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



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## Connecting Americans to Their Health Care:

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2006

## Networks 101

Lygeia Ricciardi - Markle Foundation Gerry Hinkley - Davis Wright Tremaine, LLP Micky Tripathi - Massachusetts eHealth Collaborative Clay Shirky - Markle Foundation Jon White - Agency for Healthcare Quality and Research



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Gerry Hinkley Davis Wright Tremaine, LLP



MARKLE FOUNDATION

Robert Wood Johnson Foundation

# Consumer's Guide to Understanding RHIOs – Structure and Governance

Gerry Hinkley Davis Wright Tremaine gerryhinkley@dwt.com

# Goals

- Gain an understanding of what RHIOs are about
  - organizationally
  - governance-wise
- Identify opportunities for consumer involvement within RHIOs

## "RHIO"

- Regional health information organization
- Geographic focus
- Historic relationships
- A "sense of community"
- If you've seen one RHIO . . .

## **Gathering Stakeholders**

# • Who needs to be in the room?

- Caregivers
- Safety net
- Diagnostics providers
- Payors
- Employers
- Public health
- Government
- Consumers
- Privacy/security watchdogs

# Gathering Stakeholders - 2

# • Why?

- Building trust
- Creating a leadership base
- Gathering expertise
- Raising money
- Being fair
- Being transparent
- Getting access
- Being credible

# **RHIO** Organizational Structures

- Nonprofit public benefit corporation
- Nonprofit mutual benefit corporation
- For-profit general law corporation
- Partnership or limited liability company
- Special district or authority
- Joint powers agency
- Existing entities: trade associations, regional tech consortia, governments

# **RHIO Governance**

- Bylaws, operating agreement, enabling legislation
- Membership
- Governing body
  - composition
  - responsibilities
  - accountability
- Addressing conflicts of interest

# **RHIO** Taxation

- Internal Revenue Code (IRC) Section 501(c)(3) tax-exempt organization

   promotes healthcare
- IRC Section 509(a) public/private charity
- IRC Section 501(c)(4) social welfare organization
  - promotes common good
- IRC Section 501(c)(6) business league
   promote common business interests
- For-profit and pass-through entities

# **RHIO** Functionality

- Messaging
- Public health data aggregation
- Medical records access
- Personal health records

## Consumer Involvement in RHIOs

- Get in on the ground level
  - identify funded projects
  - identify RHIO-focused vendors
- Be a voice for the consumer perspective
  - understand policy considerations
  - commitment and time
  - demonstrate the case for PHR
  - spokesmanship

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Micky Tripathi Massachusetts eHealth Collaborative



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#### **MASSACHUSETTS eHEALTH COLLABORATIVE**

Consumer's Guide to Understanding RHIOs: Report from the Front

December 2006



#### MAeHC ROOTS ARE IN MOVEMENT TO IMPROVE QUALITY, SAFETY, EFFICIENCY OF CARE



- Universal adoption of electronic health records
- MA-SAFE



- \$50M commitment to heath information infrastructure
- Recognition of "systems" problem



- Company launched September 2004
  - Non-profit registered in the State of Massachusetts
- CEO on board January 2005
- Backed by broad array of 34 MA health care stakeholders

## **34 ORGANIZATIONS REPRESENTED ON MAeHC BOARD**

#### Hospitals and hospital associations

- Baystate Health System
- Beth Israel Deaconess Medical Center
- Boston Medical Center
- Caritas Christi
- Fallon Clinic, Inc.
- Lahey Clinic Medical Center
- Massachusetts Hospital Association
- Massachusetts Council of Community Hospitals
- Partners Healthcare
- Tufts-New England Medical Center
- University of Massachusetts Memorial Medical Center

#### **Governmental agencies**

 Executive Office of Health and Human Services

#### Health plans and payer organizations

- Alliance for Health Care
   Improvement
- Blue Cross Blue Shield of Massachusetts
- Fallon Community Health Plan
- Harvard Pilgrim Health Care
- Massachusetts Association of Health Plans
- Massachusetts Health Quality Partners
- Tufts Associated Health Maintenance Organization

#### Healthcare purchaser organizations

- Associated Industries of Massachusetts
- Massachusetts Business Roundtable
- Massachusetts Group Insurance Commission

#### **Non-voting members**

 Center for Medicare & Medicaid Services

#### Massachusetts eHealth Collaborative

#### Healthcare professional associations

- American College of Physicians
- Massachusetts League of Community Health Centers
- Massachusetts Medical Society
- Massachusetts Nurses
   Association

#### **Consumer, public interest, and labor**

- Health Care for All
- Massachusetts Coalition for the Prevention of Medical Errors
- Massachusetts Health Data Consortium
- Massachusetts Taxpayers
   Foundation
- Massachusetts Technology Collaborative
- MassPRO, Inc.
- New England Healthcare Institute

#### WHERE ARE WE GOING TO SPEND \$50M? (I)



#### WHERE ARE WE GOING TO SPEND \$50M? (II)



Massachusetts eHealth Collaborative

#### WHAT ARE WE SPENDING \$50M ON?



#### PHYSICIANS "GOING LIVE", BY COMMUNITY



Massachusetts eHealth Collaborative

### **GOAL: BRING TOGETHER DATA TO IMPROVE PATIENT CARE**



#### HEALTH INFORMATION EXCHANGE Northern Berkshire Example





#### NORTHERN BERKSHIRE HEALTH INFORMATION EXCHANGE



#### SUSTAINABILITY: THE UNANSWERED QUESTION



#### **Consumer engagement**

- Permission
- Privacy & security
- PHRs

#### Physician engagement

- Quality improvement
- Clinical utility



#### Sustainability

## **OPT-IN PERMISSION MODEL**



Send



**Consumer engagement** 

## **COMPANY-TETHERED PHRs**



### **COMMUNITY-TETHERED PHRs**



## **MAeHC QUALITY DATA WAREHOUSE**



#### CLINICAL MEASURES FOR PHYSICIAN PERFORMANCE AQA Recommended Starter Set

- 1. Breast Cancer Screening
- 2. Colorectal Cancer Screening
- 3. Cervical Cancer Screening
- 4. Tobacco Use #
- 5. Advising Smokers to Quit
- 6. Influenza Vaccination
- 7. Pneumonia Vaccination
- 8. Drug Therapy for Lowering LDL Cholesterol#
- 9. Beta-Blocker Treatment after Heart Attack
- 10. Beta-Blocker Therapy Post MI
- 11. ACE Inhibitor /ARB Therapy#
- 12. LVF Assessment#
- 13. HbA1C Management
- 14. HbA1C Management Control
- 15. Blood Pressure Management#
- 16. Lipid Measurement
- 17. LDL Cholesterol Level (<130mg/dL)
- 18. Eye Exam
- **19. Use of Appropriate Medications for People w/ Asthma**
- 20. Asthma: Pharmacologic Therapy#
- 21. Antidepressant Medication Management
- 22. Antidepressant Medication Management
- 23. Screening for Human Immunodeficiency Virus#
- 24. Anti-D Immune Globulin#
- 25. Appropriate Treatment for Children with Upper
- 26. Appropriate Testing for Children with Pharyngitis

#### DRIVERS OF BUSINESS SUSTAINABILITY



#### THE GRID AND THE LAST MILE



#### ACTIVITY SPREAD GEOGRAPHICALLY ACROSS THE COUNTRY



Source: MAeHC

## A NATIONAL GRID?



Source: Dr. J Marc Overhage, Regenstrief Institute

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Clay Shirky Markle Foundation



MARKLE FOUNDATION

Robert Wood Johnson Foundation

# Connecting for Health: Technical Issues in Federated Networks

# AHRQ/June 7, 2005 Clay Shirky Clay.Shirky@NYU.edu

## Connecting for Health Background

- Support accurate, timely, and secure handling and sharing of patient information.
- Increase quality of care, economic sustainability, and preserve privacy of patient information.
- Create value for many different kinds of participants -- from private, non-profit, and government entities to individual healthcare professionals and patients.

# Principles

- Privacy
- Availability of patient data
- Local control of data
- Patient access to data
- Federated governance
- Rapid Deployment

   5 Year Time Frame

- Decentralized
- Interoperable
- No 'Rip and Replace'
- Decoupled development
- Use Internet/No new wires
- Audited
- Secured
- Authenticated

## The Architectural Problem: D Wants Records Held at B and G



## Simple Solution: Aggregate All Records



## Works at small scale, but...

- Hard to synchronize ~10^5 data sources
- Overrides autonomy of data holders
- Massive duplication
- Mixes policy regimes (e.g. State laws)
- Increases privacy threats
- Increases privacy concerns

## Alternate Solution: Centralize Record *Locations*



## Alternate Solution: 3 Basic Interfaces: Publish/Find/Get



## **Record Matching**

Comparison Scoring		part of Initiate's Identity Hub Software			www.initiatesystems.com	
		This example from their literature				
						Example
Rec#	Name	Address	Phone	DOB	SSN	Score
101	John Q Public	1043 W. Easy St,	5556060	10-24-1950	482891822	20.0
		Phoenix, AZ.85535				
102	Jon Public	1043 W. Easy St,	5556060	10-24-1950	482891822	18.0
		Phoenix, AZ.85535				
103	J Public		5553232	<b>10-</b> 25- <b>1950</b>	482891822	11.0
104	John Q Long	552 Green Dr,		11-15-1962	57265225	5.0
		Phoenix, AZ.85535				
105	Danny Smith		5552745	10-24-1950	48289244	5.0
106	Kevin Dohert	1028 W. Easy Ave,	5554289		48224857	4.0
		Phoenix, AZ .85535				



## **Open Issues**

- You don't make standards, you *adopt* them
- Co-adoption of technical and policy standards
- Tension between standardization and autonomy
- Questions of levels of standardization
   NHIN/Per RHIO/Per entity/None
- Tension between compatibility and progress
- Most large secure systems are either
  - Highly centralized (e.g. DoD)
  - Tolerant of failure (e.g. Credit card network.)

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