



*Confidentiality, Ethics, Privacy, and  
Access*

REPORT FROM  
CONFIDENTIALITY, ETHICS,  
PRIVACY AND ACCESS

Group B



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# KEY RECOMMENDATIONS

- Assure consumer support through—
  - Consumer involvement in standards development through participation of consumer advocates at all levels (local, regional, national)



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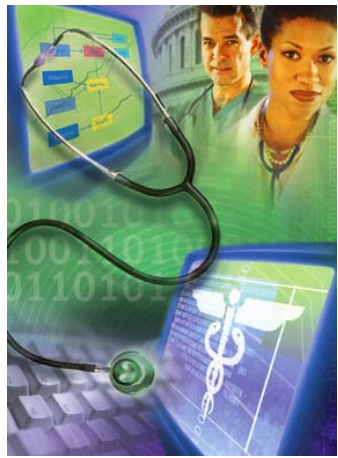
- Assure consumer support through—
  - Strong security management
  - Clearly defined and enforced access restrictions, with authentication, non-repudiation and audit trails
  - Extending protection to telehealth and email communications
  - System transparency, with registration and disclosure of non-TPO users and uses
  - Effective enforcement



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# KEY RECOMMENDATIONS

- Assure consumer support by—
  - Educating consumers about the benefits of health information sharing for--
    - Themselves directly
    - Public health
    - Research



## *Confidentiality, Ethics, Privacy, and Access*

# KEY RECOMMENDATIONS

- Provide readily ascertainable and understandable privacy rules
  - Provide federal leadership in resolving preemption issues
- Provide comprehensive, readily accessible educational resources and compliance materials, including model agreements for participants



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# KEY RECOMMENDATIONS

- Develop standards and tools to ensure accurate location and matching of patient health information
  - e.g., a privately-managed, patient-controlled, voluntary, unique individual health identifier



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# KEY RECOMMENDATIONS

- HHS should support or conduct research and development of privacy-enhancing technologies and mechanisms for incorporation into the NHII



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# KEY RECOMMENDATIONS

- Define the incidents of ownership and control in detail, and explain them accurately, e.g.:
  - When should an individual be able to withhold information from the record in whole or in part, and what are the implications for the provider?
  - When should an individual be able to restrict access by specific providers?





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## KEY RECOMMENDATIONS

- Recognize that there are significant ethical issues beyond privacy—
  - Managing genetic information
  - Appropriate use of IT tools
  - Relation between informed consent and privacy
  - Scope of consent for secondary use of data