



Moving the National Health Information Technology Agenda Forward: Personalized Health Care and Confidentiality, Privacy, and Security Work Group Updates

Secretary's Advisory Committee on Genetics, Health, and Society
(SCGHS)

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Challenges to the Advancement of Genomics

- Discrimination on the basis of genetic information
- Genetic information is
 - Unique to an individual
 - Predictive of the person's future health
 - Immutable once disclosed
- Genetic information provides information about other related family members
- Linking of data with non-covered entity types of data



Health IT and Genomics

- Health IT Can Add Additional Value to Genomics
 - Help enhance adoption & utility
 - Dependent upon trust in the privacy & security of the information

Change is Underway: Drivers of Health IT Adoption

Rising Health Care Costs
and Health Information Technology as A Solution

Substantial Benefits
for Consumers and the Economy

Administration Leadership
on Health Information Technology Adoption

Strong Endorsement
from Industry and Commercial Leaders



Drivers of Health Information Technology

Key Health IT Components

A Robust, Interoperable, Health IT Environment that brings together:

- Electronic Health Records (EHR)
- Personal Health Records (PHR)
- Public Health Information



- Standards (Data, Technical and Security)
- Interoperable Health Information Exchange Network
(Nationwide Health Information Network - NHIN)

Office of the National Coordinator (ONC)

Executive Order, April 2004:

The President created the National Coordinator position

- To advance the vision of developing a nationwide interoperable health information technology infrastructure
- To achieve the President's goal of widespread adoption of interoperable electronic health records (EHR) by 2014

Key Role for ONC:

Provide **leadership** for the development and nationwide implementation of an **interoperable health information technology infrastructure** to improve

- The quality and efficiency of health care and
- The ability of consumers to manage their health

National Health IT Agenda



The Purpose of the National Health IT Agenda

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Key Role for ONC:

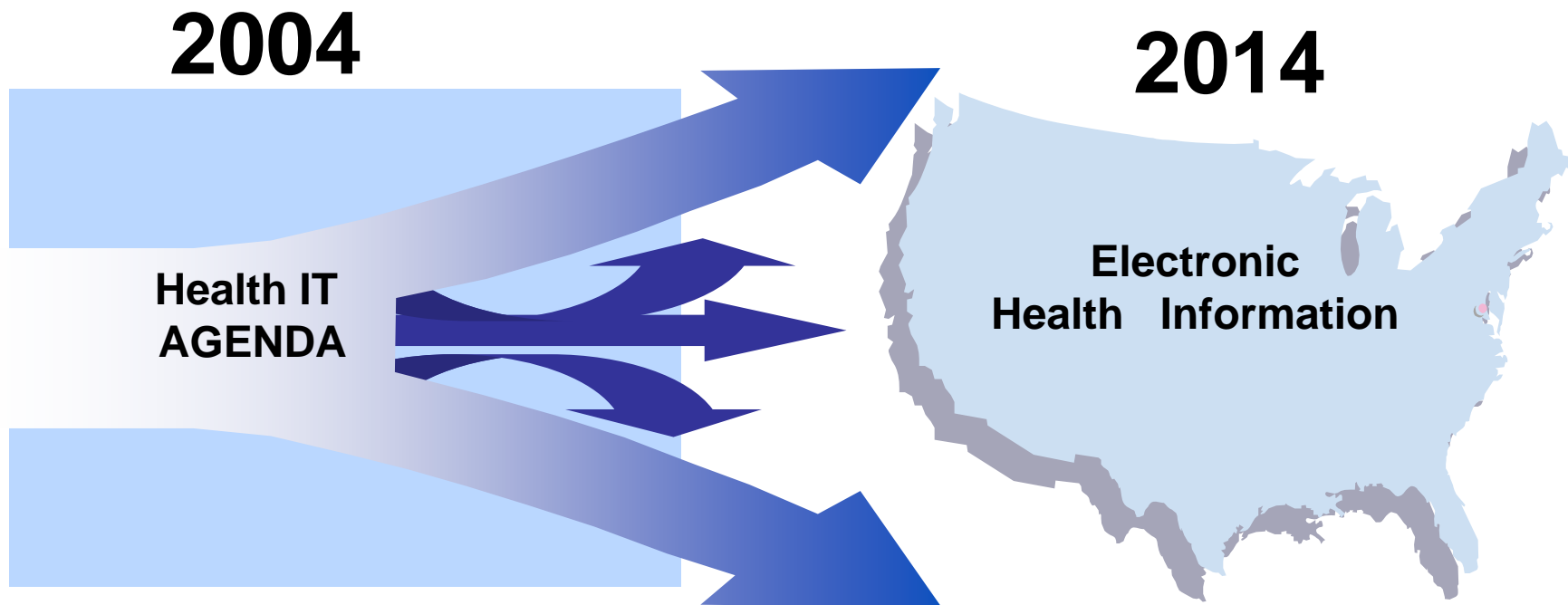
Provide **leadership** for the development and nationwide implementation of an **interoperable health information technology infrastructure to improve**

- **The quality and efficiency of health care and**
- **The ability of consumers to manage their health**



Health IT is a critical component
for the **transformation** to occur in
individual and population health

The Framework for Health IT Adoption



Widespread adoption of interoperable electronic health records by 2014

- Improve quality and efficiency of health care
- Improve individual and population health

EHRs PHRs Public Health
Home Telehealth

Standards ... Interoperability

Nationwide Health Information Network

ONC Activities Support Four Strategic Goals

Goal 1: Inform Health Care Professionals

- Increase Adoption of EHRs
- Clinical Decision Support
- Access to online lab results, medication history, and registration functions

Goal 2: Interconnect Health Care

- Nationwide Health Information Network Prototypes
- Standards Harmonization Process
- Certification of Health Record & Network Systems
- Privacy and Security Solutions for Interoperable Health Information Exchange
- Federal Health Architecture
- State Alliance for e-Health

Goal 3: Personalize Health Management

- Personal Health Records
- Access to online lab results, medication history, and registration functions

Goal 4: Improve Population Health

- Federal biosurveillance programs

Organizational Framework to Facilitate Nationwide, Interoperable Health IT Adoption: AHIC

American Health Information Community (AHIC – “The Community”)

- A federal advisory committee (FACA), funded & staffed by ONC
- Chaired by Secretary Leavitt
- 17 members; public – private collaboration
- Provides input and recommendations to HHS
 - How to make health records digital and interoperable
 - Assure that the privacy and security of those records are protected, in a smooth, market-led way
- Detailed work performed in work groups and brought back to The Community for deliberation and decisions



American Health Information Community (AHIC) Work Groups

Seven work groups established

- Involving over 120 experts and stakeholders
- Over 50 meetings in 2006
- Focus of Work Groups - Identify and make recommendations regarding policy, technical, business and social issues related to their charges and priorities

November 29, 2005

**CONSUMER
EMPOWERMENT**

CHRONIC CARE

BIOSURVEILLANCE

EHRs

May 16, 2006

**CONFIDENTIALITY,
PRIVACY &
SECURITY**

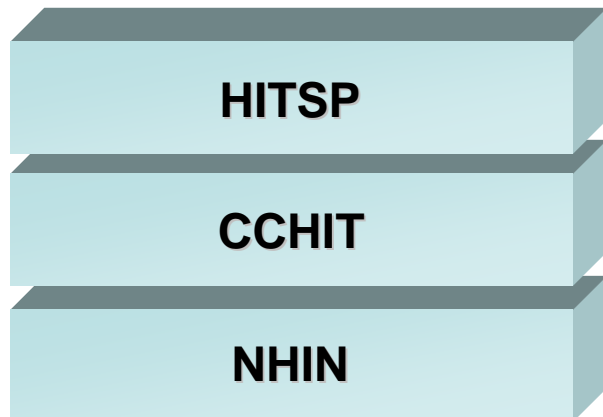
QUALITY

October 31, 2006

**PERSONALIZED
MEDICINE
(GENOMICS)**

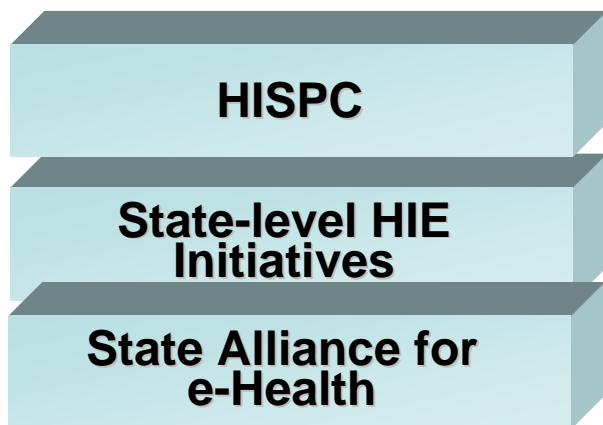
Additional Collaborative Activities to Foster Health IT Adoption

Public - Private



- **HITSP** – Health IT Standards Panel
- **CCHIT** – Certification Commission for Health IT
- **NHIN** - Nationwide Health Information Network Related Initiative

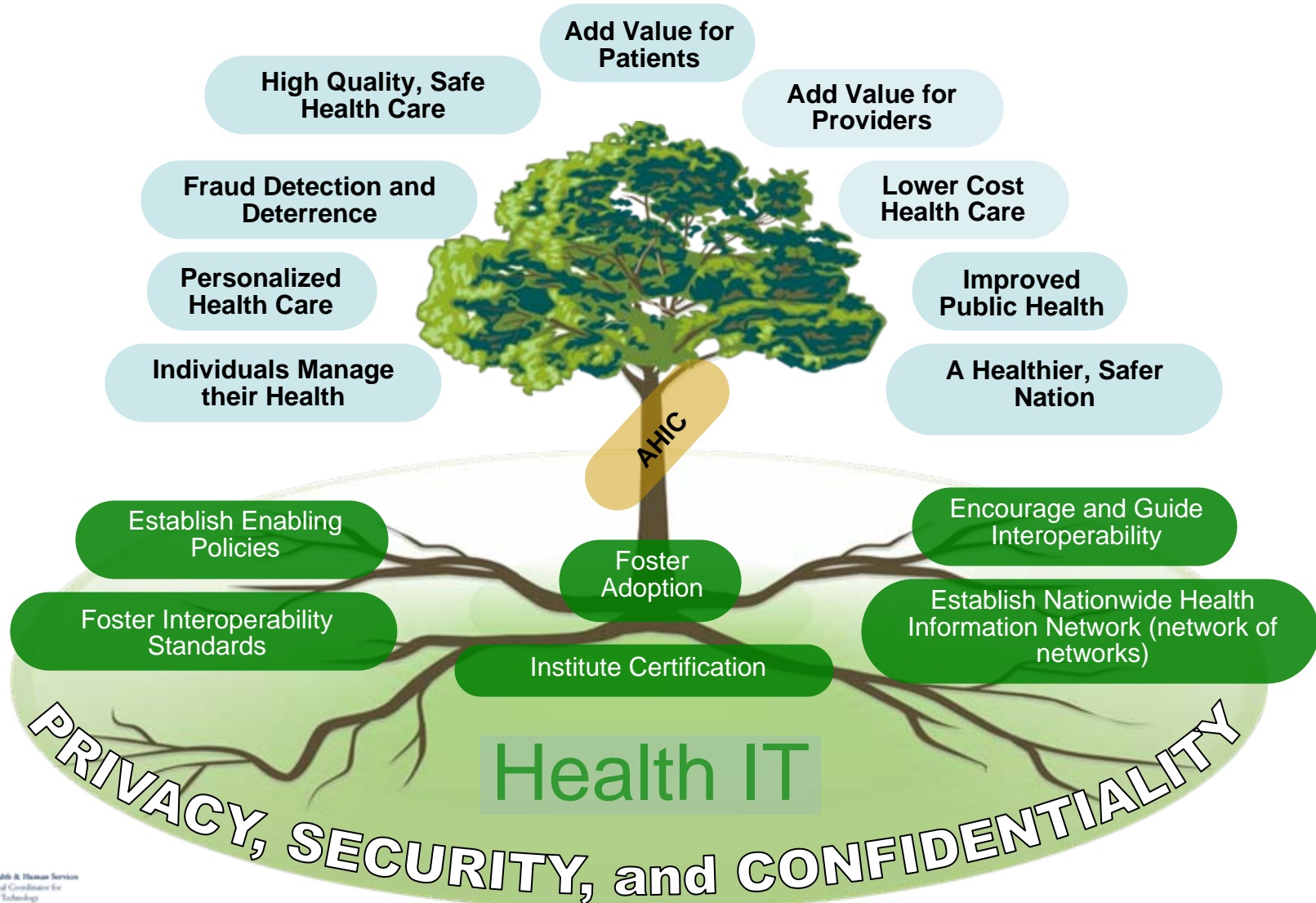
State-based



- **Privacy and Security Solutions** – formation of state level Health Information Security and Privacy Collaboration
- **State-level HIE Initiatives** – examination of established state HIE and identification of key *issues* and *strategies*
- **State Alliance for e-Health** – *executive-level advisory body* for consensus-based solutions for *state policy* relative to HIE and Health IT

and
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Health IT Support for Transforming Health Care



American Health Information Community

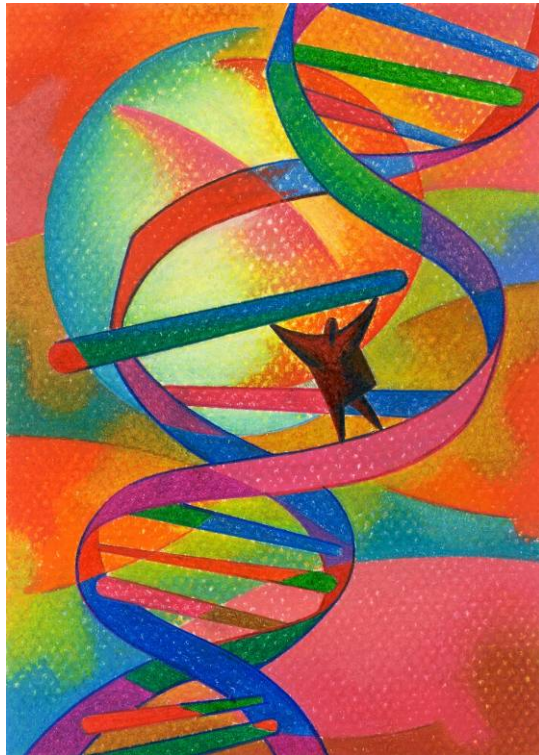
- ✓ Priority Setting
- ✓ Growing and Maturing
- ✓ Recommendations and Results
- Privacy! Privacy! Privacy!
- Widespread adoption of interoperable Health IT
- Transition of AHIC to a public-private entity in the private sector



Personalized Health Care (PHC) Workgroup

Broad Charge for the Workgroup:

Make recommendations to the American Health Information Community for a process to foster a broad, community-based approach to establish a common pathway based on **common data standards** that encourage the **incorporation of interoperable, clinically useful genetic laboratory test data and analytical tools into electronic health records** to support clinical decision-making for the health care provider and patient.



Specific Charge for the Workgroup:

Make recommendations to the American Health Information Community to consider means to **establish standards for reporting and incorporation of common medical genomic tests data into electronic health records**, and **provide incentives for adoption** across the country including federal government agencies.

Health IT Can Facilitate Knowledge Management

Organize information to improve quality, safety, and efficiency

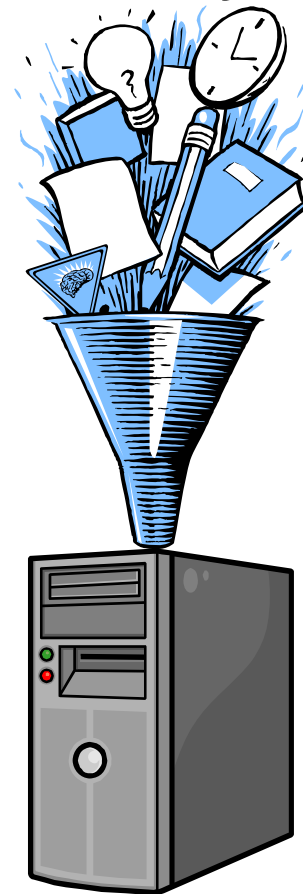
A common set of definitions & standards for:

- Electronic systems
- Clinical databases
- Knowledge repositories

Manage systems & information to generate knowledge concerning:

- Better information based on individual differences
- Medical product evaluations
- Evidence development
- Post-marketing assessments of safety & efficacy
- Capacities to track & report on adverse events

Move from collecting health information for billing or reimbursements to automating the core process of health care



Health IT Can Contribute to Better Health

Support the Physician:

- Keep up-to-date re new medical breakthroughs
- Reflect best practices
- Just-in-Time Decision Support
- Improved diagnosis
- Improved predictions about disease course & outcomes

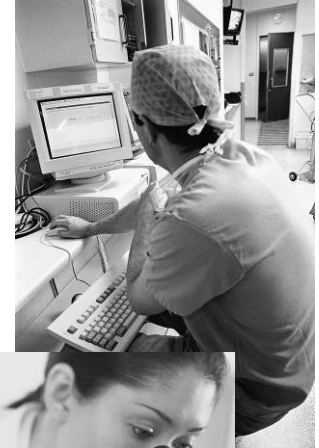
Support the Researcher

- Health measurement tools
- Rich information resource

Support the Consumer

- Fosters R&D into new areas
- Leads to better care through decision support
- Generates accessible consumer information
- **Safer, higher quality, personalized care**

**The right diagnosis & treatment,
the first time – every time!**



Transforming Health ^{and} Care

**The right diagnosis & treatment,
the first time – every time!**

**Anticipation & prevention of illness:
True transformation from health care**

to *health*

Meeting of the Secretary's Advisory Committee on
Genetics, Health, and Society (SACGHS)

Privacy and Security

Privacy and Security and Health IT

Goal: A nationwide interoperable health information technology infrastructure must ensure that patients' individually identifiable health information is secure and protected.

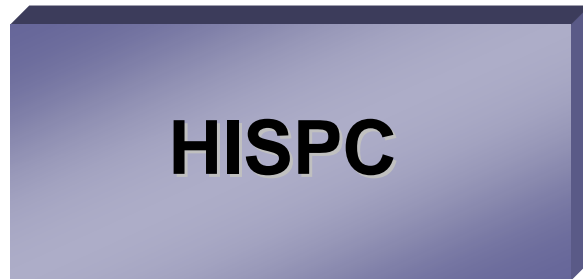


Health IT, Genetics, and HIPAA

- HIPAA as a baseline and a foundation for protection
 - State laws add greater protections including genetic information
- Privacy and security risks may change as opportunities for data sharing/aggregation increases
- Health IT presents new challenges and opportunities
 - Non-covered entities (e.g., health information exchanges, genetic databases)
 - New roles and capabilities for consumers
 - Opportunities for additional clarity and/or guidance
- HIPAA issues being raised by Privacy & Security Solutions Contract



HISPC & State Alliance



- **ID Variation in Policies and Laws**
- **State Solutions and Implementation Plans**
- **Future Regional/ Multi-state Collaboration**

- **Consensus Building by State Leaders**
- **Health Information Protection Task Force**

Confidentiality, Privacy, and Security (CPS) Workgroup

Broad Charge for the Workgroup:

Make recommendations to the Community regarding the **protection of personal health information** in order to **secure trust, and support appropriate interoperable electronic health information exchange.**



Specific Charge for the Workgroup:

Make actionable confidentiality, privacy, and security recommendations to the Community on **specific policies that best balance the needs between appropriate information protection and access to support and accelerate the implementation of the consumer empowerment, chronic care, and electronic health record related breakthroughs.**

CPS Workgroup, Cont.

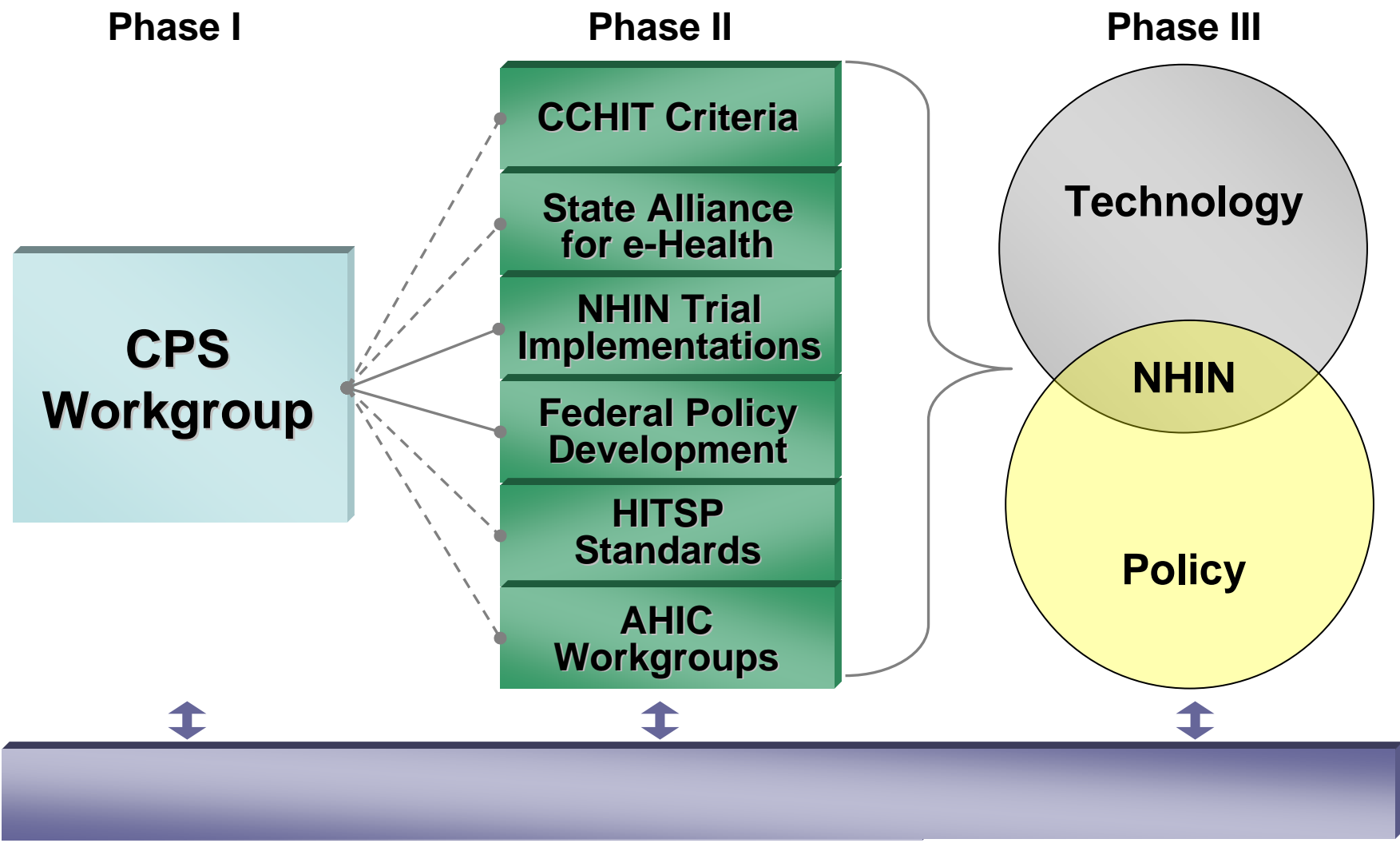


- Patient identity proofing recommendations accepted by AHIC



- Implications of having some participants in electronic health information exchange not be subject to existing federal privacy and security laws
- PHR Privacy Policies

CPS Workgroup – Privacy & Security Activities



Questions & Comments

www.hhs.gov/healthit