillance
  - Enhance research opportunities



# Challenges for the Next Decade: Identifying Issues

## Law, Ethics, and New Developments in Biomedical Informatics

- Conference sponsored by NCVHS and the University of Utah in March, 2010
- Identified many high priority issues for Privacy to address
  - Understanding the protection of sensitive information
  - Understanding governance
  - Understanding the advantages and disadvantages of data de-identification
  - Understanding the regulatory roles of state governments, the many agencies in the federal government, and standard-setting organizations in the private sector
  - Understanding how to build on or move beyond HIPAA



# Current Priorities

- Recommendations regarding the categories of sensitive health information
- Governance: how do we assure that the privacy protections in place are actually followed?

