



HHS Priorities *for America's Health Care*

Personalized Health Care

<http://www.hhs.gov/myhealthcare/index.html>

Secretary's Advisory Committee on Genetics,
Health and Society
March 26, 2007



Secretary Leavitt's Priorities

- **Personalized Health Care**
- Medicaid Modernization
- Health Information Technology
- Medicare Rx
- Prevention
- Health Care Value Incentives
- Emergency Response
- Pandemic Preparedness
- New Orleans Health Care System
- Global Health

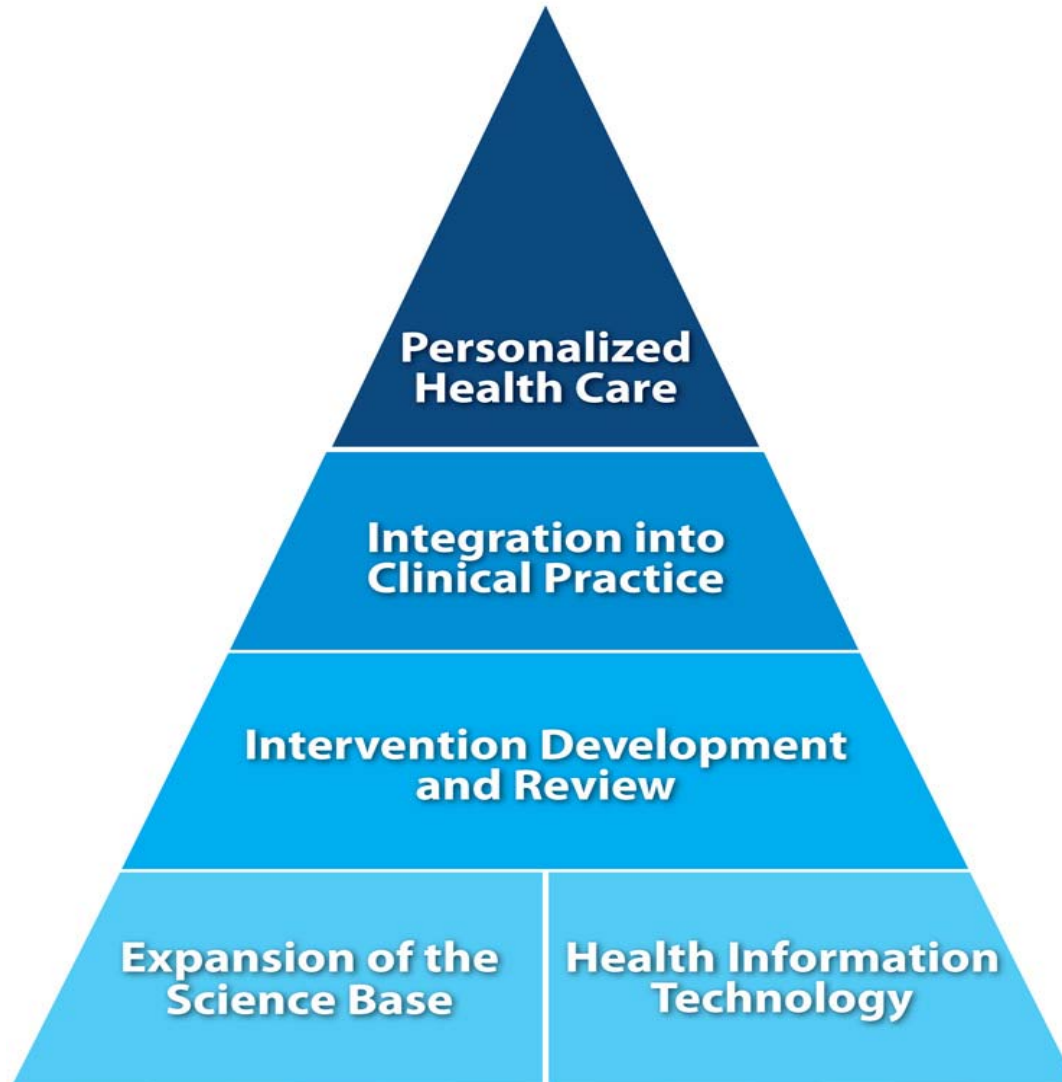


Secretary's Vision

- **Personalized Health Care:** “Health care is tailored to the individual. Prevention is emphasized. Propensities for disease are identified and addressed through preemptive intervention. Discovery and innovation move drugs to the market and to medical practice faster and at lower cost.”
- **The Long Term Objective:** Advances in basic research have positioned us to harness new and increasingly affordable potential in medical and scientific technology. With clinical tools that are increasingly targeted to the individual, our health care system can give consumers and providers the means to make more informed, individualized, and effective choices.
- **The Secretary's 2-year Objective:** Establishes concepts and priorities that support health care system transformation to achieve long term objectives.



Building a Base for Personalized Health Care





Goals : PHC Initiative

Goal 1:

Link Clinical and Genomic Information to Support Personalized Health Care

A. Establish an interoperable public/private data partnership of networks to deliver information on individual medical outcomes and linking findings to genetic laboratory test.

- Provides a standardized, open electronic system to link genetic test results used in medical practice and individual response to treatments
- Delivers to researchers findings on medical outcomes years faster
- Provides evidence base for developing more individualized and effective treatment
- Supports pioneering HIT work for linking clinical data, and helps broaden the evidence base underlying quality of care standards.



Goals : PHC Initiative

Goal 1 (cont.):

Link Clinical and Genomic Information to Support Personalized Health Care

B. Establish Common Pathway for Data Integration through Electronic Personal Health Records

- Utilize American Health Information Community (AHIC) Personalized Health Care Working group to consider policies for facilitating the inclusion of medical genetic test results and family history information in electronic health records



Goals : PHC Initiative

Goal 2:

Support the Appropriate Use of Genetic Information

- Protect individuals from genetic discrimination
- Encourage policies and practices that provide sufficient protections to consumers that genetic test information is used only for their medical benefit
- Provide oversight of genetic testing to assure analytical and clinical validity
 - Regulation of testing platforms and systems
 - Proficiency in practices for performing tests and data interpretation
- Standardize access policies to federally funded databases of genetic information



AHIC Working Group on PHC

Evaluate needs and opportunities to utilize health information technology to advance personalized health care.

- Chaired by:
 - Douglas Henley, American Association of Family Physicians (AHIC member)
 - John Glaser, Harvard Partners
- Representation from
 - Federal agencies : AHRQ, FDA, VA, DoD, NHGRI, NLM
 - Industry : Pfizer, Merck, Affymetrix, 23andME
 - Health plans : Permanente Federation, Intermountain Health, Wellpoint
 - Laboratories : Quest, Virginia Commonwealth University Department of Pathology
 - Consumer organizations : National Partnership for Women and Families, Patient Advocate
 - ELSI representatives : Genetics and Public Policy Center, Baylor College of Medicine Center for Medical Ethics, University of Louisville Institute of Bioethics



AHIC Working Group on PHC

Broad Charge for the Workgroup:

Make recommendations to the AHIC for a process to foster a broad, community-based approach to establish a common pathway based on common data standards that encourages 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 AHIC to consider means to establish standards for reporting and incorporation of common medical genomic tests and family medical history data into electronic health records, and provide incentives for adoption across the country including federal government agencies.

Issues to Consider:

Standards for Genetic Test Results and Family Medical History
Lab-EHR Interoperability
Clinical Decision Support Systems
Confidentiality and Privacy Concerns