

Consumer-Purchaser

DISCLOSURE

PROJECT

Improving Health Care Quality through Public Reporting of Performance

National Health Information Network: The Consumer Perspective

NCVHS Workgroup on National Health Information Infrastructure

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April 26-27, 2005

RWJF – Project Sponsors

Participating Organizations

3M

AARP

AFL-CIO

American Benefits Council

Buyers Health Care Action Group

Carlson Companies

**California Healthcare Foundation
Reform**

Consumer Coalition for Quality Health

Employee Benefits Research Institute

Employer Health Care Alliance Coop.

ERISA Industry Committee

Ford Motor Company

General Motors

The Leapfrog Group

National Coalition for Cancer Survivorship

March of Dimes

Midwest Business Group on Health

Motorola

National Association of Manufacturers

National Black Women's Health Project

National Business Coalition on Health

National Citizen's Coalition for Nursing Home

National Partnership for Women and Families

National Business Group on Health

National Breast Cancer Coalition

Niagara Health Care Quality Coalition

Pacific Business Group on Health

The Robert Wood Johnson Foundation

State Medicaid Directors Association

Union Pacific Railroad

U.S. Chamber of Commerce

Our Primary Objectives

- Build support for the Disclosure Goal to have a comprehensive national set of publicly reported provider measures by January 1, 2007
- Support measure development
- Encourage endorsement of national standards
- Encourage implementation of national standards

The Consumer Perspective on Electronic Health Records

- Rule #1: consumers are not monolithic
- Three basic categories
 - Professional data privacy advocates
 - Other professional consumer advocates
 - Everyone else

The American Public Will Benefit...

- Coordination of care
- Patient safety and improved quality
- Economic efficiency of care delivery
- Improved service
- Administrative simplification
- Improved public reporting

But They Don't Know It

- Do not understand how the current paper-based system works (or doesn't) until they encounter its deficiencies
- Can't connect the potential benefits of EHR with frustrations associated with the current system

Result:

Data Privacy Fears Tend to Dominate

- Legitimate concerns must be addressed
- Some privacy advocates go overboard
- Relatively easy to generate public fear

The result:

Exaggerated data privacy risks could create a political climate that will derail and/or delay a comprehensive solution that will generate significant benefits to the American public.

We Must Inform the American Public

- Engage main street America
 - What's in it for them
 - How do we address their fears
- Engage progressive consumer advocates and labor leaders
- Tell the story in terms my mother understands
- Celebrate and promote early successes

Non-Negotiable Principles

- Consumers own their data
- Avoid excessive restrictions on access by legitimate parties that undermine usefulness of EHRs and associated data
 - Care delivery
 - Payment and eligibility
 - Performance measurement
 - Basic research

Non-Negotiable Principles

- National standards
- Incentives for providers and plans to adopt standards
 - Measure and publicly report adoption of EHR's
 - Link adoption to financial and non-financial incentives
- Firewalls to protect confidentiality of individual data with substantial consequences for violations

For More Information



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