

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

2006

Policies

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This presentation has not been approved by the
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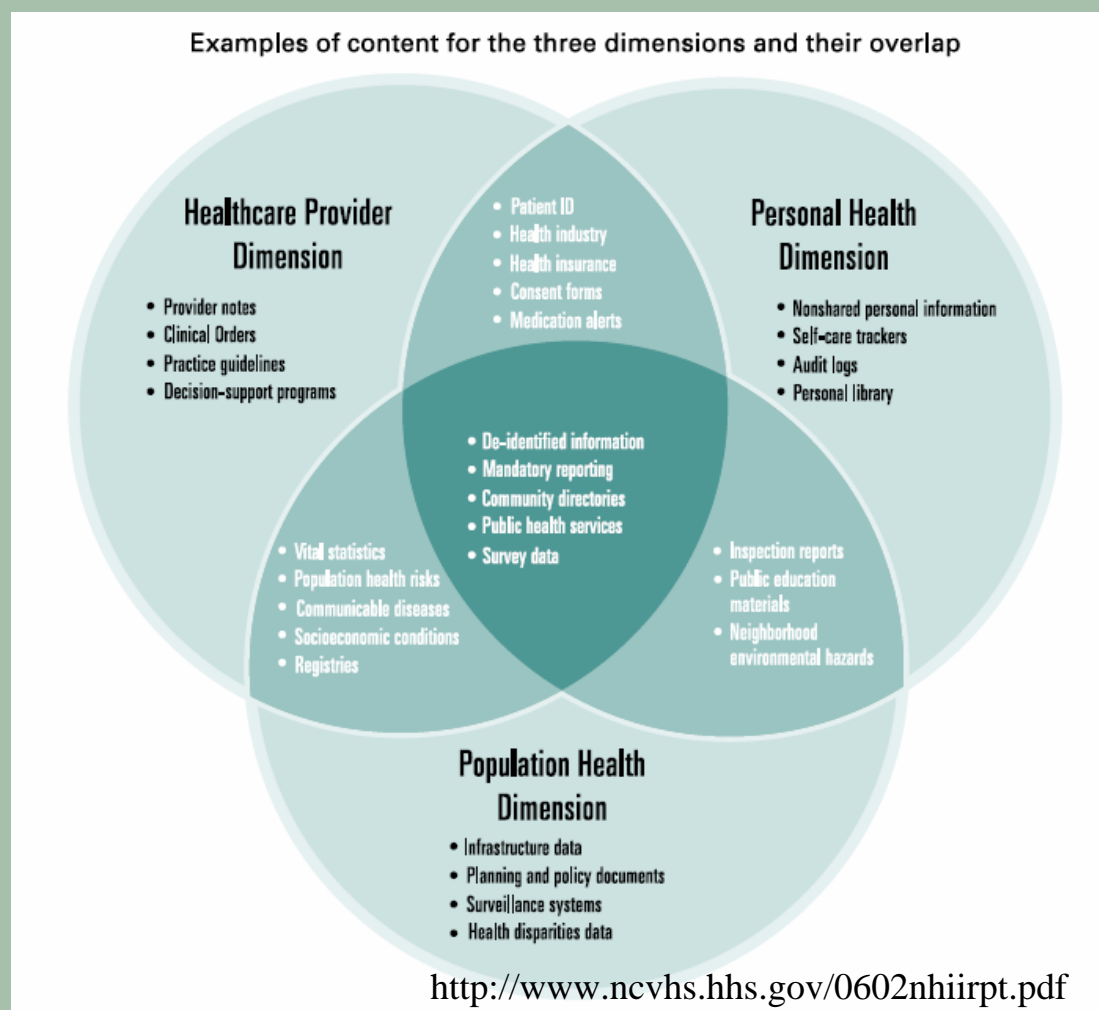


What is a PHR?

<http://www.ncvhs.hhs.gov/0602nhiirpt.pdf>

- NCVHS proposes adopting the term “personal health record” to refer to the collection of information about an individual’s health and health care, stored in electronic format
- The term “personal health record system” refers to the addition of computerized tools that help an individual understand and manage the information contained in a PHR

Three dimensions of access



An intervention framework for personal health

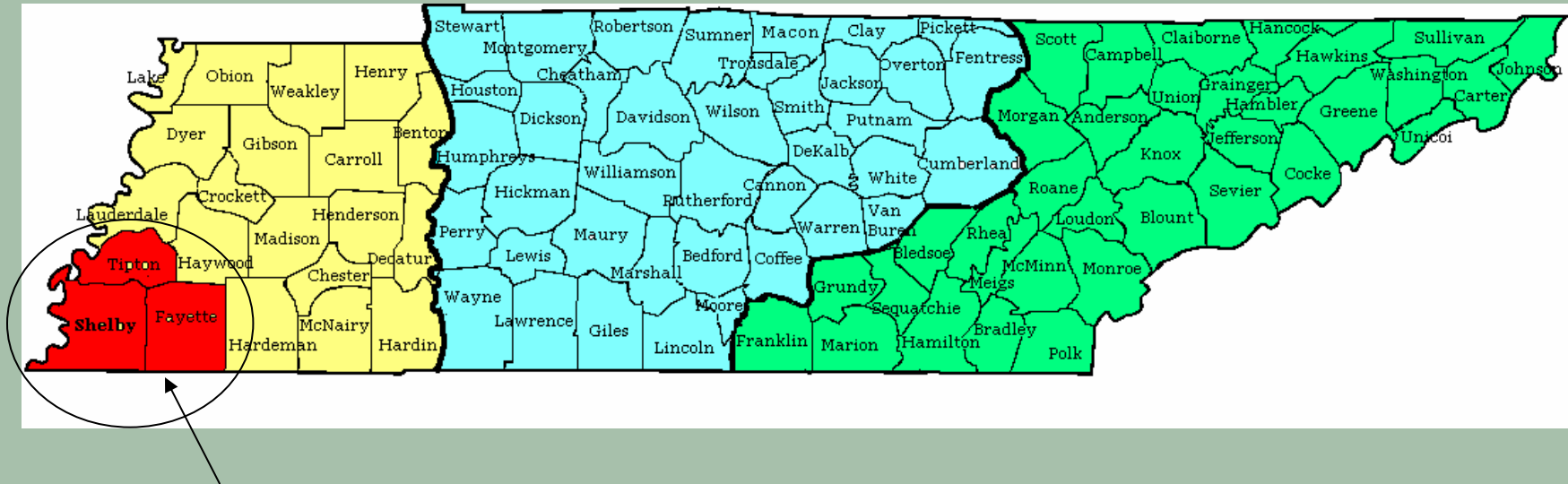
		STEPS	EXAMPLES / ISSUES
INTERVENTIONS	OUTCOMES	Value	Qualitative value – e.g., time, control Clinical value – e.g., adherence Administrative value – e.g., benefits
		Change in behavior	New ways of using time New ways of using information New models for delivery
	Use of technology in care	PHR Integration with EHR / EMR Public health / population health	
INFRASTRUCTURE	Data availability and exchange	Identification, authentication, authorization, labs, meds, allergies, major events, personal observations	
	Standards and policies for data, confidentiality, use, etc.	Data representation, encryption, authentication, authorization, roles, use, replacement, resolution of conflicting facts	

Vanderbilt AHRQ 2004 Proposal: Adapted from <http://www.volunteer-ehealth.org/pdfdocs/AHRO-10-30-04.pdf>, p 10

Questions

- What lessons have we learned from functioning health information exchanges?
- How can these exchanges relate to personal health records in terms of:
 - Policies (e.g., confidentiality, use)
 - Technologies
 - Models for clinical care
 - Outcomes

One million people in three counties



Tennessee borders 8 other states

Our initiative covers 3 counties and includes Memphis.

11% of one TennCare population visited more than on ED in a year

20 – 25% of hospital visits in Memphis are from Mississippi or Arkansas residents

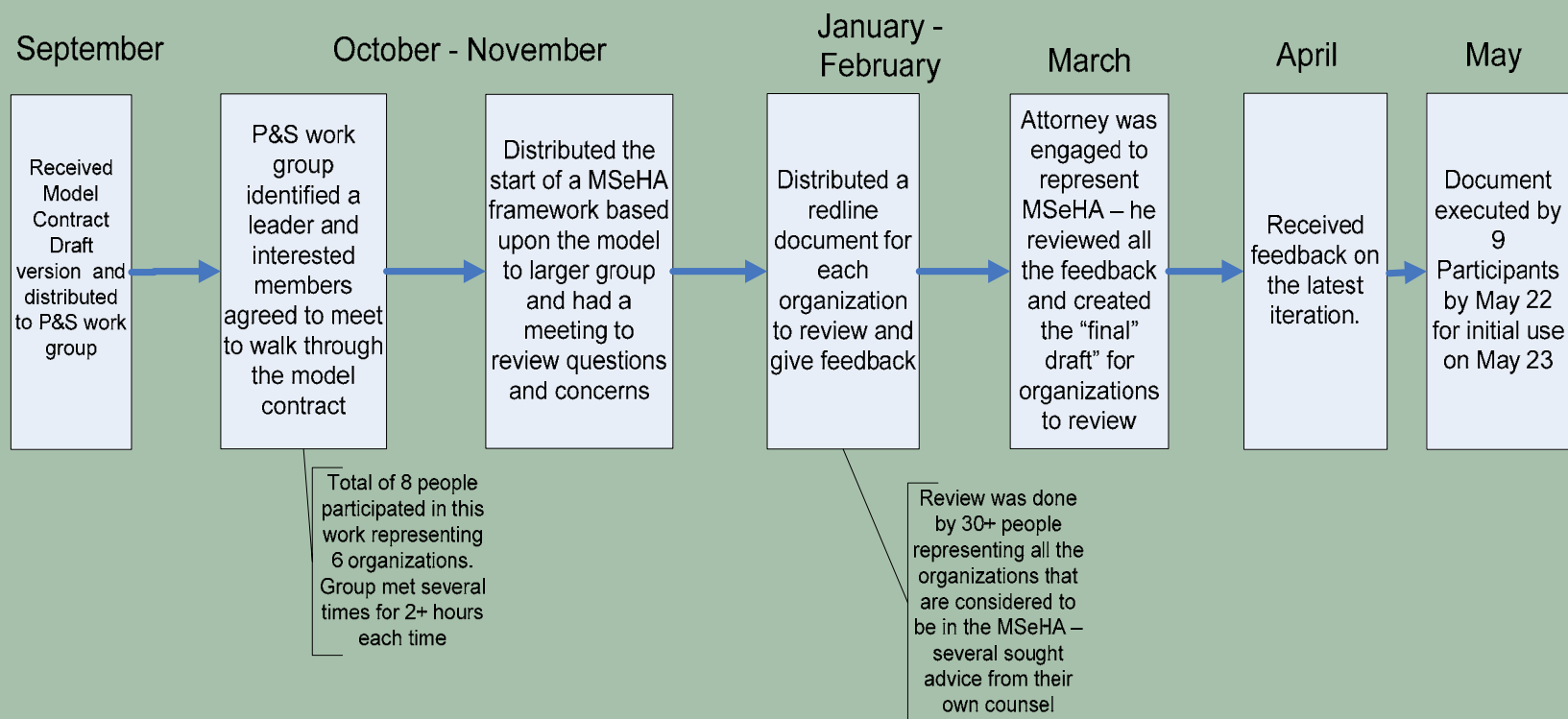
Project Overview

- Operational system managed through a new non-profit organization (MidSouth eHealth Alliance); 15 “publishers” and used now in emergency departments
- Comprehensive information – not just claims
- Members bound together by formal data-sharing and user agreements

Legal and Policy Framework

- Based on Connecting for Health (CFH) Principles
- Derived from CFH model contracts
- Development process
- Registration agreement
- Participation agreement
- User agreements
- Operations committee

Policy development takes time



Our overall approach was to do as much work as we possibly could without incurring legal fees

MSeHA = Mid-South eHealth Alliance P & S = Privacy and Security

Principles: Markle

- Openness and Transparency
- Accountability and oversight
- Data issues
 - Data integrity and quality
 - Purpose specification and minimization
 - Collection limitation
 - Use limitations
- Security safeguards and controls
- Individual participation and controls
- Remedies

Nine Domains / Themes (HHS / HISPC)

- Authentication
- Authorization
- Patient and provider identification across multiple sites
- Security of information transmission
- Protections to prevent modification
- Audits to record and monitor activity
- Administrative and physical security safeguards
- State law restrictions about information types and classes
- Information use and disclosure policies that arise when institutions share health care information

Source: <http://www.health.state.mn.us/e-health/mpsp/ninevardomains.pdf>

Policy: NCVHS, February 2006

- Rights, obligations, and potential liabilities of all stakeholders
- Consumers participation
- Security and confidentiality
- Exchange with EHR and other data sources

<http://www.ncvhs.hhs.gov/0602nhiirpt.pdf>

Security: NCVHS recommendations

- Terms and conditions of use
- Consumer control and restrict access
- Consumer control of partial access
- Consumer ability to audit access
- Industry- standard security and authentication schemes

<http://www.ncvhs.hhs.gov/0602nhiirpt.pdf>

What we think we have right in Memphis

- Transparent and open policies
- Board and operations committee oversight
- Data – use limitations; integrity; purpose specification
- Individuals can “opt out”
- Security practices in place – including very strong access controls and audits

What we wish we could do better in Memphis

- Understand the trade-offs; why are we so concerned if others are following simpler procedures? (e.g., name, password)
- Authentication – two-factor, but is this even enough?
- Authorization – based on location & role
- Identity management processes – how to scale and maintain them?

What we really don't know

- What trade-offs must we consider?
- Where does use of a PHR (or misuse) violate laws (e.g., HIPAA, G-L-B, FACTA) ?
- How much uniformity must there be?
 - Technical
 - Policy
 - Social
 - Clinical
- Who decides? The “market”? (what market?)
- What happens when things “break”?

Some trade-offs

- Individual preference vs. technical capability or administrative burden
- Rights of the individual vs. rights on the public / payer / or other agent
- Early “cementing” of definitions to reach consensus vs. a portfolio of initiatives that may be difficult to reconcile
- Power (capital, size) vs. autonomy

Lessons learned

- Leadership is essential; information is power; information is politics
- Portfolio of efforts with open learning
- Competition over the right things
- Change takes time; everybody gives
- Technology & policy are intertwined
- Patient confidentiality comes first
- Broad research agenda is essential



Previous

- [The MidSouth eHealth Alliance Data Sharing Agreements and Supporting Documents](#)
- [FORE / AHIMA Report](#)
- [The Tennessee eHealth Advisory Council](#)
- [Tennessee one of 9 States Participating in HHS / AHIMA Study](#)
- [Governor Bredesen, Healthcare Leaders Launch Campaign to Help Thousands of Tennessee Physicians Start e-Prescribing](#)
- [Volunteer eHealth Initiative Described in Recent AHRQ-funded Report](#)
- [Technical Advisory Panel Member Featured in Wall Street Journal](#)
- [Doctors Explore Prescription Usage](#)
- [Harvard and Industry Partners Announce Open-Source, User-Centric Identity Management Project](#)
- [CareSpark to co-Sponsor May 6 EMR Meeting](#)

📅 **Tuesday, September 26, 2006**

The MidSouth eHealth Alliance Data Sharing Agreements and Supporting Documents

As of September, 2005, the MidSouth eHealth Alliance (MSeHA) and the AHRQ/TN State regional demonstration project is receiving comprehensive clinical data (labs, reports, diagnoses, etc.) from 15 organizations and is in operation in several emergency departments in the greater Memphis Area.

Our work led us to conclude that data-sharing agreements are critical. This process was based on data-sharing and other documents from the Markle Connecting for Health Policy Group. The process took much longer than expected but served as a vital means of bringing over 50 people within the region to a more common, patient-centered goal.

The MidSouth eHealth Alliance is a non-profit company chartered specifically to manage the data exchange demonstration project and is supported by multiple sub-groups and an inclusive operations committee working continually on updating policies and procedures. We present on this site three documents produced in the course of our work.

<http://www.volunteer-ehealth.org>