More and Better Data for Research: Federal Health Information Technology Developments

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AcademyHealth
Annual Research Meeting
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Federal Health IT Milestones

1996

- **HIPAA** –Administrative Simplification section of Health Insurance Portability and Accountability Act of 1996
- **NCVHS** - National Committee on Vital and Health Statistics, a long-standing (50+ years) advisory committee to HHS, which was strengthened and expanded by HIPAA

2001

- **CHI** - Consolidated Health Informatics project, an HHS-VA-DOD eGov initiative which designated 1st U.S. gov't-wide clinical data standards

2003

- US-wide license for **SNOMED CT** - Systematized Nomenclature of Medicine Clinical Terms
- **MMA** – Medicare Modernization Act of 2003 – mandated e-prescribing and a time-limited Commission on Systemic Interoperability (January-October 2005)

Executive Order, April 27, 2004

"..to provide leadership for the development and nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care…"

State of the Union Address, January 31, 2006

"We will make wider use of electronic health records and other health information technology infrastructure to improve the quality and efficiency of health care."

Recent Events

September 2005

- American Health Information Community – advisory committee of industry leaders & federal agency heads – HHS Sec. chair

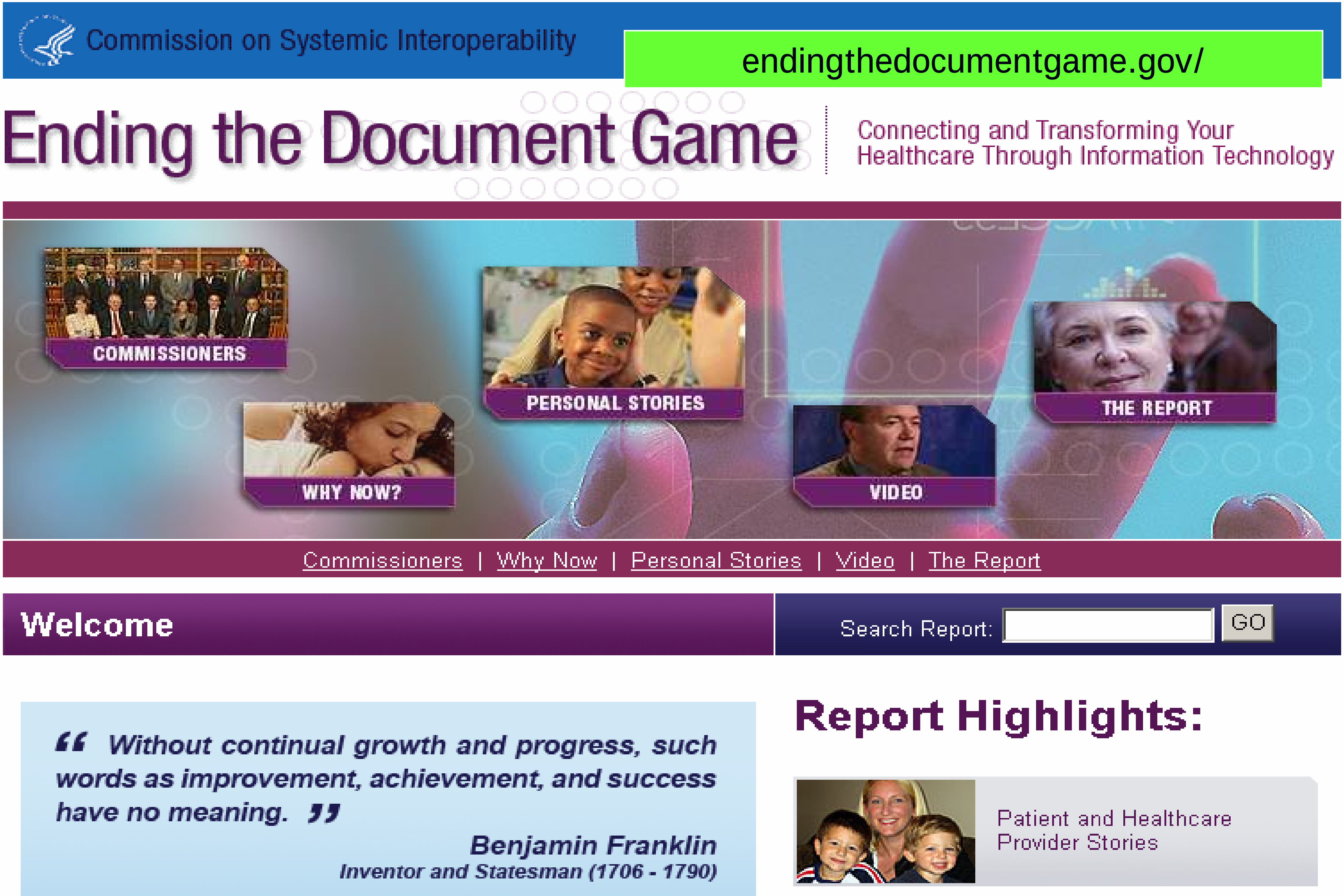
October 2005

- Office of National Coordinator for Health Information Technology (ONC), HHS awards contracts for
  - (1) *standards harmonization
  - (2) compliance certification
  - (3) privacy/security solutions

- *Commission on Systemic Interoperability releases final report

*NLM involved at HHS request

endingthedocumentgame.gov/


Commission on Systemic Interoperability
COMMISSIONERS
PERSONAL STORIES
THE REPORT
WHY NOW?
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Ending the Document Game

Connecting and Transforming Your Healthcare Through Information Technology

Welcome

> “ *Without continual growth and progress, such words as improvement, achievement, and success have no meaning.* ”
>
> ***Benjamin Franklin***
> *Inventor and Statesman (1706 - 1790)*

Report Highlights:

Patient and Healthcare Provider Stories

Recent Events

November 2005

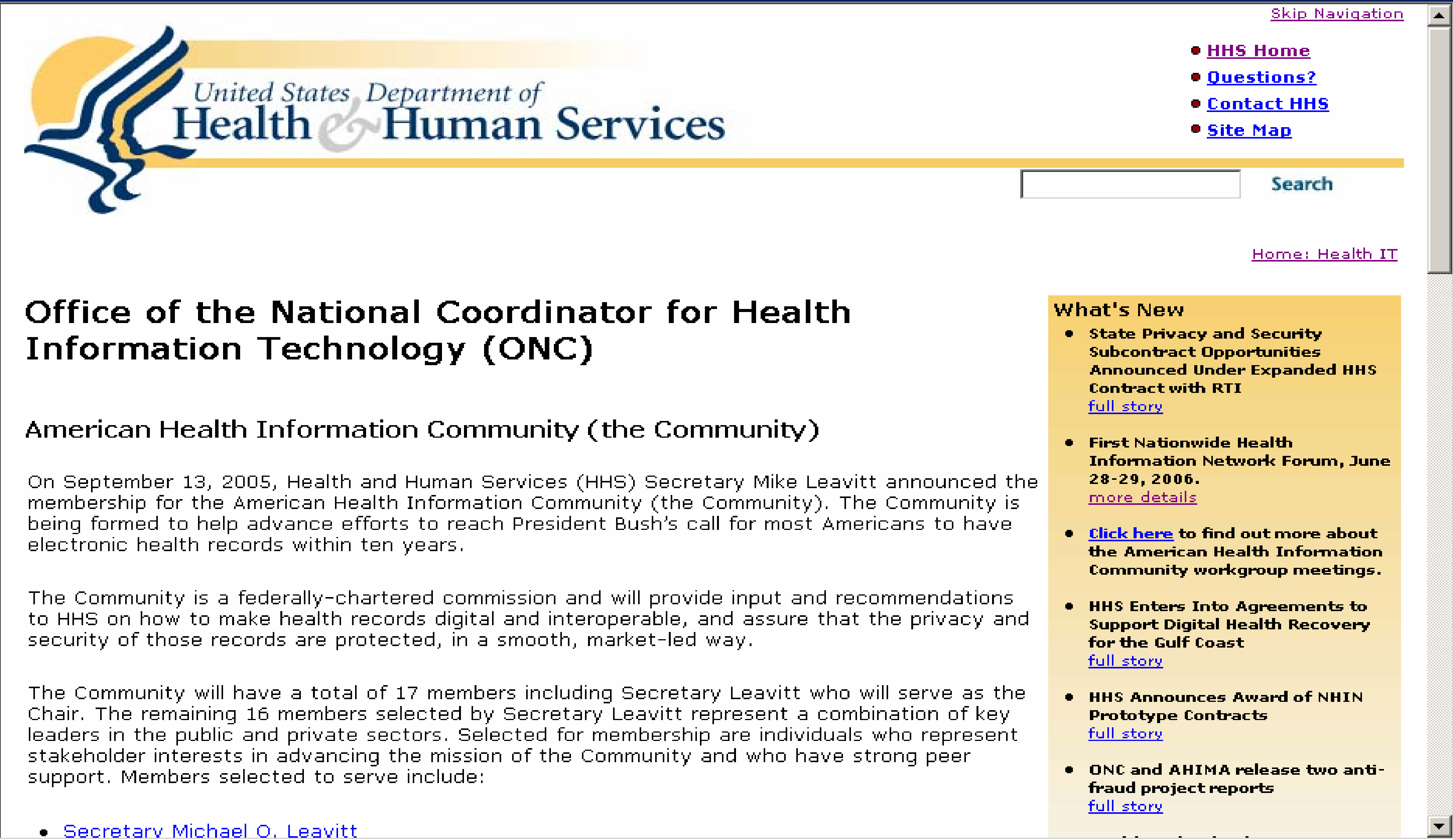
- Medicare e-prescribing foundation standards named
- ONC awards 4 contracts for National Health Information Network (NHIN) architecture prototypes

January 2006

- Interagency Health Information Technology Policy Council
- *HHS Health Information Technology Policy Council

***NLM involved at HHS request**

The Community (AHIC)



Office of the National Coordinator for Health Information Technology (ONC)

American Health Information Community (the Community)

On September 13, 2005, Health and Human Services (HHS) Secretary Mike Leavitt announced the membership for the American Health Information Community (the Community). The Community is being formed to help advance efforts to reach President Bush's call for most Americans to have electronic health records within ten years.

The Community is a federally-chartered commission and will provide input and recommendations to HHS on how to make health records digital and interoperable, and assure that the privacy and security of those records are protected, in a smooth, market-led way.

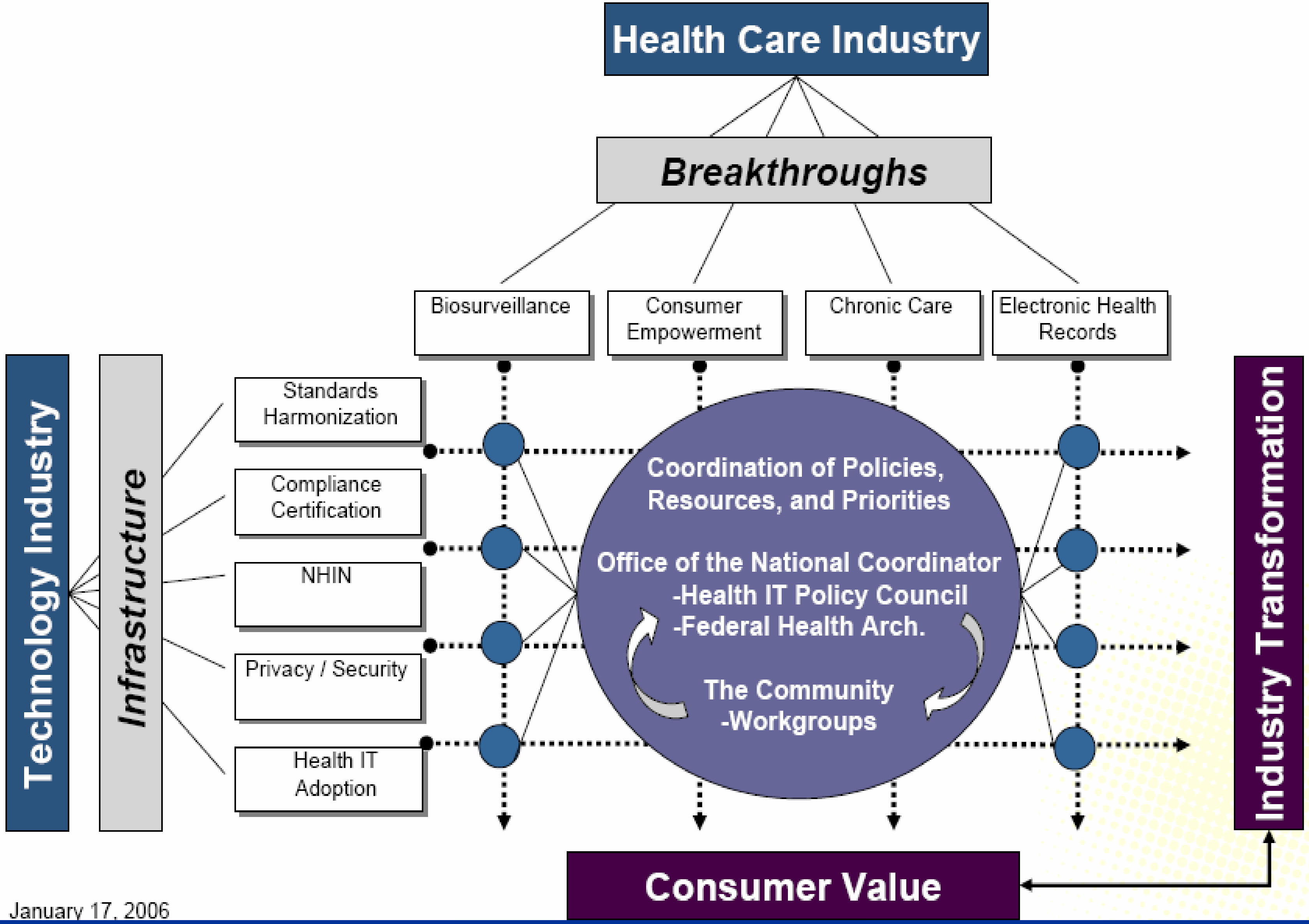
The Community will have a total of 17 members including Secretary Leavitt who will serve as the Chair. The remaining 16 members selected by Secretary Leavitt represent a combination of key leaders in the public and private sectors. Selected for membership are individuals who represent stakeholder interests in advancing the mission of the Community and who have strong peer support. Members selected to serve include:

- Secretary Michael O. Leavitt

What's New

- **State Privacy and Security Subcontract Opportunities Announced Under Expanded HHS Contract with RTI**
  full story
- **First Nationwide Health Information Network Forum, June 28-29, 2006.**
  more details
- **Click here to find out more about the American Health Information Community workgroup meetings.**
- **HHS Enters Into Agreements to Support Digital Health Recovery for the Gulf Coast**
  full story
- **HHS Announces Award of NHIN Prototype Contracts**
  full story
- **ONC and AHIMA release two anti-fraud project reports**
  full story

Health Information Technology Deployment Coordination



Health Care Industry

Breakthroughs

Biosurveillance

Consumer Empowerment

Chronic Care

Electronic Health Records

Technology Industry

Infrastructure

Standards Harmonization

Compliance Certification

NHIN

Privacy / Security

Health IT Adoption

Coordination of Policies, Resources, and Priorities

Office of the National Coordinator
-Health IT Policy Council
-Federal Health Arch.

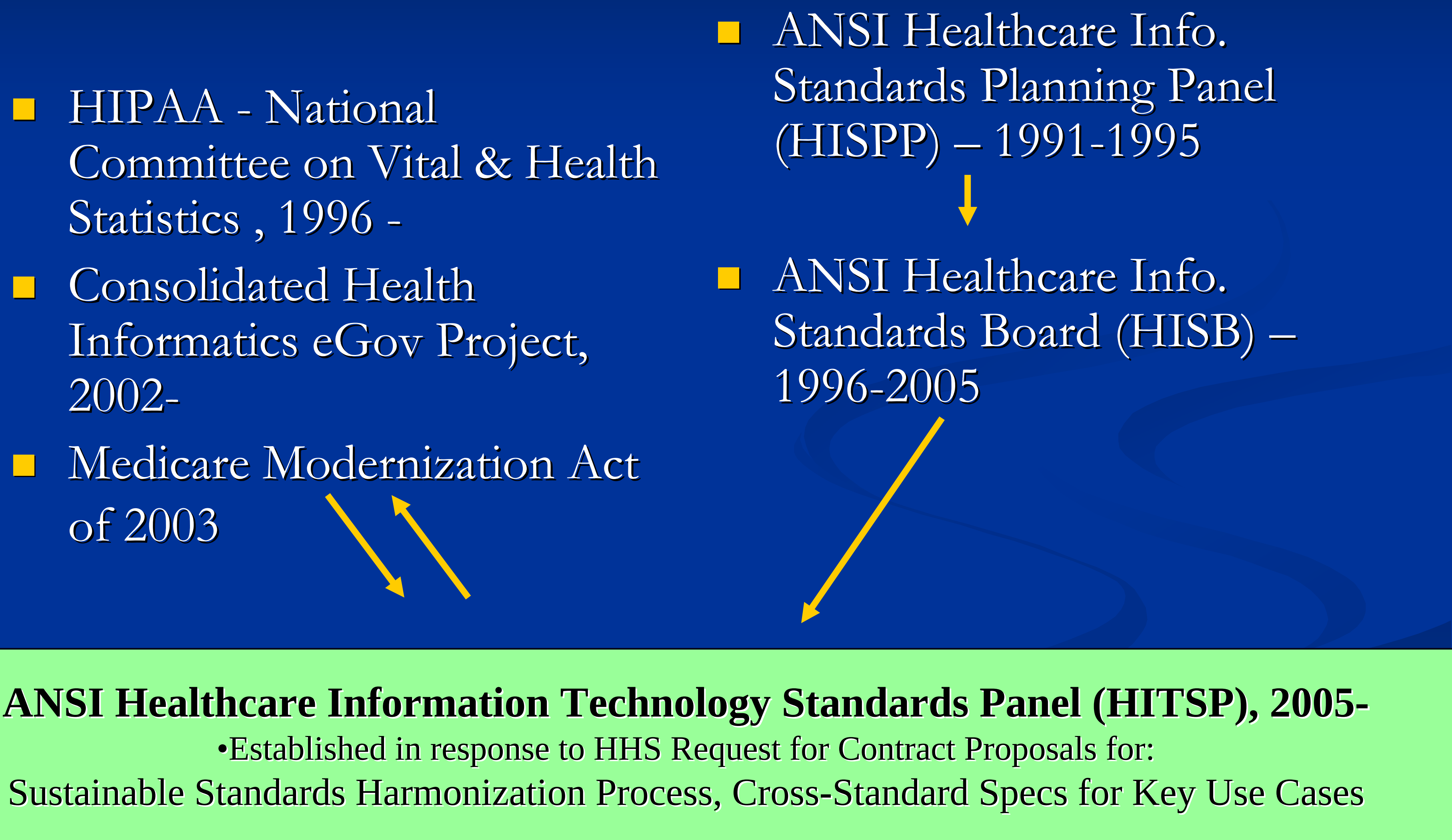
The Community
-Workgroups

Industry Transformation

Consumer Value

January 17, 2006

U.S. Gov't Standards Selection and ANSI Coordination



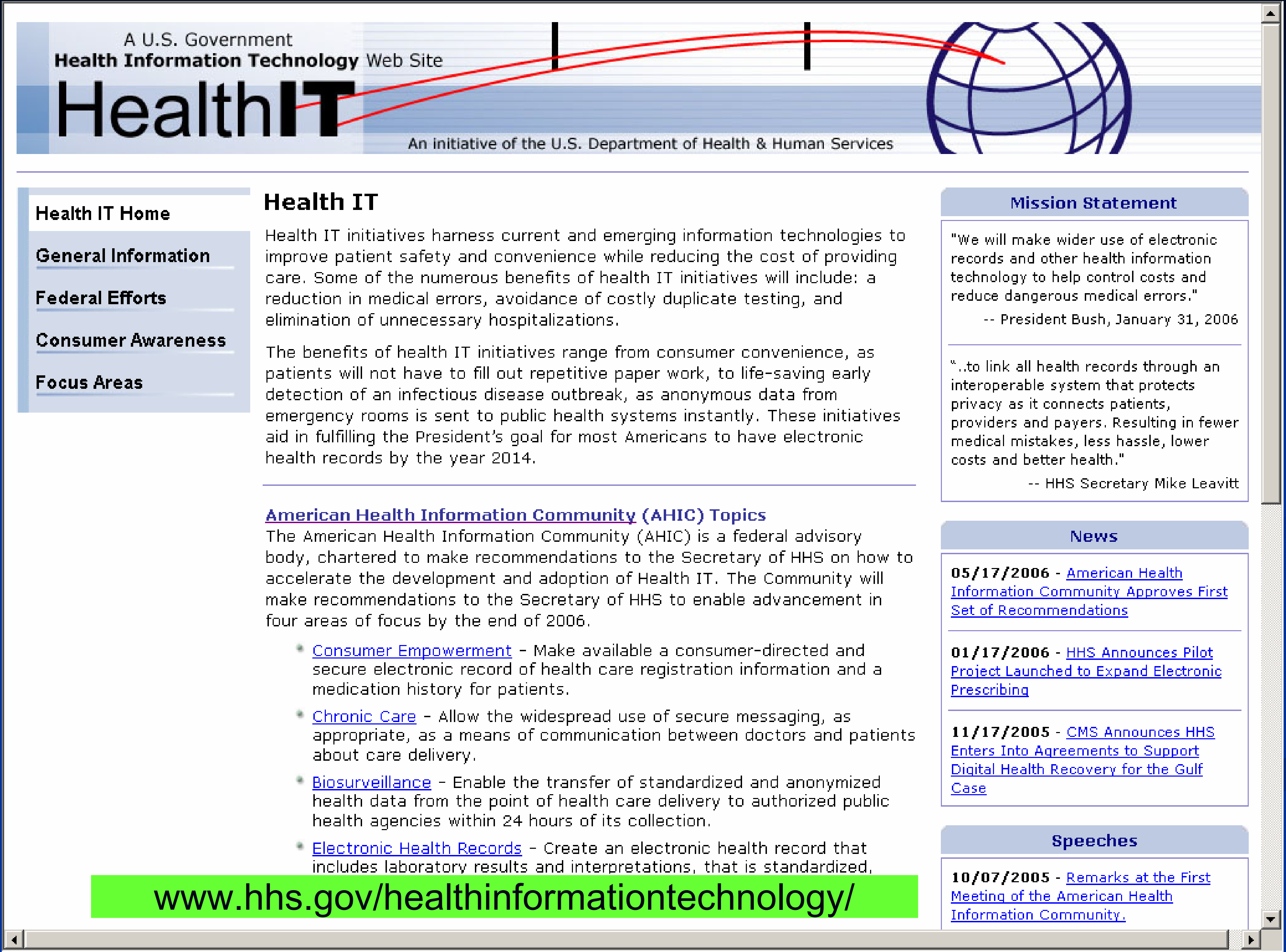
- HIPAA - National Committee on Vital & Health Statistics , 1996 -
- Consolidated Health Informatics eGov Project, 2002-
- Medicare Modernization Act of 2003

- ANSI Healthcare Info. Standards Planning Panel (HISPP) – 1991-1995
- ANSI Healthcare Info. Standards Board (HISB) – 1996-2005

ANSI Healthcare Information Technology Standards Panel (HITSP), 2005-

•Established in response to HHS Request for Contract Proposals for:

Sustainable Standards Harmonization Process, Cross-Standard Specs for Key Use Cases



Health IT

Health IT initiatives harness current and emerging information technologies to improve patient safety and convenience while reducing the cost of providing care. Some of the numerous benefits of health IT initiatives will include: a reduction in medical errors, avoidance of costly duplicate testing, and elimination of unnecessary hospitalizations.

The benefits of health IT initiatives range from consumer convenience, as patients will not have to fill out repetitive paper work, to life-saving early detection of an infectious disease outbreak, as anonymous data from emergency rooms is sent to public health systems instantly. These initiatives aid in fulfilling the President's goal for most Americans to have electronic health records by the year 2014.

American Health Information Community (AHIC) Topics

The American Health Information Community (AHIC) is a federal advisory body, chartered to make recommendations to the Secretary of HHS on how to accelerate the development and adoption of Health IT. The Community will make recommendations to the Secretary of HHS to enable advancement in four areas of focus by the end of 2006.

- Consumer Empowerment – Make available a consumer-directed and secure electronic record of health care registration information and a medication history for patients.
- Chronic Care – Allow the widespread use of secure messaging, as appropriate, as a means of communication between doctors and patients about care delivery.
- Biosurveillance – Enable the transfer of standardized and anonymized health data from the point of health care delivery to authorized public health agencies within 24 hours of its collection.
- Electronic Health Records – Create an electronic health record that includes laboratory results and interpretations, that is standardized,

Mission Statement

"We will make wider use of electronic records and other health information technology to help control costs and reduce dangerous medical errors."
-- President Bush, January 31, 2006

"..to link all health records through an interoperable system that protects privacy as it connects patients, providers and payers. Resulting in fewer medical mistakes, less hassle, lower costs and better health."
-- HHS Secretary Mike Leavitt

News

05/17/2006 - American Health Information Community Approves First Set of Recommendations

01/17/2006 - HHS Announces Pilot Project Launched to Expand Electronic Prescribing

11/17/2005 - CMS Announces HHS Enters Into Agreements to Support Digital Health Recovery for the Gulf Case

Speeches

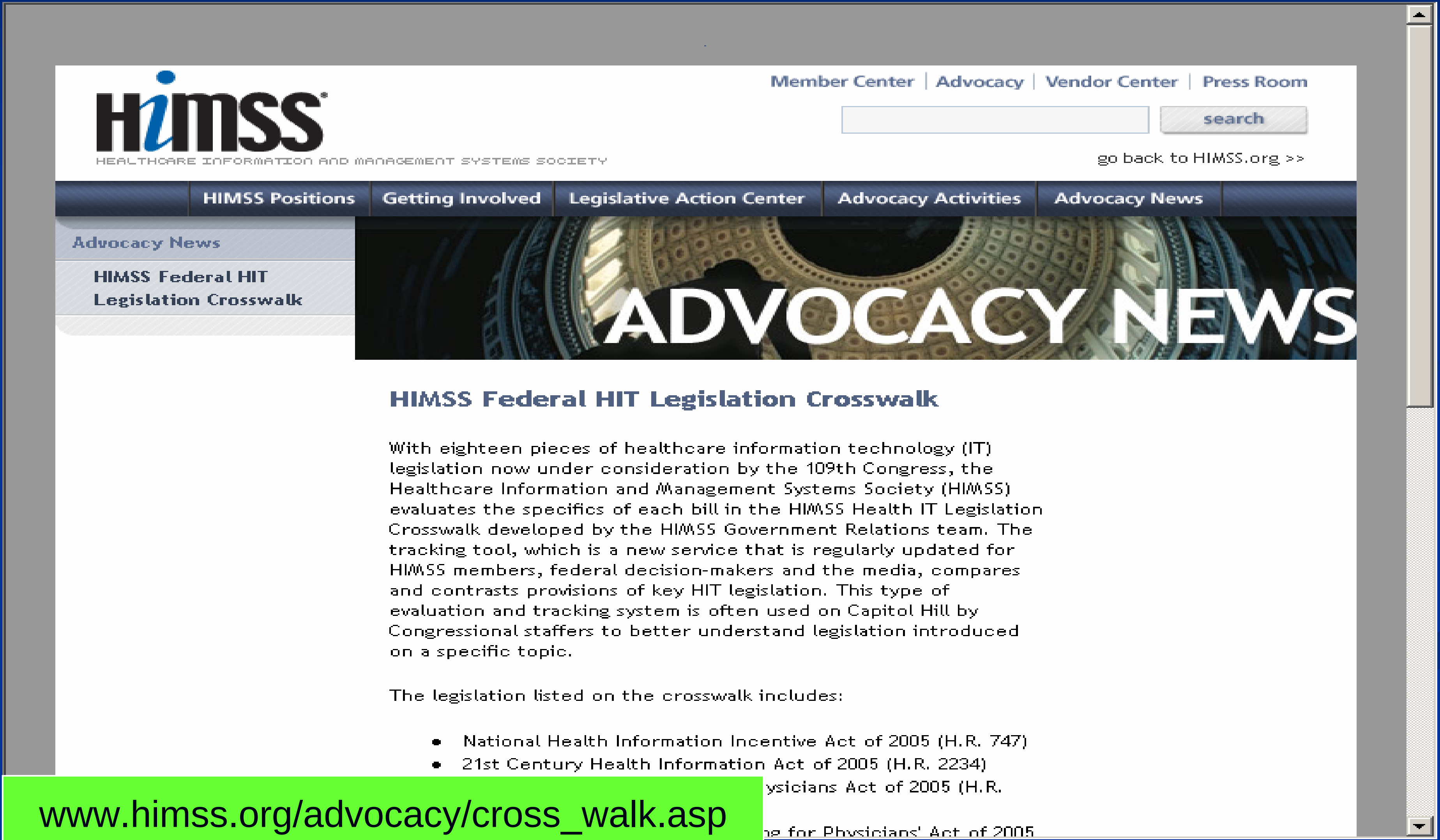
10/07/2005 - Remarks at the First Meeting of the American Health Information Community.

www.hhs.gov/healthinformationtechnology/

HHS Secretary Leavitt's 500-Day Plan to Transform Health Care Systems

- Expressing a clear vision of health information technology that conveys the benefits to patients, providers and payers
- Convening national collaboration re: developing setting, and certifying HIT standards and outcomes for interoperability, privacy and data exchange
- Realizing the near-term benefits of health information technology in: adverse drug-incident reporting, e-prescribing, lab and claims-sharing data, clinic registrations, insurance forms
- Creating an integrated network of population data, genetic information, and medical records to accelerate discovery
- Improving the clinical research network
- Providing early warning of threats through improved domestic and international surveillance

Congress Drafting Health IT Bills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Advocacy News
HIMSS Federal HIT Legislation Crosswalk
ADVOCACY NEWS

HIMSS Federal HIT Legislation Crosswalk

With eighteen pieces of healthcare information technology (IT) legislation now under consideration by the 109th Congress, the Healthcare Information and Management Systems Society (HIMSS) evaluates the specifics of each bill in the HIMSS Health IT Legislation Crosswalk developed by the HIMSS Government Relations team. The tracking tool, which is a new service that is regularly updated for HIMSS members, federal decision-makers and the media, compares and contrasts provisions of key HIT legislation. This type of evaluation and tracking system is often used on Capitol Hill by Congressional staffers to better understand legislation introduced on a specific topic.

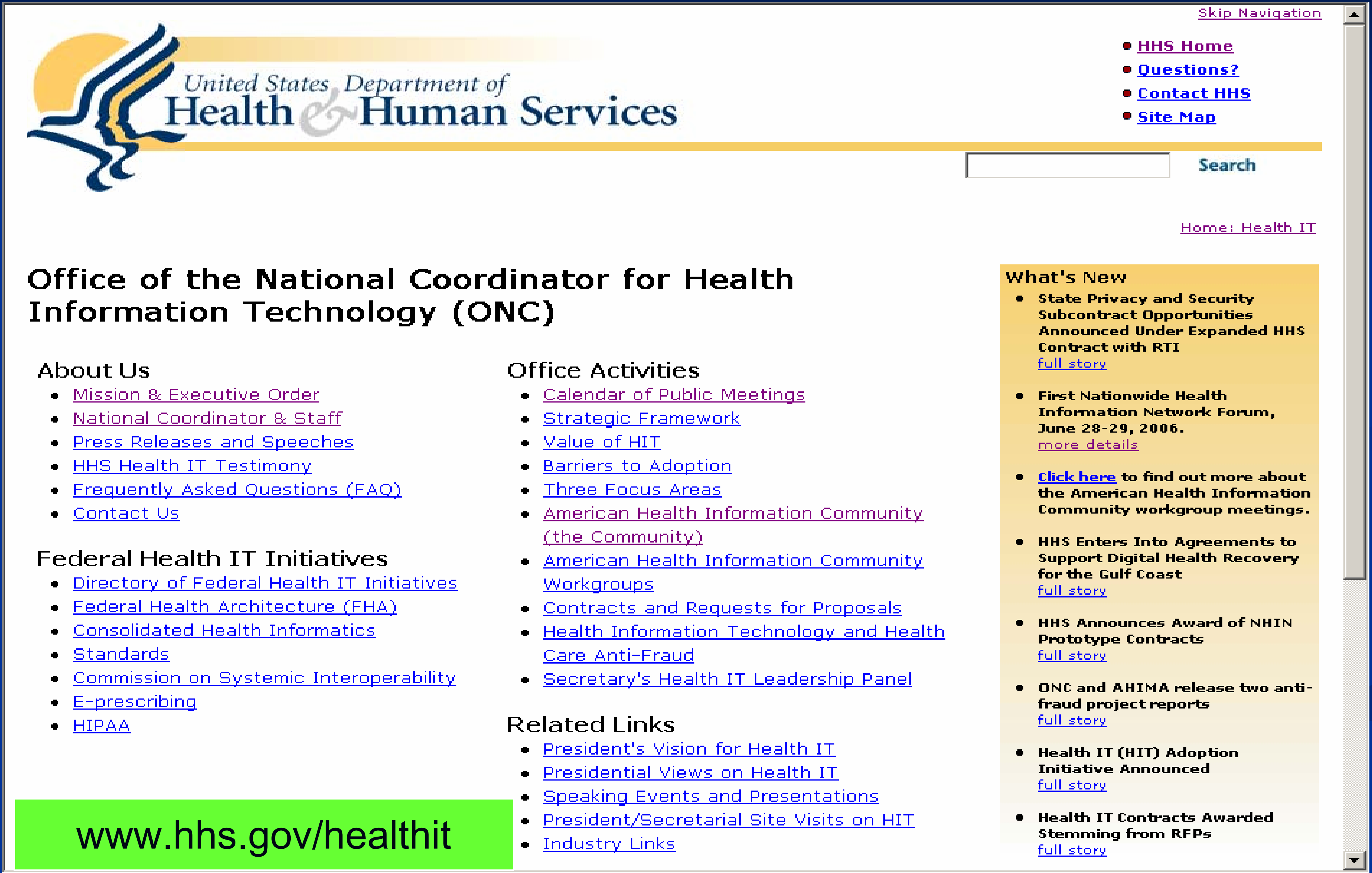
The legislation listed on the crosswalk includes:

- National Health Information Incentive Act of 2005 (H.R. 747)
- 21st Century Health Information Act of 2005 (H.R. 2234)
- ysicians Act of 2005 (H.R.

ng for Physicians' Act of 2005

www.himss.org/advocacy/cross_walk.asp

ONC



Office of the National Coordinator for Health Information Technology (ONC)

About Us

- Mission & Executive Order
- National Coordinator & Staff
- Press Releases and Speeches
- HHS Health IT Testimony
- Frequently Asked Questions (FAQ)
- Contact Us

Federal Health IT Initiatives

- Directory of Federal Health IT Initiatives
- Federal Health Architecture (FHA)
- Consolidated Health Informatics
- Standards
- Commission on Systemic Interoperability
- E-prescribing
- HIPAA

Office Activities

- Calendar of Public Meetings
- Strategic Framework
- Value of HIT
- Barriers to Adoption
- Three Focus Areas
- American Health Information Community (the Community)
- American Health Information Community Workgroups
- Contracts and Requests for Proposals
- Health Information Technology and Health Care Anti-Fraud
- Secretary's Health IT Leadership Panel

Related Links

- President's Vision for Health IT
- Presidential Views on Health IT
- Speaking Events and Presentations
- President/Secretarial Site Visits on HIT
- Industry Links

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- **ONC and AHIMA release two anti-fraud project reports**
  full story
- **Health IT (HIT) Adoption Initiative Announced**
  full story
- **Health IT Contracts Awarded Stemming from RFPs**
  full story

www.hhs.gov/healthit

NLM HIT Standards Activities

- Support, license, develop, and distribute standard clinical vocabularies (LOINC, SNOMED, RxNorm) in UMLS
- *Distribute FDA-approved structured product labels via "Daily Med"
- *Direct efforts to map clinical terminologies to HIPAA administrative code sets
- *Direct contract to align HL7 with standard vocabularies and to define HL7 mechanism for exchange of entire EHRs
- Work with NIH to promote use of standards in the clinical research enterprise

*** Partially supported by funds from AHRQ and the Office of the Secretary, HHS**

Mapping Projects planned/underway

- CHI standards to HIPAA code sets
  - SNOMED CT – ICD-9-CM, ICD-10-CM
  - SNOMED CT – CPT
  - LOINC – CPT

- SNOMED CT to "other" vocabularies
  - Medical Dictionary for Regulatory Affairs (MedDRA)
  - International Classification of Primary Care (ICPC)
  - Medcin
  - ICF

- Will require:
  - Robust testing/validation
  - Alignment of update schedules

- Draft mappings available for testing via the UMLS soon

Key NLM Assumptions about Mappings

- Participants must include:
  - Producers of vocabularies on both ends; prospective users and recipients of the output, e.g., health care providers, payers, as testers and validators
- Mapping may/will prompt changes/corrections to content and adjustment to update schedules
- Mappings must be updated every time either end is updated
- Mappings will be distributed in the UMLS (not exclusively); use will be governed by terms applicable to both ends
- Mapping is still an R & D problem - it will take iteration to build highly functional maps

NLM- HL7 Contract Arrangement

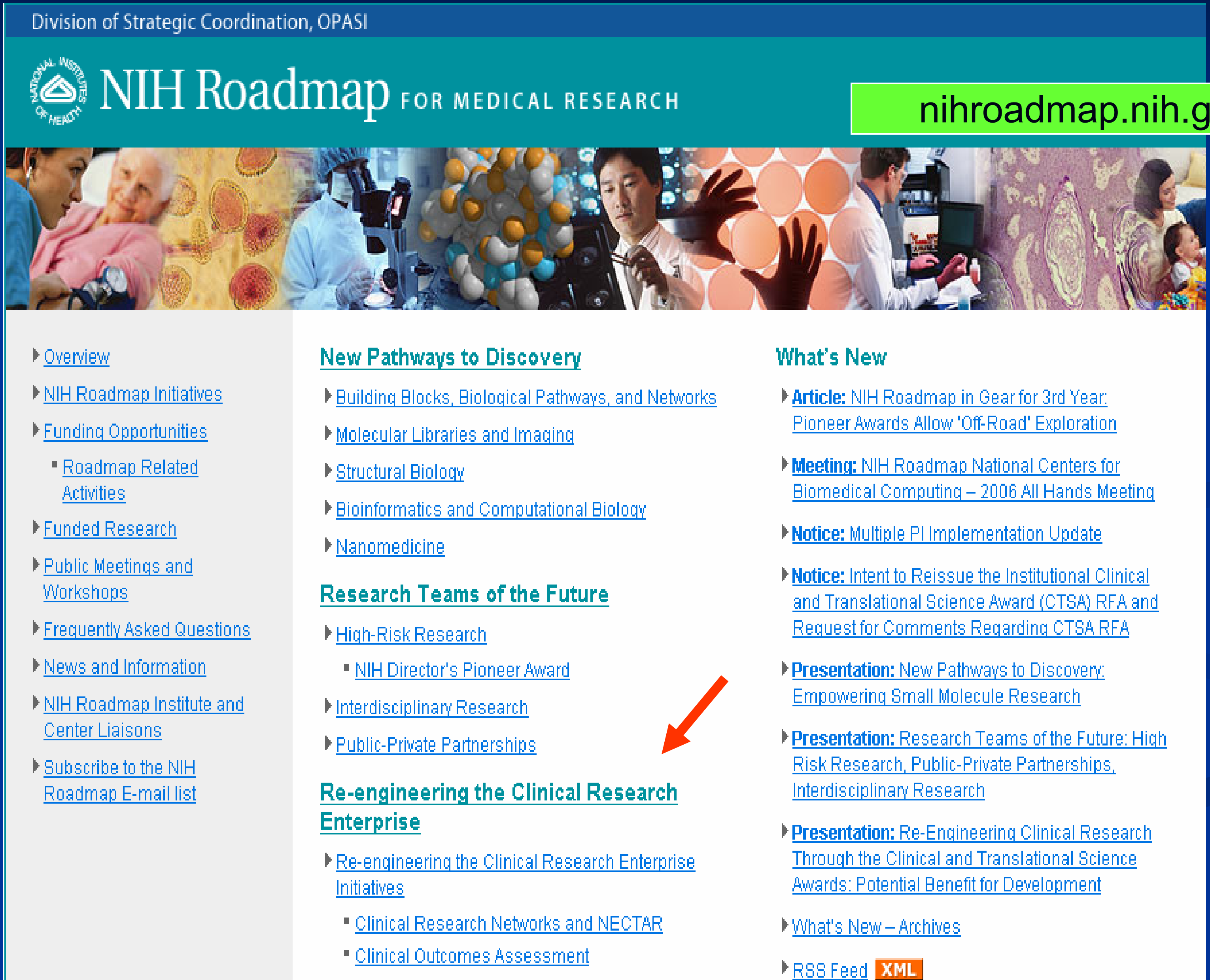
September 2004 – August 2007

- Align HL7 message standard with standard vocabularies *(NLM-initiated)*
  - Specify which subsets of standard vocabularies are valid for particular message segments
  - Replace HL7-maintained lists of coded values with subsets of standard vocabularies, where feasible

- Conduct pilot transfer of EHR data using HL7 Messaging and Implementation guides independent of source and destination architectures *(on behalf of HHS)*
  - Two NHIN prototype contractors participating in pilots

Broaden participation: Clinical Research

nihroadmap.nih.gov



Division of Strategic Coordination, OPASI

NIH Roadmap FOR MEDICAL RESEARCH

- Overview
- NIH Roadmap Initiatives
- Funding Opportunities
  - Roadmap Related Activities
- Funded Research
- Public Meetings and Workshops
- Frequently Asked Questions
- News and Information
- NIH Roadmap Institute and Center Liaisons
- Subscribe to the NIH Roadmap E-mail list

New Pathways to Discovery

- Building Blocks, Biological Pathways, and Networks
- Molecular Libraries and Imaging
- Structural Biology
- Bioinformatics and Computational Biology
- Nanomedicine

Research Teams of the Future

- High-Risk Research
  - NIH Director's Pioneer Award
- Interdisciplinary Research
- Public-Private Partnerships

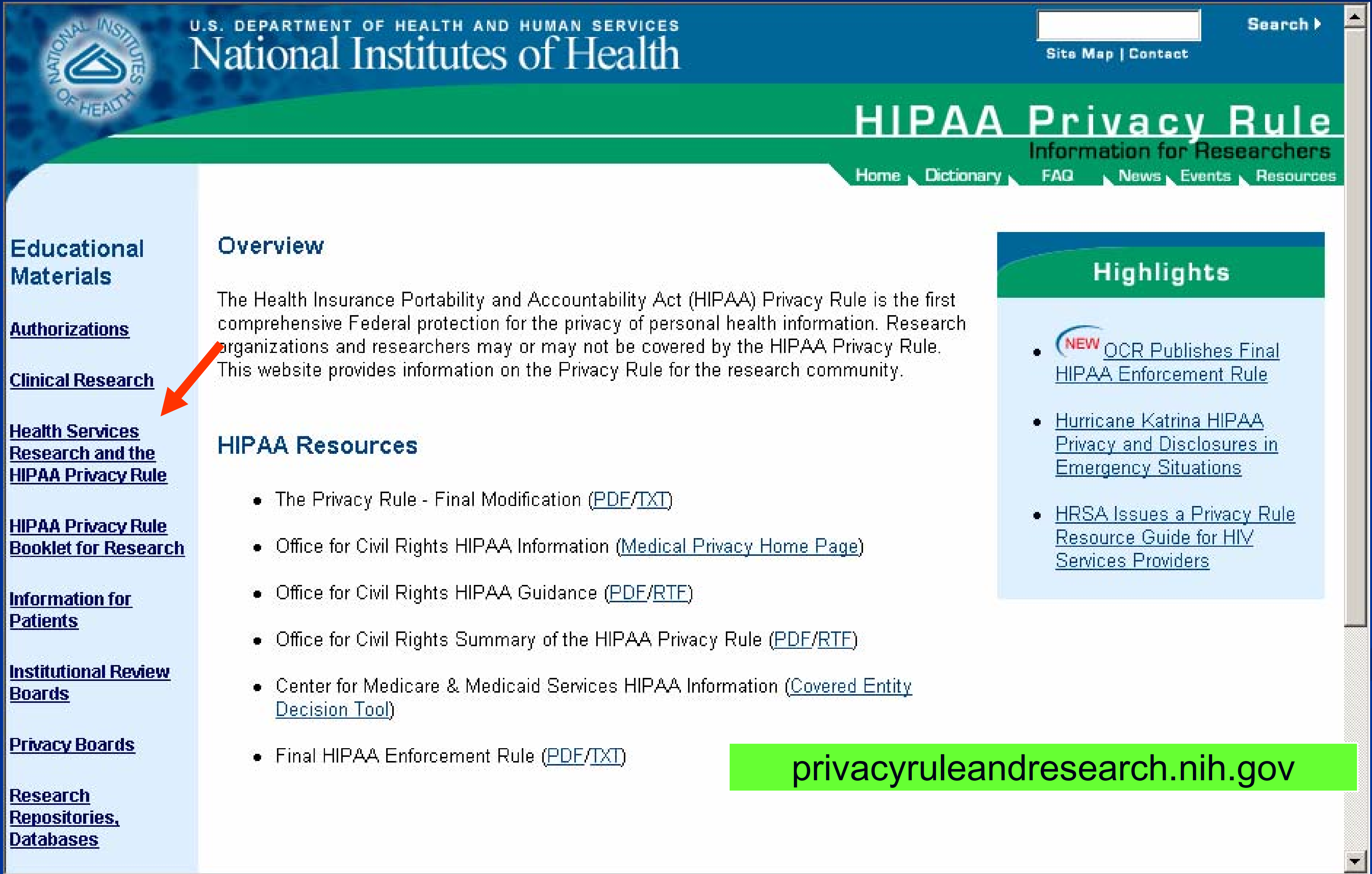
Re-engineering the Clinical Research Enterprise

- Re-engineering the Clinical Research Enterprise Initiatives
  - Clinical Research Networks and NECTAR
  - Clinical Outcomes Assessment

What's New

- **Article:** NIH Roadmap in Gear for 3rd Year: Pioneer Awards Allow 'Off-Road' Exploration
- **Meeting:** NIH Roadmap National Centers for Biomedical Computing – 2006 All Hands Meeting
- **Notice:** Multiple PI Implementation Update
- **Notice:** Intent to Reissue the Institutional Clinical and Translational Science Award (CTSA) RFA and Request for Comments Regarding CTSA RFA
- **Presentation:** New Pathways to Discovery: Empowering Small Molecule Research
- **Presentation:** Research Teams of the Future: High Risk Research, Public-Private Partnerships, Interdisciplinary Research
- **Presentation:** Re-Engineering Clinical Research Through the Clinical and Translational Science Awards: Potential Benefit for Development
- What's New – Archives
- RSS Feed XML

Resources for Researchers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Educational Materials

- Authorizations
- Clinical Research
- Health Services Research and the HIPAA Privacy Rule
- HIPAA Privacy Rule Booklet for Research
- Information for Patients
- Institutional Review Boards
- Privacy Boards
- Research Repositories, Databases

Overview

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule is the first comprehensive Federal protection for the privacy of personal health information. Research organizations and researchers may or may not be covered by the HIPAA Privacy Rule. This website provides information on the Privacy Rule for the research community.

HIPAA Resources

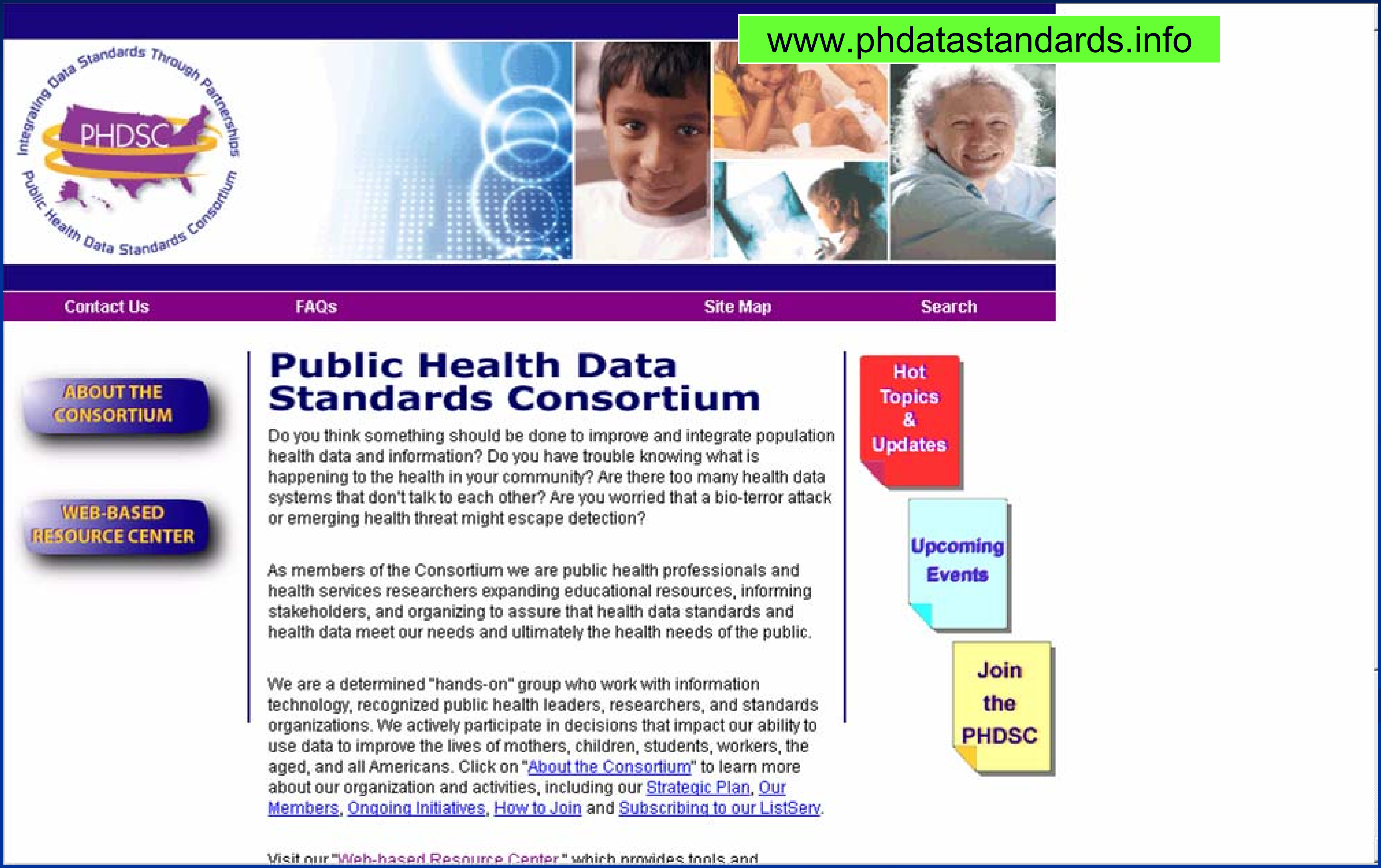
- The Privacy Rule - Final Modification (PDF/TXT)
- Office for Civil Rights HIPAA Information (Medical Privacy Home Page)
- Office for Civil Rights HIPAA Guidance (PDF/RTF)
- Office for Civil Rights Summary of the HIPAA Privacy Rule (PDF/RTF)
- Center for Medicare & Medicaid Services HIPAA Information (Covered Entity Decision Tool)
- Final HIPAA Enforcement Rule (PDF/TXT)

Highlights

- NEW OCR Publishes Final HIPAA Enforcement Rule
- Hurricane Katrina HIPAA Privacy and Disclosures in Emergency Situations
- HRSA Issues a Privacy Rule Resource Guide for HIV Services Providers

privacyruleandresearch.nih.gov

Broaden participation: Public Health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Public Health Data Standards Consortium

Do you think something should be done to improve and integrate population health data and information? Do you have trouble knowing what is happening to the health in your community? Are there too many health data systems that don't talk to each other? Are you worried that a bio-terror attack or emerging health threat might escape detection?

As members of the Consortium we are public health professionals and health services researchers expanding educational resources, informing stakeholders, and organizing to assure that health data standards and health data meet our needs and ultimately the health needs of the public.

We are a determined "hands-on" group who work with information technology, recognized public health leaders, researchers, and standards organizations. We actively participate in decisions that impact our ability to use data to improve the lives of mothers, children, students, workers, the aged, and all Americans. Click on "About the Consortium" to learn more about our organization and activities, including our Strategic Plan, Our Members, Ongoing Initiatives, How to Join and Subscribing to our ListServ.

Visit our "Web-based Resource Center" which provides tools and

Take Home Messages

- Emphasis has shifted from health data standards to the broader picture of HIT and EHR.
- Will take time to put in place but ultimately will affect health care, public health functions, and the data available for HSR
- It's not too early (*or too late*) to get involved:
  - to contribute to standards development, testing, and refinement
  - to study the impact of standards on health care, public health, and clinical research
- If you work with HIT investigate the use of the UMLS and other NLM resources at http://www.nlm.nih.gov