

**Connecting Americans  
to Their Health Care:**  
*Empowered Consumers,  
Personal Health Records  
and Emerging Technologies*



**NATIONAL CONFERENCE  
DECEMBER 7-8, 2006  
WASHINGTON, D.C.**

Connecting Americans to Their Health Care:  
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**2006**

## **Improving Access and Protecting Privacy**

Janlori Goldman - Health Privacy Project

Alan Westin - Columbia University

Harriet Pearson - IBM

Jodi Daniel - Office of the National Coordinator for  
Health Information Technology



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## **Improving Access and Protecting Privacy**

Alan Westin

Columbia University



MARKLE FOUNDATION

Robert Wood Johnson Foundation



# Privacy and EHR Systems: Can We Avoid A Looming Conflict?

**Dr. Alan F. Westin**

**Professor of Public Law and  
Government Emeritus, Columbia  
University**

**Principal, PRIVACY CONSULTING GROUP**

**At the Markle Conference on "Connecting  
Americans to Their Health Care,"  
Washington, D.C. December 7-8, 2006**



# My Experiences with HC and Privacy

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- opinion surveys and empirical studies my prime tools
- **10 national surveys on HC and privacy since 1978 (latest September, 2006)**
- field studies for NAS, NBS AND OTA -- e.g. Computers, Health Records, and Citizen Rights (1975)
- **policy proposals, e.g. Building Privacy by Design into Emerging EHR Systems (2005)**
- **since 1993, privacy assessments for HC providers, insurers, pharmacy firms, and HR departments, through my Privacy Consulting Group (PCG)**
- Current PCG publications are on my final Resources slide

# The Pre-EHR Privacy Baseline

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- **health information highly sensitive**
- **trust in HC practitioners high**
- **main worry: health information going to non-health organizations or publicly disclosed**
- **concerns also over data security and uses of new genetic information**
- **public majority ambivalent about HC computer effects -- a “worried positive...”**
- **led to demands for federal health privacy law**
- **but HIPAA Privacy Rule and enforcement not seen as solving all privacy problems, even pre-EHR**

# 2006 Surveys on EHR and Privacy

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- several important surveys in 2005 -- summarized in my 2005 ppt listed on Resources slide. (Will refer today to some 2005 results for trend-lines)
- for 2006, two new surveys:
  - Harris Interactive/Westin, on EHR and Privacy; online, 2747 adult respondents, September, 2006; adjusted to represent entire adult population
  - Harris Interactive/Wall St. Journal, Health Care Poll; online, 2624 adult respondents, September 2006

# Still Low Awareness of EHR National Program

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- **Harris/Westin 2006 described current U.S. EHR national program efforts; asked: “Have you read or heard anything about this program?”**
- only 26% of the adult public said yes; represents 60 million out of 230 million adults. (62% said had not read or heard; 12% weren't sure) About the same result as in 2005
- **awareness highest -- as expected -- among better-educated, higher-income, and online-using**
- rather surprising -- given extensive mass media coverage
- **3 out of 4 adults not yet “involved with” or paying attention to EHR developments**



# Online Users See EHR Positives

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- Harris-WSJ 2006 documented broad public optimism re EHR benefits -- but at lower majorities than recorded in 2005
- **55% believe EHR can decrease frequency of medical errors significantly (was 62% in 2005)**
- 60% believe EHR can reduce healthcare costs significantly (was 73% in 2005)
- **68% believe EHR can improve patient care by reducing unnecessary tests and procedures (was 73% in 2005)**
- 62% of online users also believe “The use of Electronic Medical Records makes it more difficult to ensure patients’ privacy” (was 67% in 2005 -- a small gain in confidence)

# EHR Privacy Concerns, From Harris/Westin 2005

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- **sensitive health data may be leaked..... 70%**
- increased sharing without patient's knowledge..... 69%
- **may be inadequate data security..... 69%**
- could increase not decrease medical errors..... 65%
- **Patients won't give sensitive information to providers... 65%**
- federal health privacy rules will be reduced ..... 62%

# EHR Developers and Privacy and Security

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- **when asked how much attention developers and managers of EHR programs “are paying to insure adequate patient privacy and data security measures”**
- **69% think they are paying attention**  
**(36% ‘a great deal” and 33% “some”)**
- **19% did not think so (12% paying “only a little attention”**  
**and 7% paying “not much attention at all”)**
- **positive belief is an EHR system developers asset**  
**-- for now**

# How Public Sees Privacy Risks and Benefits

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- when asked whether expected benefits to patients and society of EHR systems outweigh potential risks to privacy OR whether privacy risks outweigh expected benefits, privacy fears trump potential benefits:
  - 42% feel “privacy risks outweigh expected benefits”
  - 29% feel “expected benefits outweigh the privacy risks”
  - BUT -- 29% say they are not sure...
- shows that the creation of a majority opinion on the risk-benefit judgment is still out there -- not yet formed
- will be shaped by what EHR system developers DO and how they COMMUNICATE to patients and public

# Consumer Participation in EHR Programs

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- **most major EHR programs being rolled out without advance descriptions and choices for patients or members, as just an “administrative enhancement”**
- **is NOT how a majority of patients or members feel this change should be carried out:**
- **Harris/Westin 2006 survey asked:**
  - “How would you like to be involved when organizations providing you with health care records transition from mostly paper records to a complete electronic health record system? Please select ONE answer that best represents your view”

# Majorities (60%) Want to Be Informed and/or Exercise Choices

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- **four answers provided**
- “I might be okay with this but I would want to be notified of this change and have the effects of the handling of my personal medical information explained to me” .....**27%**
- **“I might be okay with this but I would want to be able to designate which parts of my medical records were entered or not entered into the electronic health record system” .....12%**

# Patient/Member Involvement -- 2

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- “I would want to be given the right not to have any of my medical records entered into the new electronic record system” ..... 21%
- “I don’t need to be notified of the change since I don’t think it will affect my relationship with my doctors and how they handle my information” ..... 22%
- “Not sure” ..... 17% (note the large figure here)
- while resting on low public majority awareness of EHR programs, these attitudes spell major potential trouble for EHR efforts

# What is Being Done to Inform and Offer Choices?

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- **not aware of any field studies of how EHR programs are being introduced to patients or members and how new EHR-based rights are presented**
- **not aware of patient/member surveys at EHR sites exploring how consumers react to the changes and rights policies**
- **also not aware of any experiments with allowing patients or members the right to designate record portions not to go into the general EHR system, and if these are being studied**
- **Finally, are there any EHR programs that offer a general “opt out”? If so, are these being studied?**



# A Looming Conflict?

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- **given 42+% of public feeling potential privacy risks outweigh potential EHR benefits**
- **and 60% of the public wanting advance explanations of EHR impacts and rights to choose how records used**
- **could be a sharp bump ahead for EHR developers, as weak communications and a “just say yes” approach prevail**
- **especially if advocacy groups expand a “STOP EHR PROGRAMS” movement, as urged by the Patients Privacy Rights Coalition**
- **Already happening in UK, where 53% of public and 52% of GPs oppose the UK national EHR plan, with an organized opposition**

# Informing Can Be Done Well

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- **I believe every EHR program should develop and provide a Patient's Guide to Your New EHR System: For Enhanced Participation, Privacy and Security**
- **customized to each EHR system; cover changes to all health care processes and information uses**
- **spell out health-care advantages of new system to patients or members**
- **show opportunities for greater patient participation in own health care processes and individual EHR-program choices**
- **describe privacy/fair information practices rules and rights under EHR, in clear, non-HIPAA-style prose**
- **outline data security program and safeguards**
- **offer lively Qs and As, scenarios, and personal contacts**

# Implications

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- **privacy and data security remain absolutely critical issues for the national EHR effort and each individual system**
- **majorities fear privacy risks, but adequate patient and member communications and choice options not present yet**
- **calls for empirical field studies of the EHR introduction process, patient and member communications, and new privacy, security, and participation policies**
- **along with surveys of patient and member perceptions, concerns, and experiences in various EHR program settings**
- **now is the right time in EHR activities for such studies -- not too soon and not too late**

# Resources and Contacts

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- **Privacy Consulting Group (PCG) web site is under reconstruction; to obtain these materials, please contact me at [afwestin@gmail.com](mailto:afwestin@gmail.com)**
- 1. **Building Privacy by Design into Emerging Electronic Health Record systems White Paper, 2005**
- 2. **“Public Attitudes Toward Privacy and EHR Programs,” Westin Presentation at AHRQ 2005 Conference**
- 3. **“Beyond HIPAA: Assuring Patients’ Interests in EHR Programs” Westin Presentation at IBM Forum, 2005**
- 4. **“Patient Participation and Privacy in EHR Programs,” Westin Ppt Presentation at IBM Forum, 2005**
- 5. **Report of the Harris/Westin Survey “EHR and Privacy, 2006,” will be ready by December 28, 2006**

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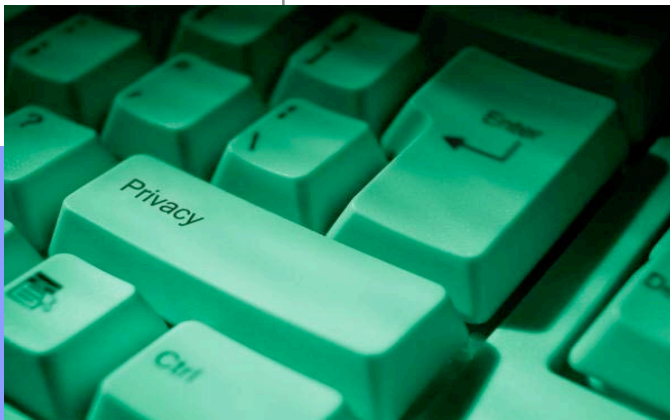
  
Robert Wood Johnson Foundation



# *Creating a New Framework for Privacy in a World of Patient-Centric Health Care*

Connecting Americans to their Health Care Conference  
December 2006

Harriet P. Pearson, VP Corporate Affairs & Chief Privacy Officer



## A Long History...

“If you want to employ intelligent, sensitive, sophisticated people, privacy is an issue you would better think about.”

*Frank T. Cary, Former CEO, IBM*  
*Wall Street Journal (Oct 2, 1975)*

### IBM's guidelines to employee privacy

*An interview with Frank T. Cary*

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Reprinted from



Harvard  
Business Review

September-October 1976

No. 26106

## IBM's privacy approach is informed by how we engage:

- **As an employer**

- Employ > 300,000 people. Directly or indirectly provide for health insurance coverage to them and their dependents.
- Spend \$1.7 billion annually, with approximately \$1 billion in the US to cover 500,000 employees and dependents.
- Want to help our employees have access to quality healthcare--with protections and policies in place to strike the appropriate balance with individual expectations of fairness and privacy.

- **As a participant in the healthcare & life sciences industry**

- IBM/Healthlink healthcare business--engaged in initiatives e.g. Denmark e-health, Mayo Clinic, US National Health Information Infrastructure, National Geographic project, Biobank Summits.

- **As a corporate citizen**

- Deeply-held value to contribute *innovations that matter to the world.*



## Our senior leadership has charged a task force on healthcare privacy issues

- **Chaired by Chief Privacy Officer, this task force comprises leaders from human resources, privacy, healthcare business and corporate citizenship.**
- **Mission: Drive IBM's actions in 3 areas:**
  - IBM's own policies and practices with respect to managing employee health information
  - Champion IBM's innovation--for our clients and the world—by creating solutions that enable privacy and security in the management of health information.
  - Engage in the development of public policy and private-sector leadership practices for managing health, including genetic, information.

## This task force has already driven changes in IBM's worldwide policies

- **Global Equal Opportunity Policy**
  - Added “genetics,” co-equal to race, gender, etc. as an attribute that will not be used to make employment decisions
- **Global Data Privacy Policy**
  - Added guidelines on genetic information, reflecting Task Force principles and applying highest-level of protection
- **CEO Sam Palmisano adopted changes and announced to all 300,000+ employees**

The New York Times  
nytimes.com

October 10, 2005

### **I.B.M. to Put Genetic Data of Workers Off Limits**

By [STEVE LOHR](#)

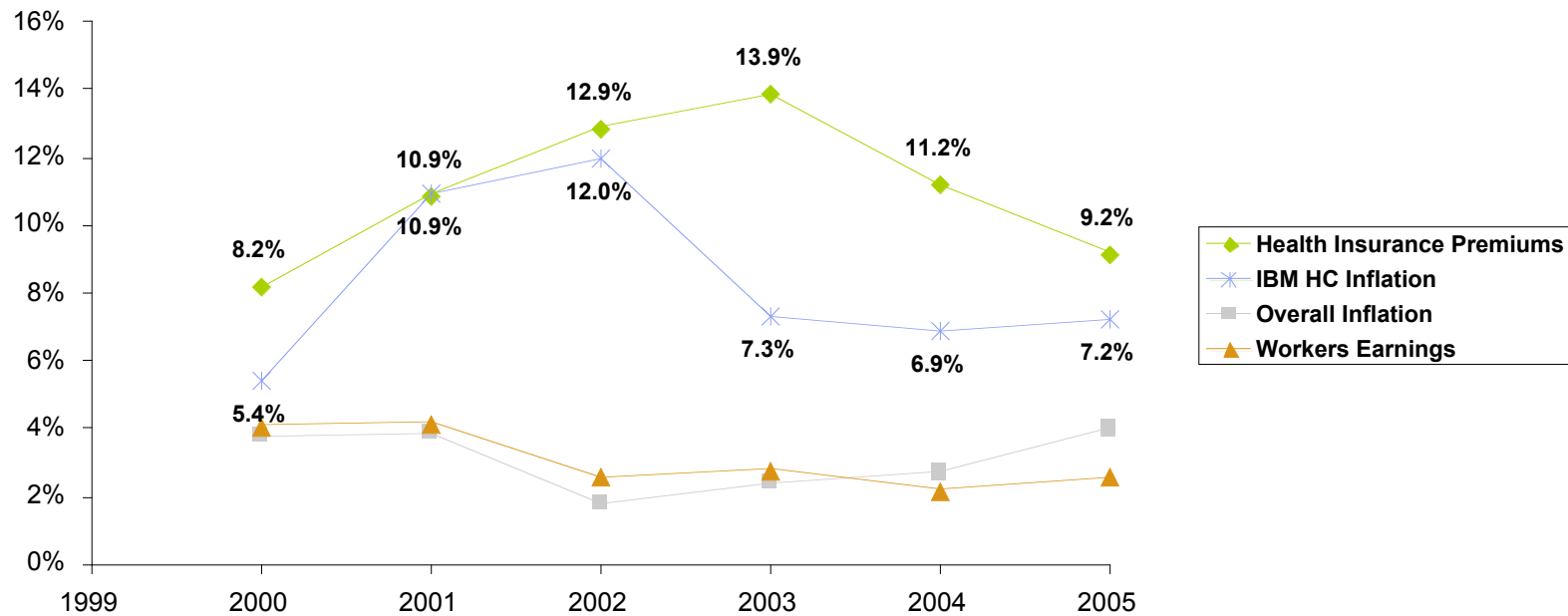
As concerns grow that genetic information could become a modern tool of discrimination, [I.B.M.](#) plans to announce a new work force privacy policy today.

I.B.M., the world's largest technology company by revenue, is promising not to use genetic information in hiring or in determining eligibility for its health care or benefits plans. Genetics policy specialists and privacy rights groups say that the I.B.M. pledge to its more than 300,000 employees worldwide appears to be the first such move by a major corporation.

The new policy, which comes as Congress is considering legislation on genetic privacy, is a response to the growing trend in medical research to focus on a person's genetic propensity for disease in hopes of tailoring treatments to specific medical needs.

# IBM's overall health benefits strategy has delivered high quality at below-industry premium increases.

US Health Insurance Premiums\*  
1999-2005



*IBM's HR organization has designed and implemented a range of programs to maximize health care spend value*

Sources: \*The Kaiser Family Foundation and Health Research and Educational Trust: Employer Health Benefits 2005 Annual Survey. Marianne Defazio for IBM growth rates.

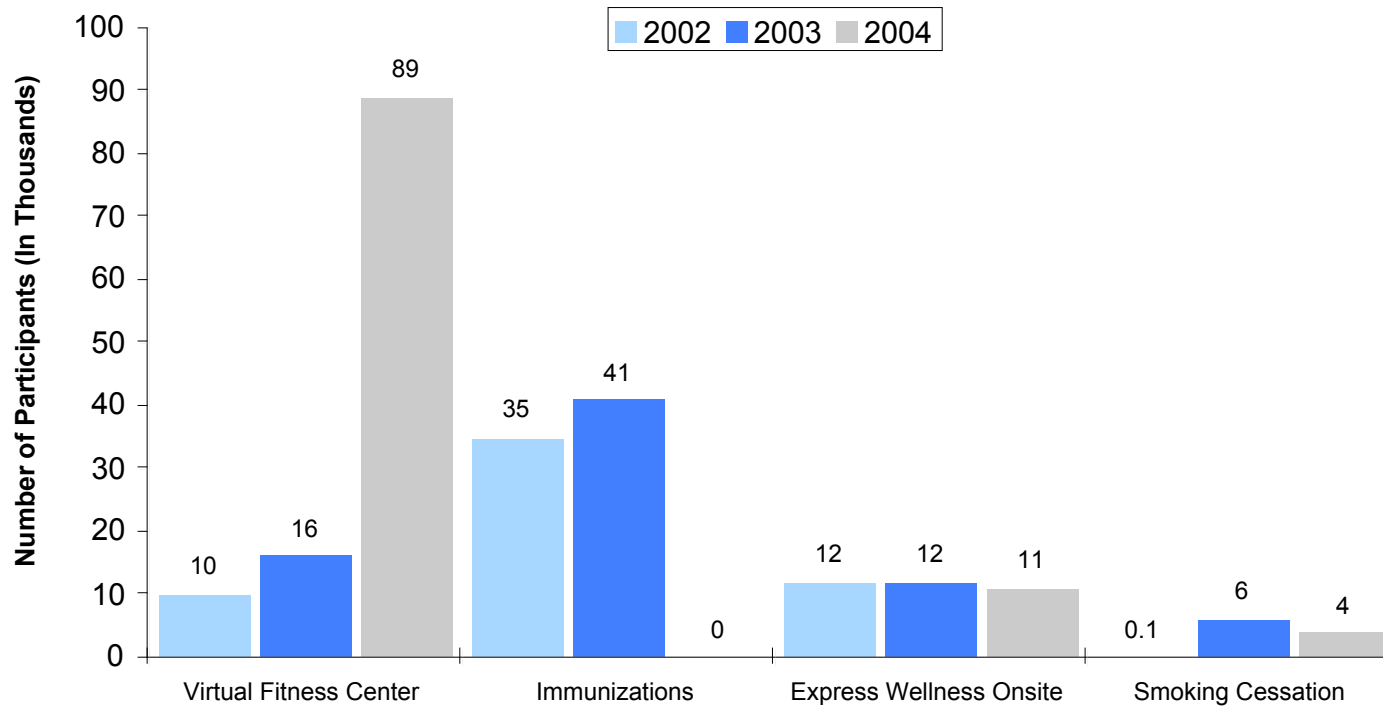
# IBM HR manages over forty programs to maximize Healthcare value

## Portfolio of IBM GWBS & HB Programs

HEALTH PROMOTION		INDUSTRIAL HYGIENE/SAFETY		MEDICAL		BENEFITS DESIGN AND MGT				
A1	Screenings	B9	Industrial Hygiene (exposure monitoring)	C23	Disability Mgt: Occupational and Non-Occupational	D30	Health Benefits Strategy, Design, and Vendor Selection			
A2	Physical Fitness	B10	Workplace Safety Programs	C24	Health Issues Management (e.g. SARS, mold)	D31	Regional Vendor Strategy			
A3	Smoking Cessation	B11	Ergonomics	C25	Workers' Compensation	D32	Prescription Drug Strategy			
A4	Weight Management	B12	Life Safety (Compliance with Local Regulations)	C26	Health Information Management	D33	Health Living Rebates			
A5	Immunizations	B13	Chemical and Toxic Gas Safety	C27	Regulatory Medical Surveillance	D34	Care Management			
A6	Personal Health Assessments	B14	Contractor Safety	C28	Travel Health	D35	Disease Management			
A7	Stress Solutions	B15	Social Responsibility (Supply Chain and IBM)	C29	Executive Health	D36	Mental Health			
A8	Virtual (Web) Wellness Offerings	B16	Acquisition / Outsourcing			D37	Dental			
		B17	Training							
		B18	Climate (Physical Work Environment)							
		B19	Compliance Auditing and Manager Self-Assessments							
		B20	Occupational Injury/Illness Reporting and Investigation							
		B21	Remote and Mobile Worker							
		B22	Personal Protective Equipment							
SUPPORT/ OTHER	E38	Public Policy Influence	E39	Business Continuity	E40	Meet Customer Requirements	E41	Uniform Global Practices	E42	Global Employee Surveys
	E43	Regulatory/Legal Compliance	E44	Professional Associations	E45	Industrial/Employee Relations	E46	Brand Protection		

# The Virtual Fitness Center has quickly become the most popular IBM wellness program, serving approximately 90,000 employees

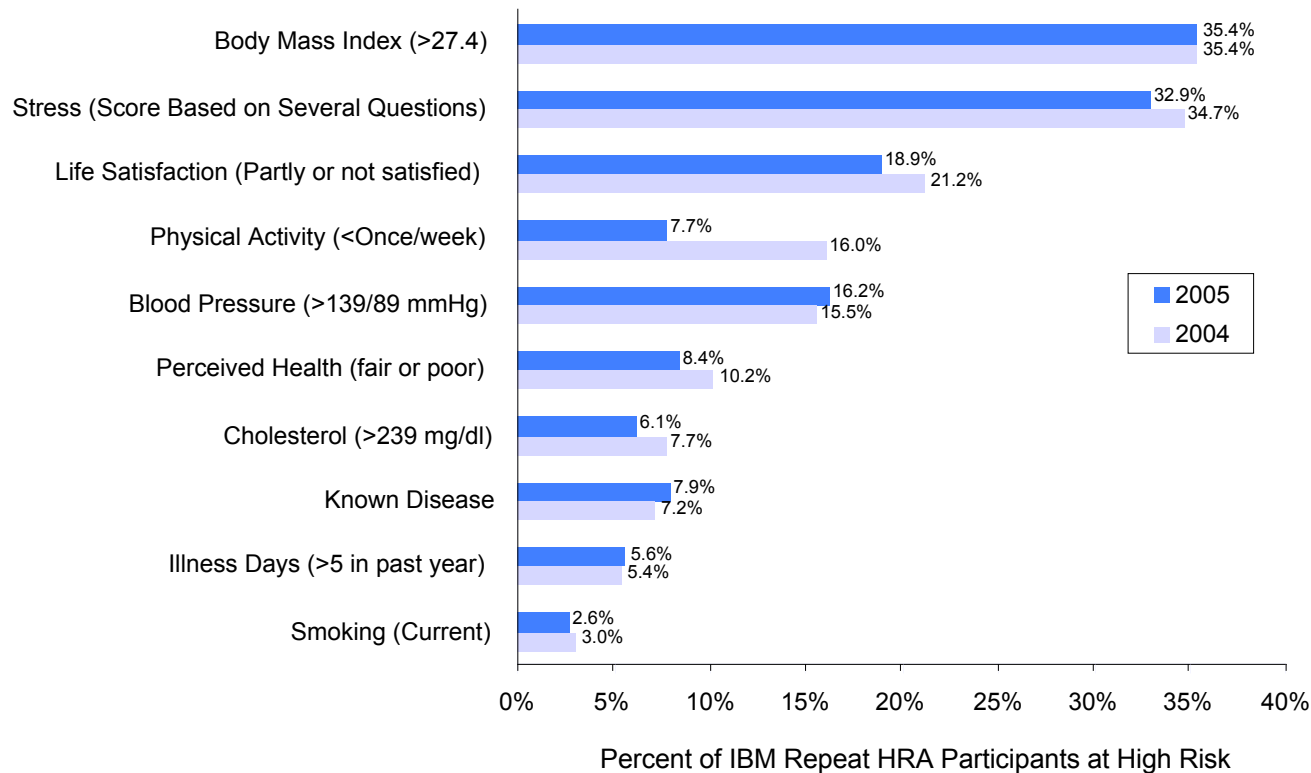
## Participation in Primary IBM Wellness Programs (US Only)



Notes: US population declined from roughly 140,000 to 130,000 from 2002 to 2004. 54,000 employees (61% of VFC users) completed HRAs in 2004.  
 Source: Stewart Sill and SCIP analysis

# Preliminary data show a reduction in health risks among repeat IBM Health Risk Assessment participants

## Metrics for High Risk IBM Employee Participating in HRA

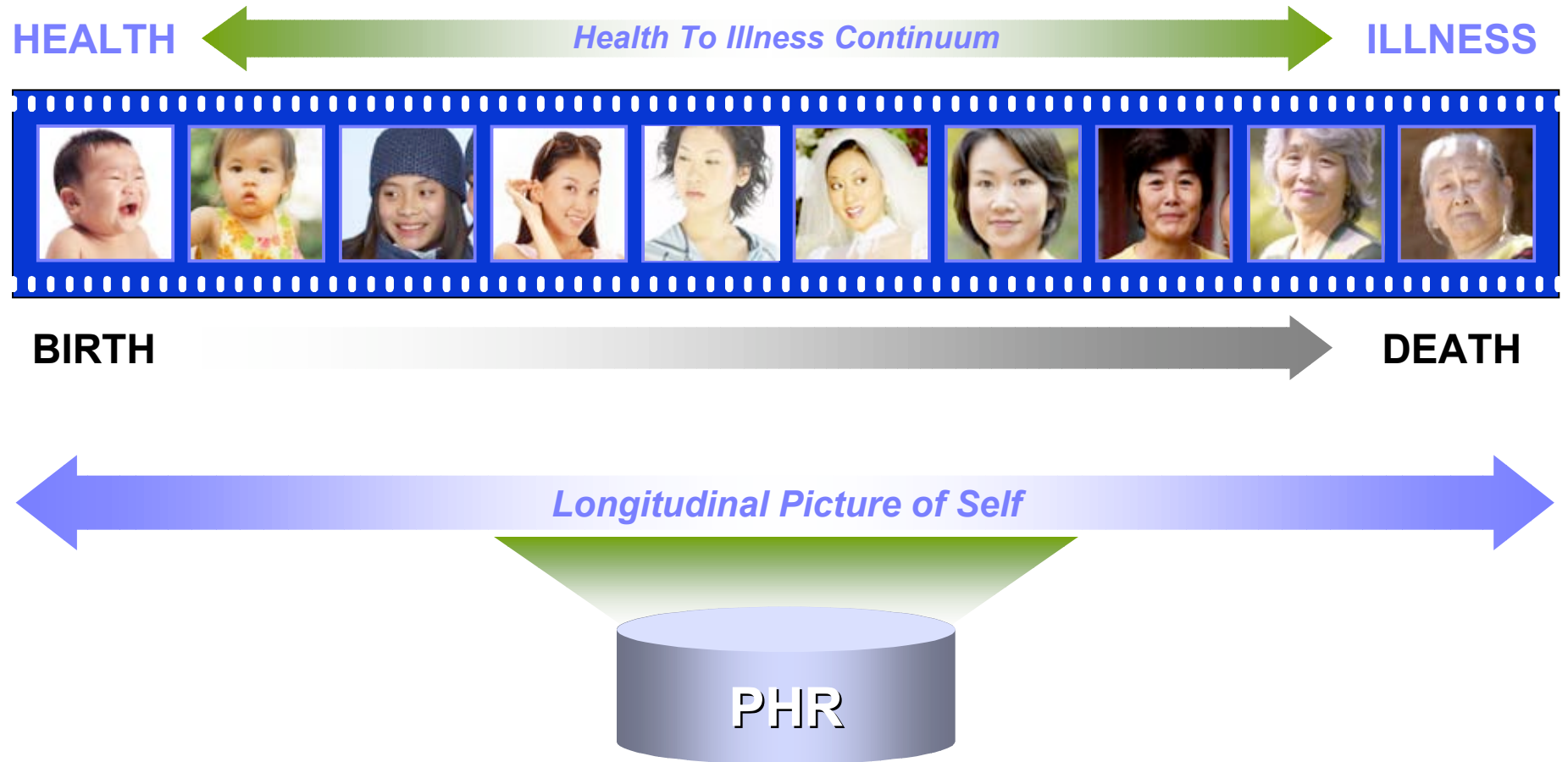


## Key Improvements

- Stress
- Life Satisfaction
- Physical Activity Levels
- Perceived Health
- Cholesterol
- Smoking

Source: Healthy Living Rebate Program Update, Joyce Young

# What is a Personal Health Record?



## IBM's PHR

- 15 million people access WebMD's PHR through their employers' or health plans' websites
- 20+ million unique visitors to www.webmd.com each month
- A customized version made available to IBM employees in September 2005
- IBM's and WebMD privacy statements provided





## PHRs and Privacy: Some Needs

- Employees/patients need reassurance that private information is appropriately managed.
- Employers need some legal certainty as to how federal and state laws regulate an employer-driven PHR.
- To the extent a PHR is not governed by federal and state laws, a framework of policies and practices to be adopted by employers needs to be outlined.
- Employers need to facilitate and adopt standards for PHRs to enable their development, use, and interoperability. These standards should address the privacy, confidentiality, and security of PHRs.

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## **Improving Access and Protecting Privacy**

Jodi Daniel

Office of the National Coordinator for Health  
Information Technology



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Robert Wood Johnson Foundation



Department of Health & Human Services  
Office of the National Coordinator for  
Health Information Technology

# Privacy in Nationwide Health IT

**December 7, 2006**

**Jodi Goldstein Daniel, JD, MPH  
Director, Office of Policy and Research  
Office of the National Coordinator for  
Health Information Technology**

# Office of the National Coordinator (ONC)

- Established in response to **Executive Order 13335**, April 27, 2004
- Responsible for realizing the President's vision of consumer centered, information rich healthcare:
  - Ensure appropriate information at time and place of care
  - Improve health care quality
  - Reduce health care costs
  - Promote a more effective marketplace
  - Improve the coordination of care and information
  - **Ensure secure and protected health information**



# Publication of a Strategic Framework: July 2004

## Goal 1: Inform Clinical Practice

- Incentivize EHR Adoption
- Reduce Risk of EHR Investment
- Promote EHR Diffusion in Rural and Underserved Areas

## Goal 3: Personalize Care

- Use of Personal Health Records, Enhancement of Informed Consumer Choice, and Promotion of Telehealth Systems

## Strategic Framework

## Goal 2: Interconnect Clinicians

- Foster Regional Collaboration
- Develop a Nationwide Health Information Network (NHIN)
- Coordinate Federal Health Information Systems

## Goal 4: Improve Population Health

- Unify PH surveillance architectures, streamline quality and health status monitoring, and accelerate research and dissemination of evidence into practice

# 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.



# ONC – Current Activities



- **AHIC** - American Health Information Community
- **HITSP** – Health IT Standards Panel
- **CCHIT** – Certification Commission for Health IT
- **NHIN** - Nationwide Health Information Network Prototypes
- **HISPC** – Health Information Security and Privacy Collaboration
- **State-level HIE Initiatives** – State-level Health Information Exchange Initiatives

# Key Privacy and Security Activities

- **Privacy & Security Solutions for Interoperable Health Information Exchange (HISPC) - 9/05**
  - Overall contract managed by RTI International in partnership with NGA
  - Under its HISPC initiative, RTI is subcontracting with 33 states and 1 territory to:
    - Identify within the state business practices that affect electronic health information exchange
    - Propose solutions and implementation plans
    - Collaborate on regional and national meetings to develop solutions with broader application
    - Provide final report on final project outcomes and recommendations



# Key Privacy and Security Activities

- **State Alliance for e-Health - 9/06**
  - Awarded to the NGA Center for Best Practices
  - A nationwide forum through which stakeholders can work together to identify inter- and intrastate-based health information technology policies and best practices and explore solutions to programmatic and legal issues related to the exchange of health information.
  - Three taskforces focused on:
    - Protection of Health Information (Privacy and Security)
    - Practice of Medicine (e.g., licensure and telehealth, CLIA, liability)
    - State Health Information Exchange Programs and Services

# Health IT Privacy Issues

- **HIPAA is an important foundation:**
  - Provides common language and a framework for HIE discussions
- **Opportunities for greater protections:**
  - Consumer involvement
  - Audits

# Health IT Privacy Issues

- **Who's covered?**
  - New entities
    - RHIOs and State Health Information Exchanges
    - Certain PHR vendors
- **How does data get distributed?**
  - Pull vs. Push
  - Pre-populating PHRs
- **What are appropriate uses and access to data?**
  - Electronic data has a potential for use and abuse outside of its clinical care purposes
  - Electronic access to EHR and PHR services
  - Verification of identity and authority of requestor
- **State identified challenges?**
  - Variability in state laws (e.g., consent) affect sharing across state lines
  - Mechanisms for identifying individuals and matching records
  - Involving consumers in solutions and consumer education

# Upcoming Events

- **Confidentiality, Privacy & Security Workgroup-Issue Prioritization**
  - Next meeting: January 8th, 2007, 1-5pm
  - Mary E. Switzer Building, 330 C Street, SW, Suite 4090
  - [http://www.hhs.gov/healthit/ahic/cps\\_main.html](http://www.hhs.gov/healthit/ahic/cps_main.html)
- **RTI Privacy and Security Project / HISPC**
  - Nationwide meeting March 5<sup>th</sup> and 6<sup>th</sup> (Bethesda)
  - <http://www.healthit.ahrq.gov/privacyandsecurity>
- **State Alliance for e-Health**
  - Steering Committee inaugural meeting January 26, 2007
  - <http://www.nga.org/center/ehealth>
- **NHIN Prototype Demonstrations**
  - Mid to late January

**For More Information Visit...**

**[www.hhs.gov/healthit](http://www.hhs.gov/healthit)**

*“Health IT can enable transformation of healthcare by allowing a better way to care - consumer by consumer, physician by physician, disease by disease and region by region. [Health IT] is ultimately about treating the industry itself so that we can have not only the best science, infrastructure and professionals in the world, but also the best value, safety and productivity.”*

*Dr. David Brailer, MD, PhD  
Vice-chairman, American Health Information Community*

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