

**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**

**Research Remarks & Morning Keynote**

David Lansky - Markle Foundation

Michael Perry - Lake Research Partners

Zoë Baird - Markle Foundation



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**2006**

# Public Opinion Toward Electronic Medical Records and Health Information

Michael Perry

Lake Research Partners



MARKLE FOUNDATION

  
Robert Wood Johnson Foundation

# Survey Methods

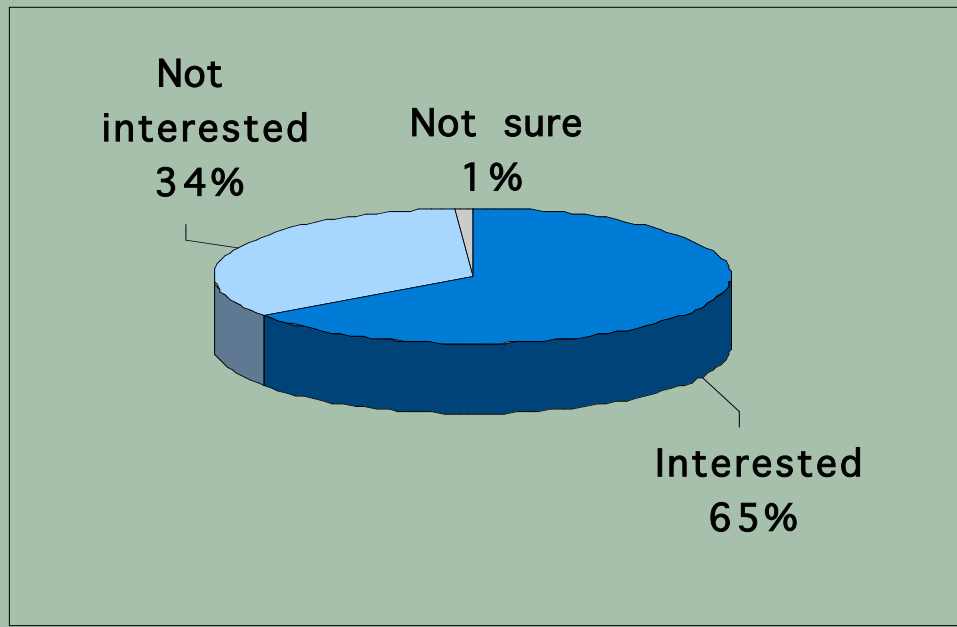
- National survey of Americans, RDD
- N=1,003 adults 18 and older
- Margin of sampling error: +/- 3.1 percentage points
- Conducted November 11 – 15, 2006

# Current Mood Toward Health Care System

- Health care is a top domestic issue
- System on wrong track, health care crisis
- Anxiety about insurance, access, costs
- Feeling of “on your own”

# Majority Interested in Accessing Information Online

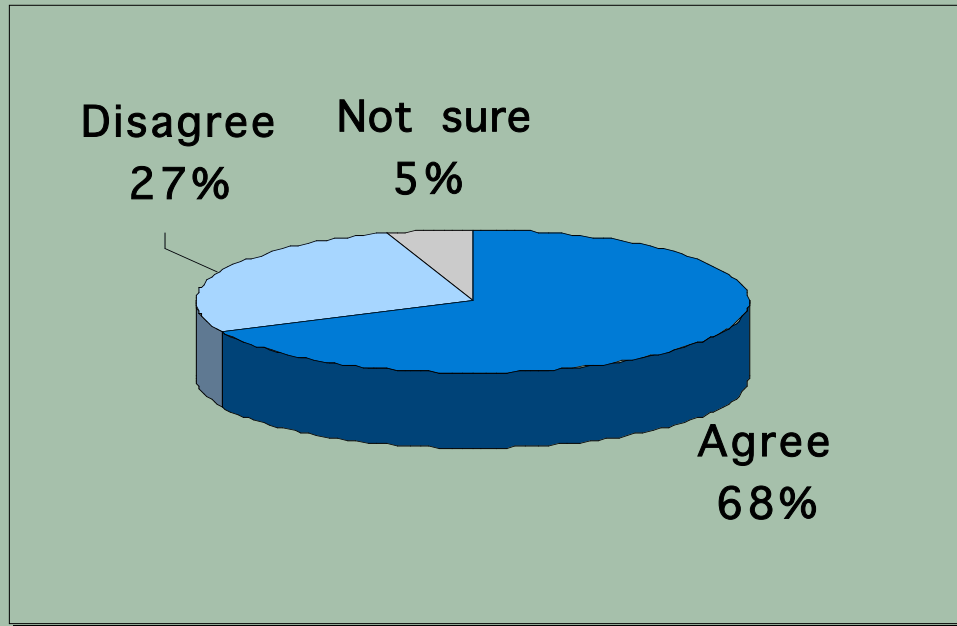
**Interest in Accessing Health Information Online**



- Majority of all subgroups express interest, even seniors (53%)
- Most interested include:
  - Under 40 (72%)
  - Daily Internet users (71%)
  - Parents (70%)

# Public Sees Online Access as a Way to Gain More Control Over Care

## Health Information Online Will Give People More Control Over Own Care



### Most likely to agree:

- 18 to 29 year olds (81%)
- African Americans (79%)
- Parents (74%)
- Frequent users of health care system (74%)
- Daily Internet users (76%)

# Ways to Manage Own Care With Secure Network

- Tracking symptoms or changes in health (90% say would be important personally)
- Tracking financial aspects of health care (80% interested)
- Tracking child's health records and services, like immunization dates (82% of parents interested)



# Benefits Relating to Quality of Care and Cost

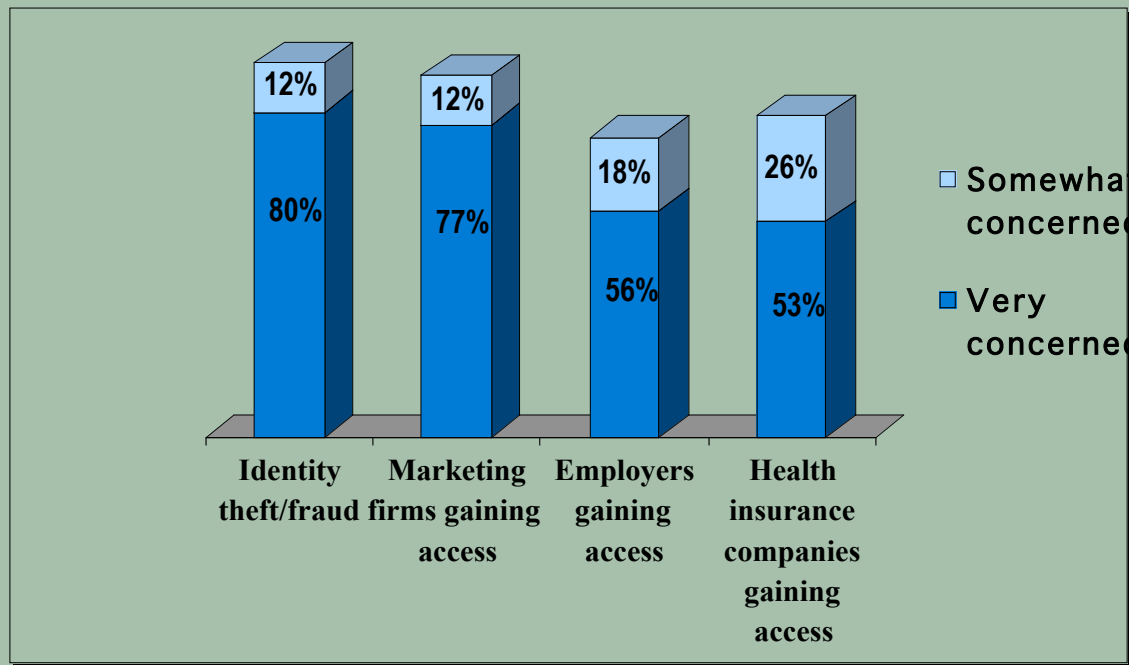
- Checking doctor's chart to make sure situation is understood (91% important)
- Checking medical records for mistakes (84% interested)
- Looking at test results (82% interested)
- Reducing unnecessary or repeated tests and procedures (88% important)

## Willingness to Share Information, If Safeguards in Place and Have Some Control

- To detect disease outbreaks (73% willing)
- To improve quality of care (72%)
- To detect medical fraud (71%)
- To detect bio-terrorist attacks (58%)

# Major Hurdle for Public is Protections

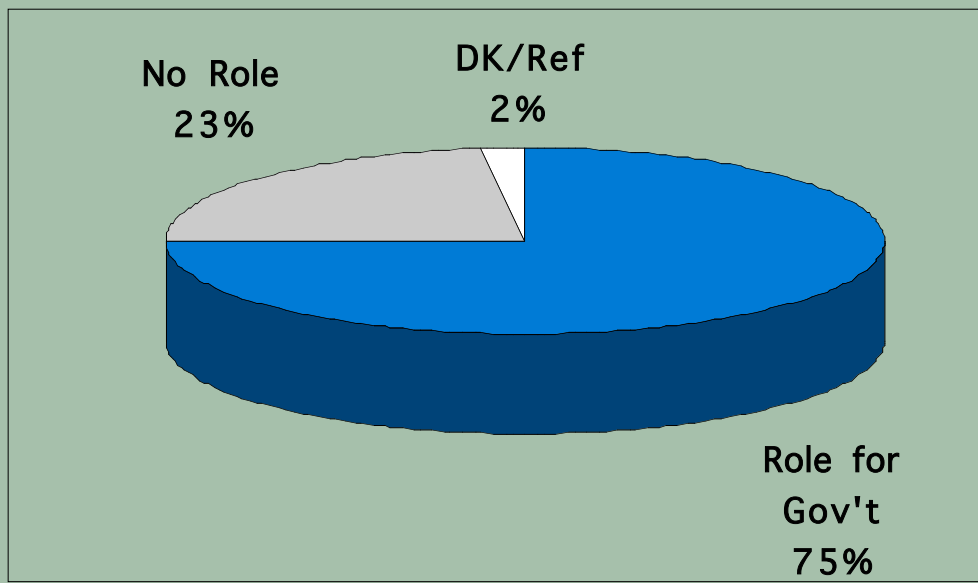
## Privacy and Access Concerns



- Most are very concerned about identity theft/fraud, and marketers getting access
- Concern also for employers and health insurers getting access

# Majority See a Role for Government in Establishing Protections

**Role for Government in Protections**



- Three-quarters see a role for government in establishing rules to protect the privacy and confidentiality of online health information

# Summary

- Public interested in access
- Interest crosses all segments of the population
- Sees many benefits of being connected to electronic records and health information
- But they have a lot of concern about privacy and security, and see a role for government in establishing protections

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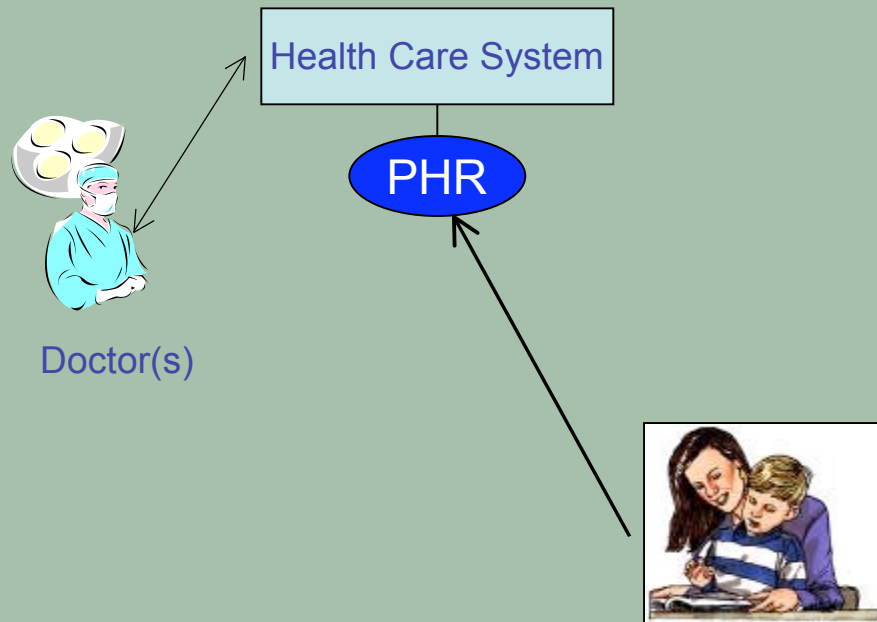
Accessing ALL of our health information  
across the network ...

David Lansky, Ph.D.  
Markle Foundation

December 8, 2006

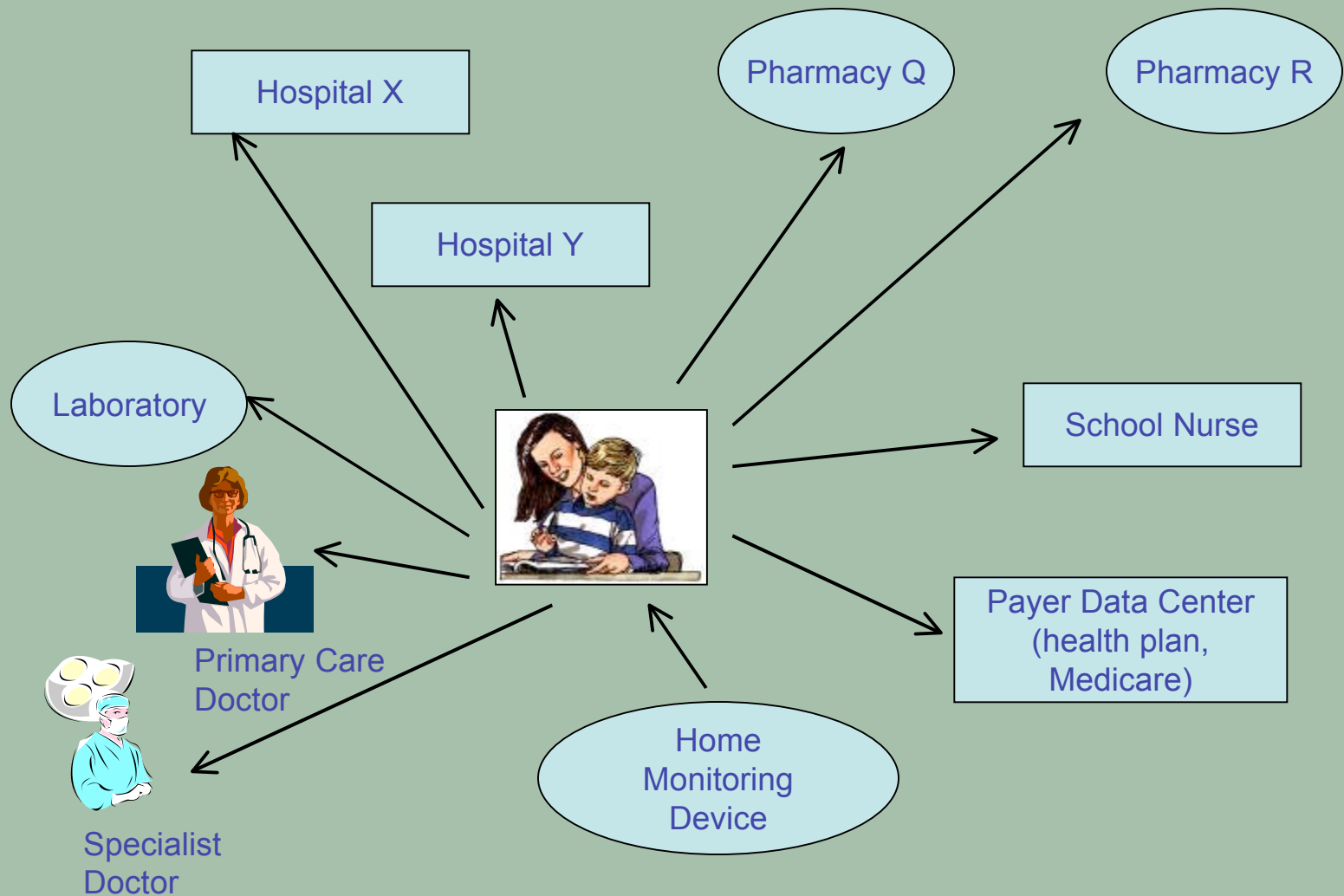


# The simple case

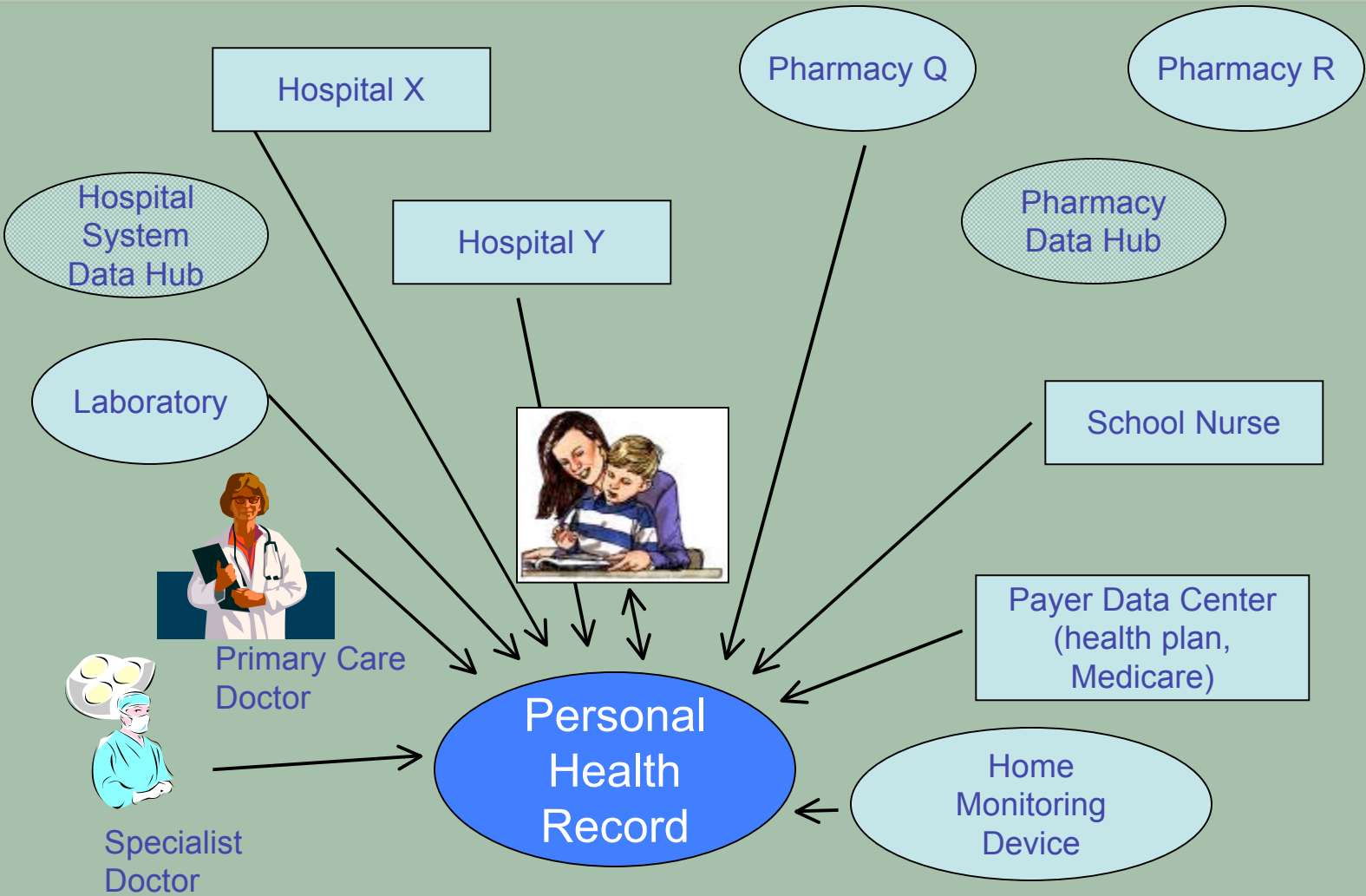




# The reality...



# The Networked PHR



# The many sources of PHR – c. 2006

1. Providers and their portals
2. Employer-sponsored
3. Health plan-connected
4. Government agencies
5. Free-standing (“untethered”)
6. Dot-coms, internet portals
7. Pharmacies and PBMs
8. Device manufacturers

Are we headed for integration ...  
or just more silos?

Log In

Send to a Friend

**Travel Planning**

- Travel Deals
- Frequent Flyer
- Promotions
- Published Fares

**At the Airport**

- Airport Information
- Airport Parking
- Airport Delays
- Security Wait Times

**Travel Tools**

- Set-up Flight Alert
- My Flight Alerts
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**After Your Trip**

- Rate an Airport
- Share Your Experiences

**Destination Info**

- Country Information
- Travel Warnings
- Travel Advisories
- Consular Information Sheets
- Airports of the World

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- Flight Rating
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**Track Flight Status for UA 83**

**Flight Status** powered by FLIGHTSTATS

By Route | **By Flight** | By Airport

Airline: (UA) United Airlines

Flight: 83

Departure Date: December 05, 2006

Go



**Did You Know?**

View current US airport delays by using the [Current Airport Delays](#) application

**Track Flight Status Results**

Flight: (UA) United Airlines 83  
 Date: Dec 05, 2006  
 Status: **En Route** On Time  
 Estimated Runway Arrival at 11:13 AM  
 Duration: 5h 49m  
 Equipment: 763



- Flight Events Timeline
- Extended Details

**Departure**

Airport: (IAD) Dulles International Airport  
 Washington, DC, US  
 Scheduled: Tue - Dec 05, 2006 08:40 AM  
 Actual: Tue - Dec 05, 2006 08:59 AM (runway)  
 Gate: C12 (Terminal 1)  
 Weather: ☀️ 26 °F (-3 °C)

- Airport Information
- Performance Scorecard
- Delays
- Security Wait Times
- Weather

**Arrival**

Airport: (LAX) Los Angeles International Airport  
 Los Angeles, CA, US  
 Scheduled: Tue - Dec 05, 2006 11:29 AM  
 Estimated: Tue - Dec 05, 2006 11:13 AM  
 Gate: 68B (Terminal 7)  
 Weather: ☀️ 55 °F (12 °C)

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**Historical Performance**

On-time: 93%  
 Ave Delay: 28 minutes  
 Rating: 3.5 of 5 ★★★★★

- Rating Details

**Codeshare Information**

This flight also marketed by (US) US Airways 6497, (SA) South African Airways 7400, (NZ) Air New Zealand 9117

**Flight Events Timeline**

**A Walt Disney World Vacation\***  
 as low as \$58 a day per person  
 \*6 night/7 day for a family of 4

**Click Now!**

and your kids will hear the big news Christmas day with a phone call from Mickey

**Walt Disney World**



**Positional Information**

Information available for flight while in US airspace

Flight: (UA) United Airlines 83  
 Equipment: 763  
 Latitude: 37-33-36.0N  
 Longitude: 87-34-12.0W  
 Speed: 392 kts  
 Altitude: 34,000 feet (10 km)  
 Bearing: 271 degrees  
 To LAX: 1,510 nm  
 From IAD: 484 nm

[Position Tracking Log](#)

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Done



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**Flight Events Timeline**

**FLEXIBLE DELIVERY**

- NET CLIENT
- WEB CLIENT
- XML API
- XML MESSAGES
- DATA FEEDS

**DECISION SUPPORT & ANALYSIS**

- SCHEDULE & ROUTING SERVICES
- VISIBILITY & NOTIFICATION SERVICES
- FLIGHT HISTORY & STATISTICS SERVICES

**ENTERPRISE INFRASTRUCTURE**

- ENTERPRISE MESSAGE BUS, SECURITY & NOTIFICATIONS
- DATA AGGREGATION & DATA SOURCE MGMT.
- REAL-TIME DATA CONNECTION MGMT.
- FLIGHT & AIRPORT DATA WAREHOUSE

**DATA SOURCES**

- ORG FLIGHT SCHEDULES
- LINE HAUL TRUCK SCHEDULES
- GDS FLIGHT STATUS (SABRE)
- FAA FLIGHT & AIRPORT STATUS
- WEATHER DATA FEED
- BTS FLIGHT DATA



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# Features of a ‘networked’ approach

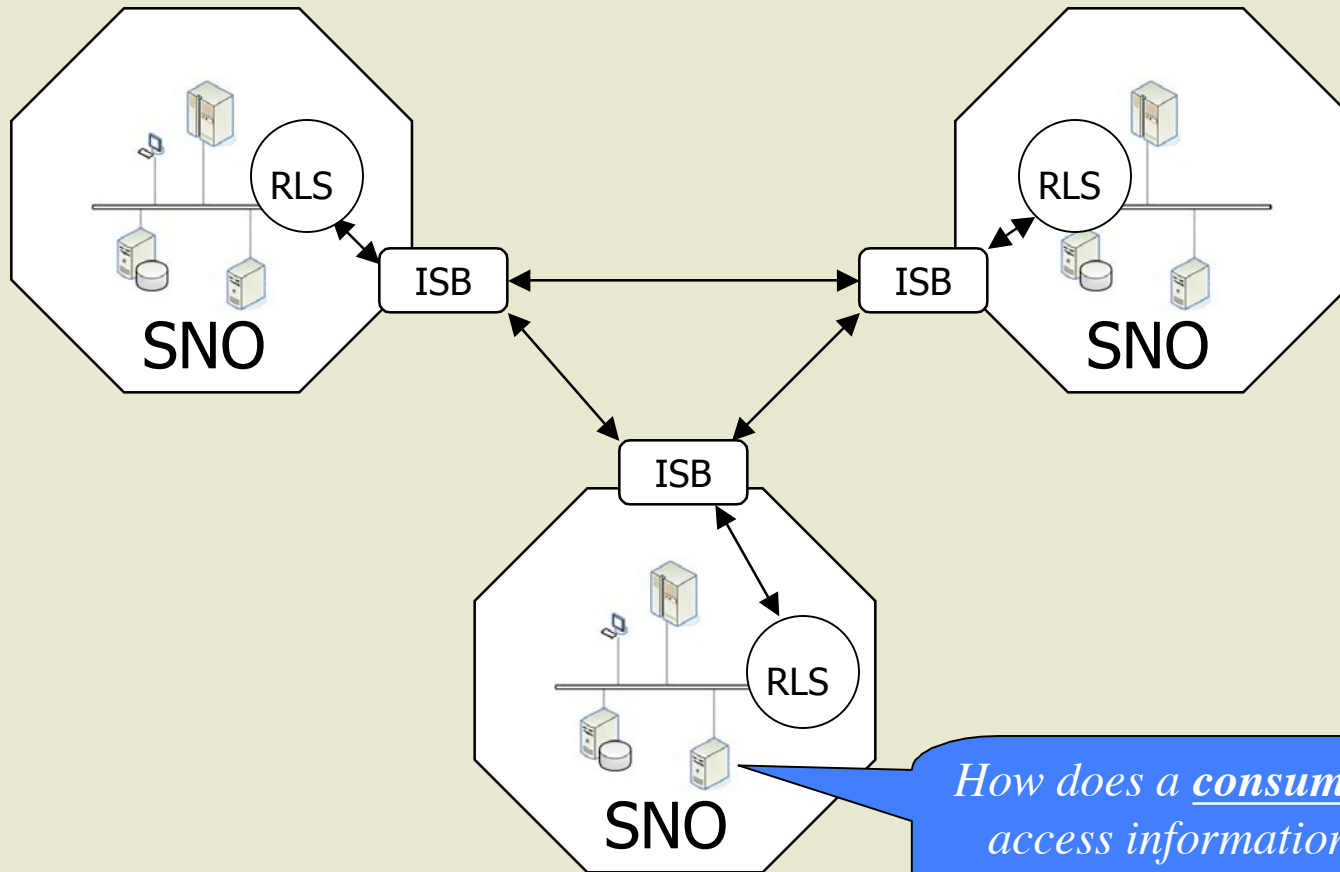
- “Networked” consumers drive transformative change in other sectors:
  - Content
  - E-commerce
  - Personal finance
  - Etc.
- A common ingredient is a fresh openness toward consumer access to, and contribution of, information
- Truly “networked” PHRs would stimulate innovation
- Consumers and health professionals gain opportunities to transform care delivery and roles

***Creating a networked PHR  
environment that achieves***

***sustainable consumer  
confidence***



# Common Framework architecture

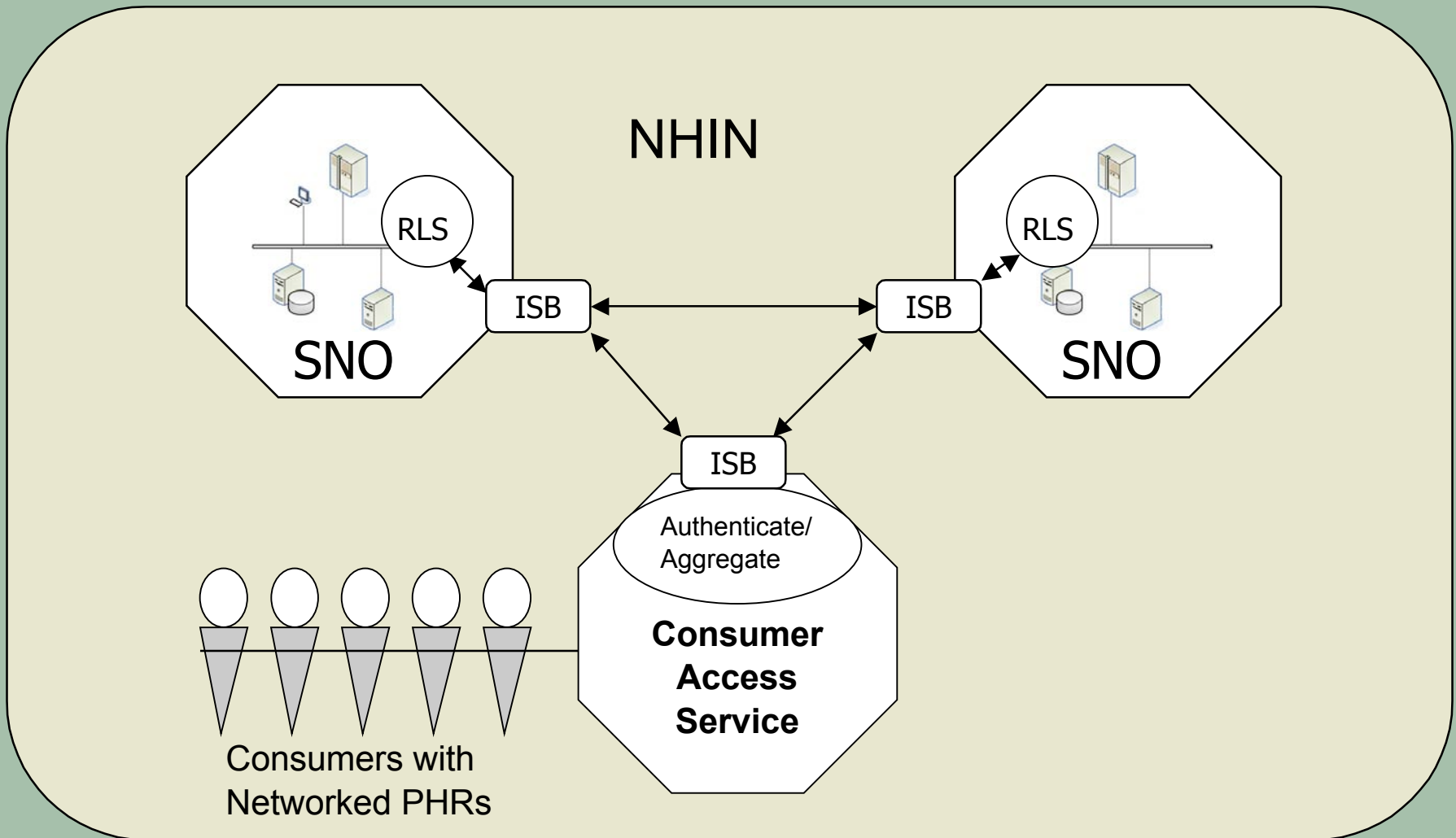


# Individual Consumers Will Need Mediating Bodies to Facilitate Their Access to the Network

## Functions:

- Distribute services to populations of consumers
- Issue individuals' identity credentials and "vouch" for them as network users
- Help consumers connect with various sources to access and aggregate their personal health data
- Assure that network-wide policies (e.g., privacy and information practices) are followed

# Consumer Access Services



# Potential Sponsors of Consumer Access Services

- Provider organizations
- Affinity groups
- “Retail” PHR providers
- Employers
- Consumer portals
- Data clearinghouses
- Retail pharmacies or PBMs
- Health plans
- Financial institutions
- Consumer portals
- Others?

# Keys to Success?

- Defining the **necessary common attributes** that cause a Consumer Access Service to be trusted by consumers
- Defining the **necessary common attributes** that cause a Consumer Access Service to be trusted by other participants on the network
- Privacy and security policies and practices will top the list of necessary common attributes

# Needed policy framework for Consumer Access Services

- Does HIPAA address privacy and security concerns?
- Authentication
- Authorization
- Consent and notification
- Consumer control of information sharing
- Audit
- Rules for secondary use, data mining
- Consumer annotations and edits to their data
- Data management systems
- Governance, transparency, remedies

# Road to a Networked PHR

- High public interest in PHR features and services coupled with concern about privacy
- Many significant offerings in the works, with risk of creating new information silos
- All will face common challenges accessing data across the “network”:
  - Standards issues
  - Architecture issues
  - Policy issues
- A **common policy and technical framework** will be essential to achieved “networked” personal health record

David Lansky, Ph.D.  
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[www.connectingforhealth.org](http://www.connectingforhealth.org)



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