Introduction to Personal Health Records – Update: Implementation challenges

David Lansky, Ph.D.
Markle Foundation

March 29, 2007

CONNECTING FOR HEALTH℠
MARKLE FOUNDATION *A Public-Private Collaborative*

National trends

- President's 10-year commitment (2014?)
- HHS: American Health Information Community – Consumer Empowerment "Breakthrough"
- Congress – Carper, Porter, Kennedy bills for federal employees
- AHIP and BCBS – 100 million Americans
- Major employers – IBM, PepsiCo, Intel consortium
- Major providers – VA, Kaiser, Partners
- Consumer organizations – AARP, National Health Council
- Internet companies – Intuit, Microsoft, Google, WebMD

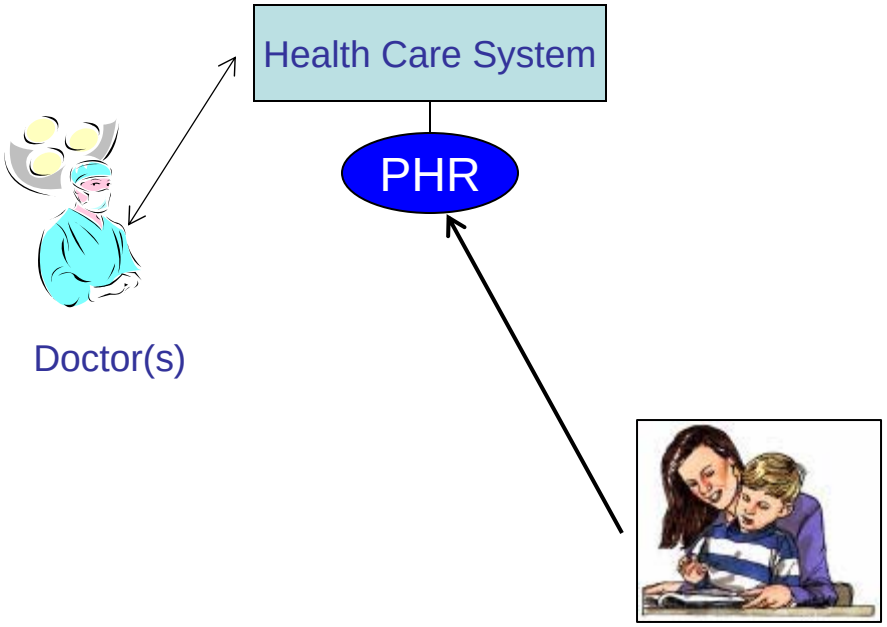
What do we know about adoption and use so far?

- Provider portals reach 15-20% of patients to whom offered
  - Computer skilled
  - High users (visits, meds)
- Most other approaches with small uptake, except incentivized (e.g., IBM - $150)
- Transactions heavily used
- Specialized products seem to have more user interest

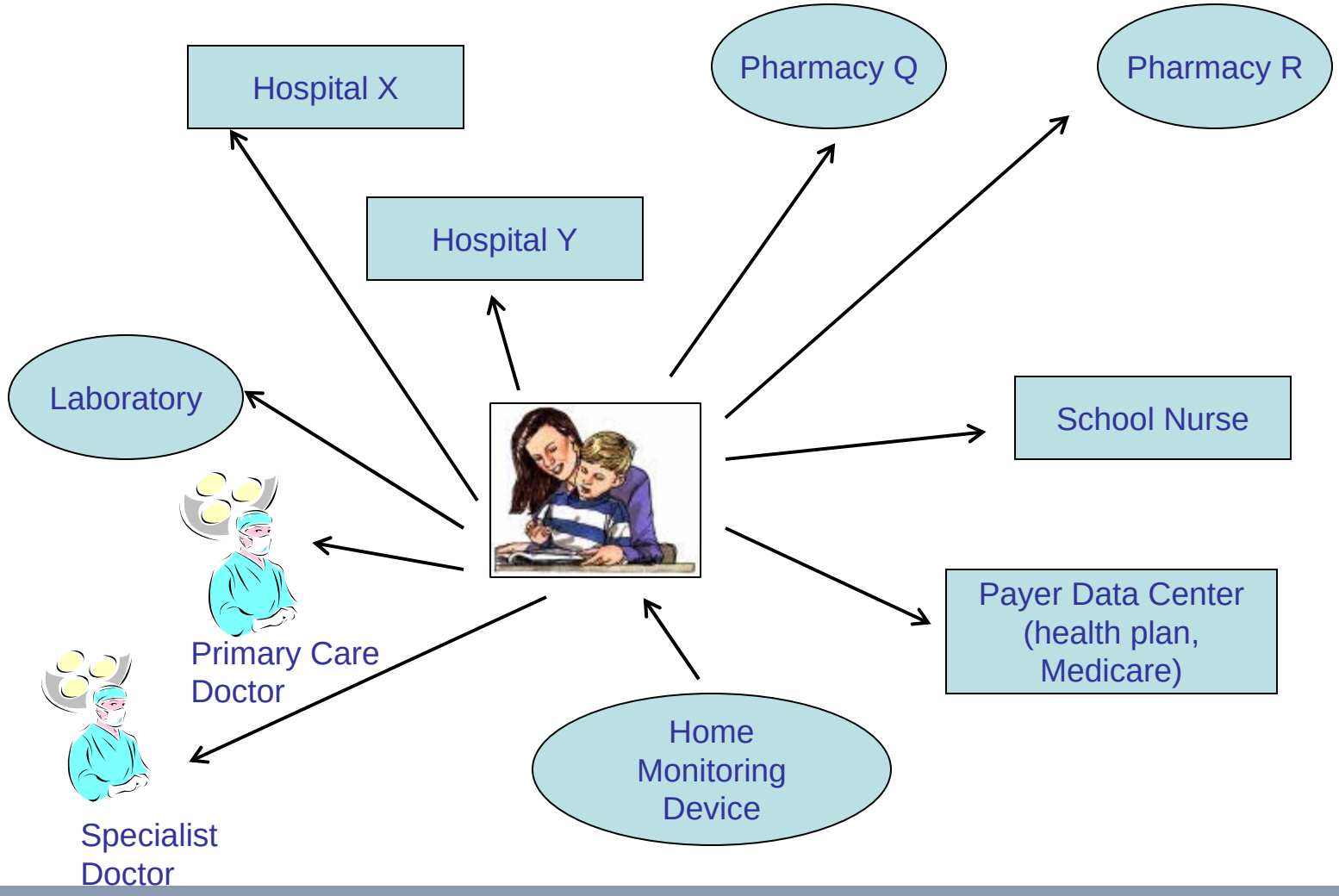
The many sources of PHR – c. 2007

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
9. *Affinity groups*
10. *Financial services companies*

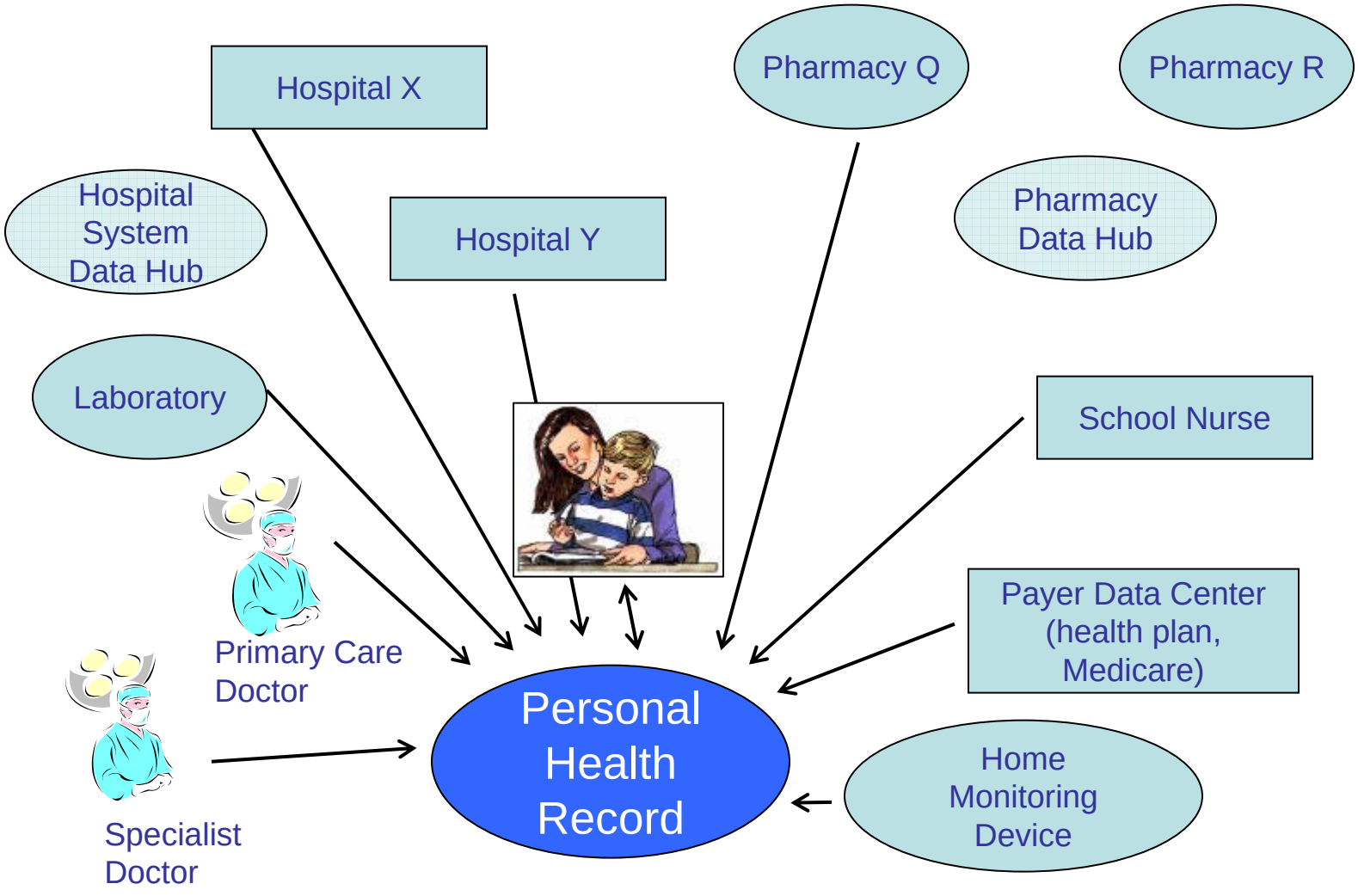
The simple case



The reality…

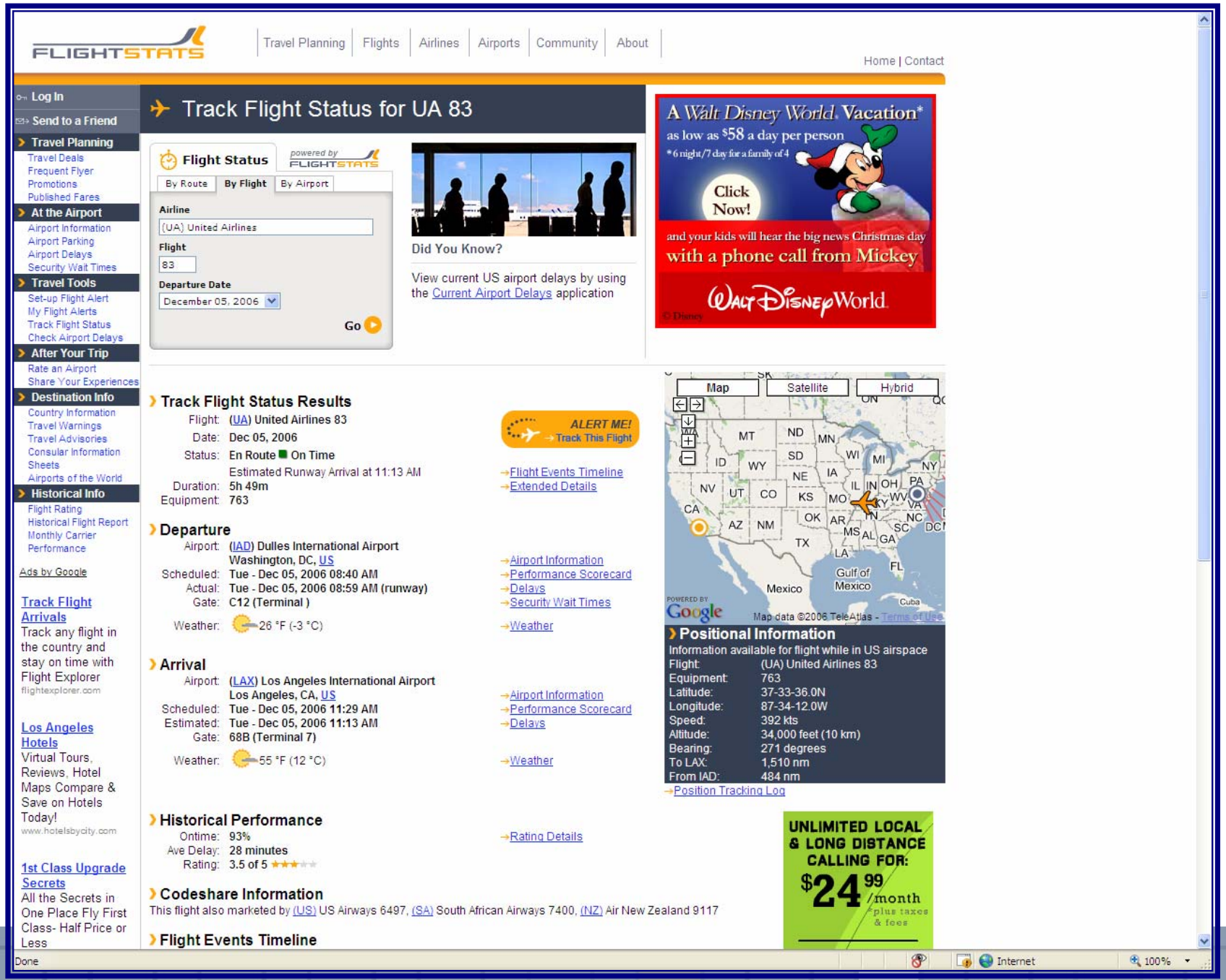

Hospital X
Pharmacy Q
Pharmacy R
Hospital Y
Laboratory
School Nurse
Payer Data Center (health plan, Medicare)
Primary Care Doctor
Specialist Doctor
Home Monitoring Device

The Networked PHR



PHR landscape

- **Key question:** Are we headed for integration or just more silos?
- **Key wildcards:**
  - Public reaction to data spills
  - Congressional privacy debate
  - Public perceptions defined by one approach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Departure Date
December 05, 2006
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Estimated Runway Arrival at 11:13 AM
Duration: 5h 49m
Equipment: 763
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Track This Flight
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)
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)
Airport Information
Performance Scorecard
Delays
Weather
Historical Performance
Ontime: 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
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Hybrid
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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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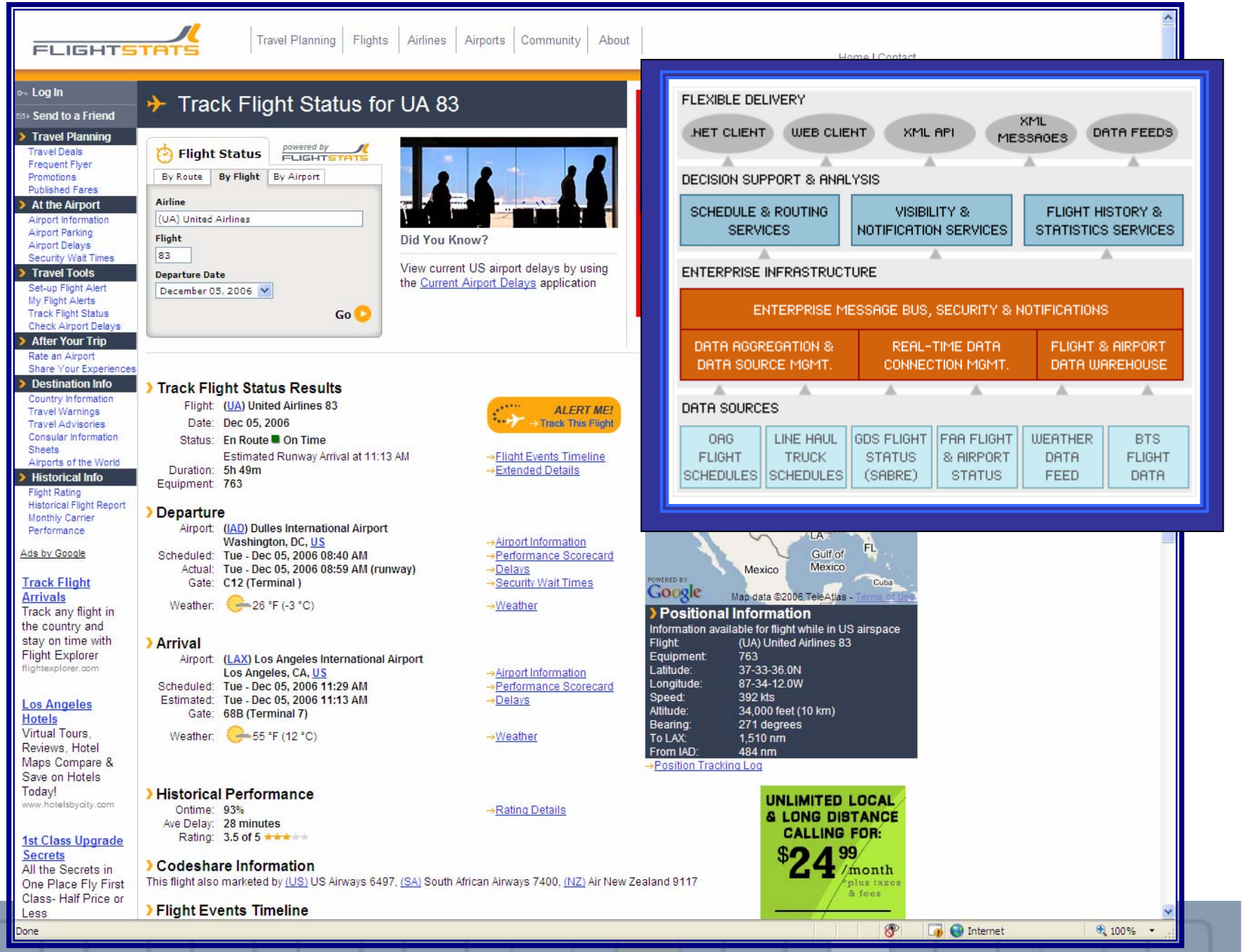


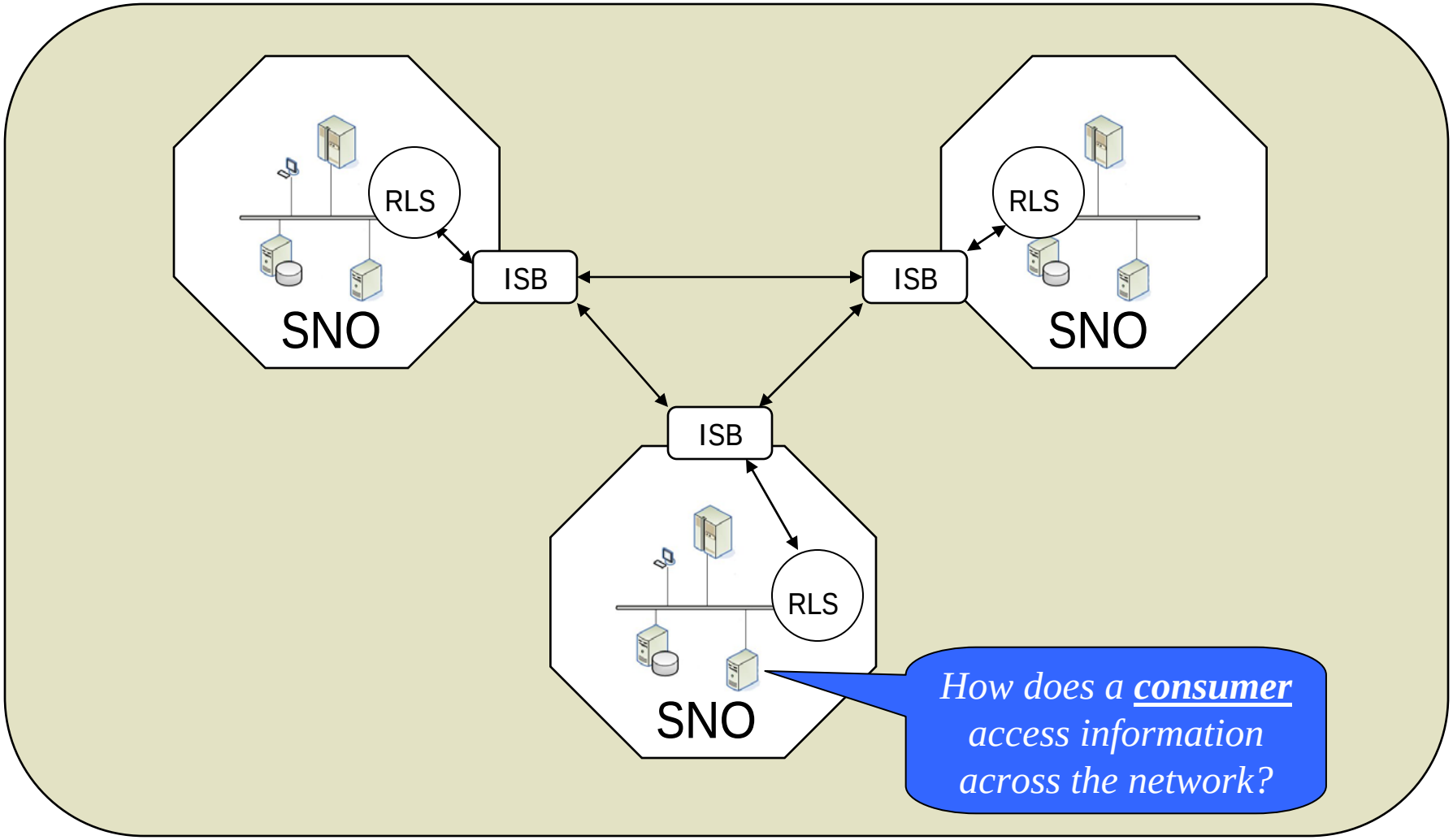
CONNECTING FOR HEALTH COMMON FRAMEWORK

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.
- *A network needs common rules, particularly for privacy.*

Creating a networked PHR environment that achieves sustainable consumer confidence

Common Framework architecture

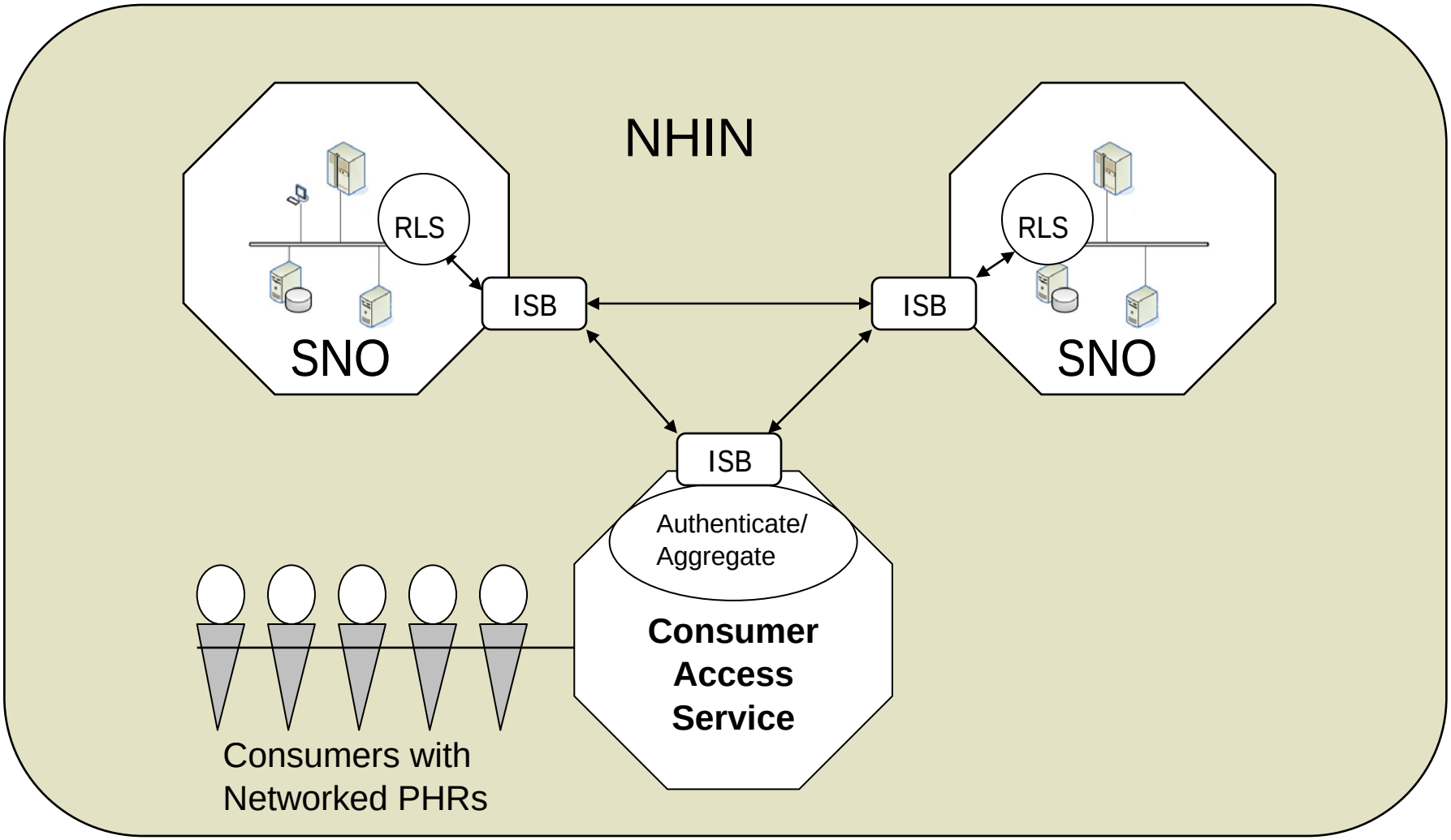


Individual Consumers Will Need Mediating Bodies to Facilitate Their Access to the Network

Functions:

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

Consumer Access Services



Potential Sponsors of Consumer Access Services

- Affinity groups (e.g., AARP, labor unions)
- “Retail” PHR providers (e.g., WebMD, Intuit, Medem)
- Consumer portals (e.g., Google, Yahoo)
- Data clearinghouses (e.g., SureScripts)
- Retail pharmacies (e.g., Walgreens, Wal-Mart)
- Health plans (e.g., AHIP, BCBS)
- Provider organizations (e.g., VA, Kaiser Permanente)

Keys to Success?

- Defining a Consumer Access Service that is trusted by consumers.
- Defining a Consumer Access Service that is trusted by other participants on the network.
- Determining minimum necessary privacy and security policies and practices.

Needed policy framework for CAS

- Does HIPAA address privacy and security concerns?
- Authentication
- Authorization
- Consent and notification
- Consumer control of information sharing, including 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.
dlansky@markle.org

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