

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



**NATIONAL CONFERENCE
DECEMBER 7-8, 2006
WASHINGTON, D.C.**

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2006

Consumer Input in Health Data Exchange

Susan Christensen - Agency for Healthcare Research and
Quality

Vicki Estrin - Tennessee Volunteer eHealth Initiative

Lisa Fenichel - Health Care for All

Art Levin - Center for Medical Consumers



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MidSouth eHealth Alliance

Funding: AHRQ Contract 290-04-0006;
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This presentation has not been approved by the
Agency for Healthcare Research and Quality



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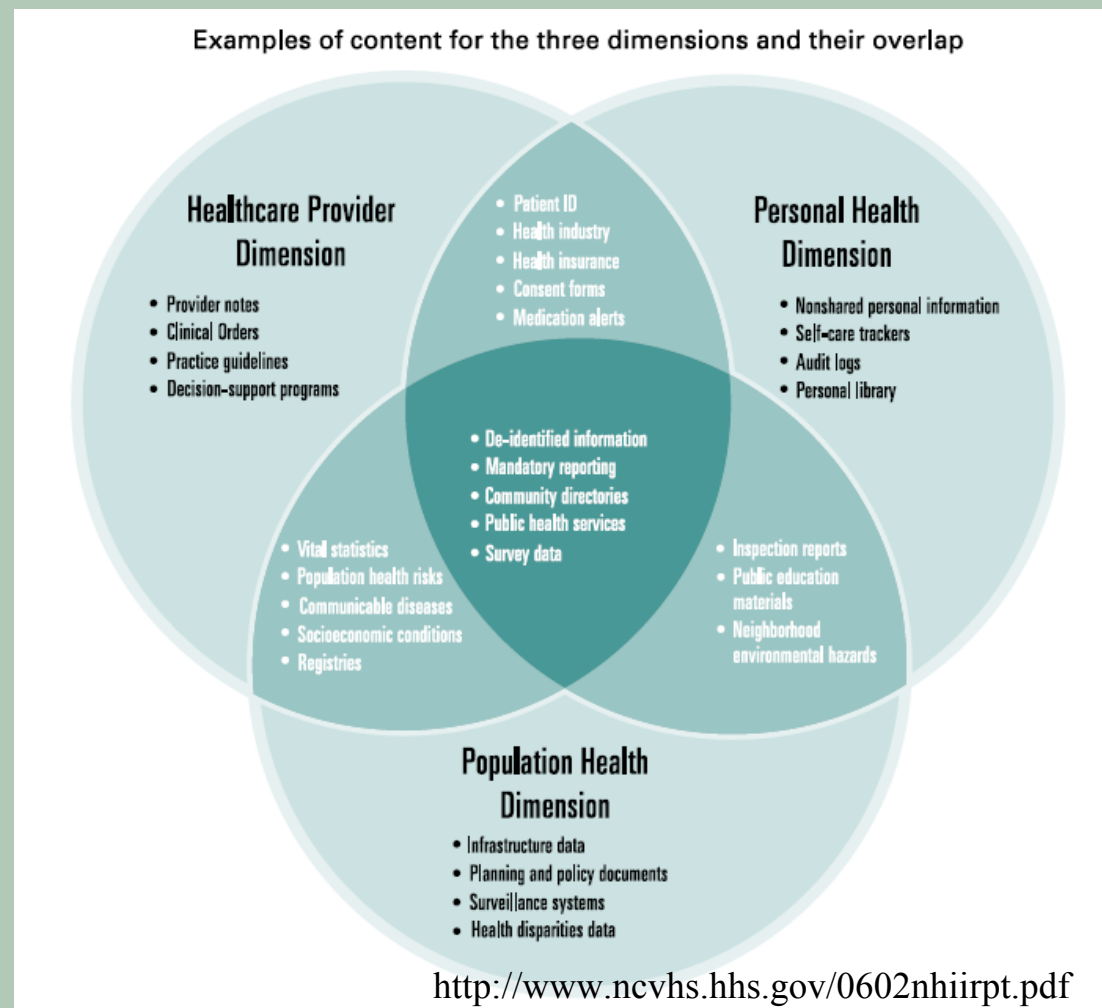

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What is a PHR?

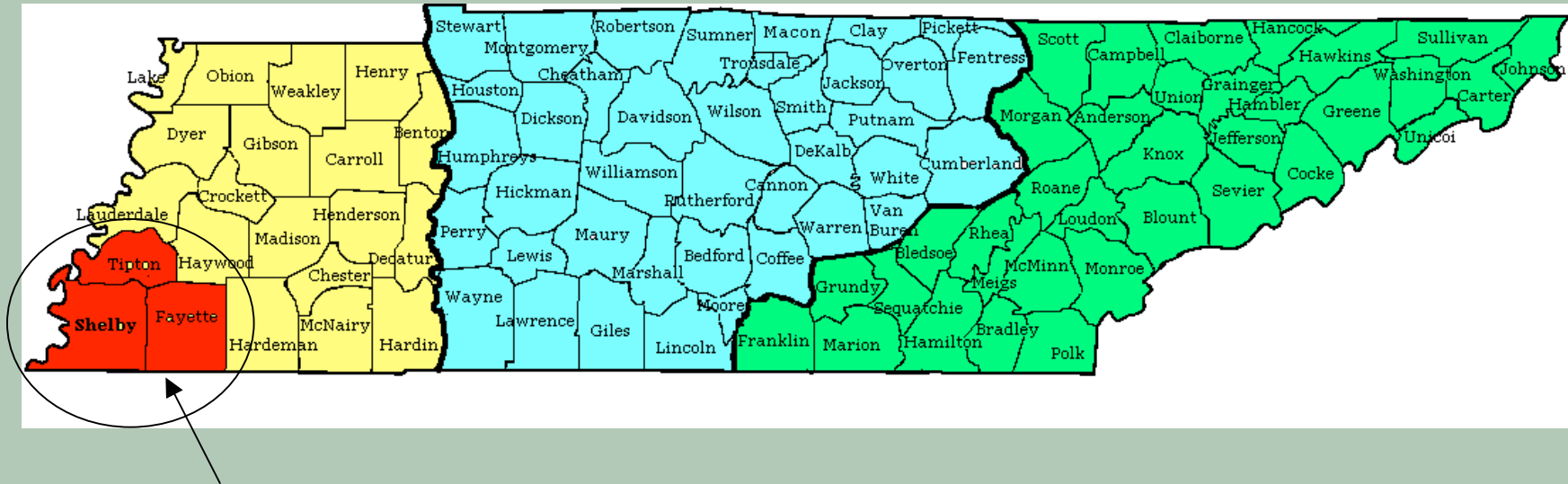
<http://www.ncvhs.hhs.gov/0602nhiirpt.pdf>

- 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



One Health Data Exchange Experience: The MidSouth eHealth Alliance



Tennessee borders 8 other states

Our initiative covers 3 counties and includes Memphis and covers one million people.

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

19% of the total population visited more than one ED in a year

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

Where are we today?

- The MidSouth eHealth Alliance is a 501 c (3) organization
 - Board began meeting in February 2005
 - Operations Committee (Board Committee) is responsible for managing and recommending policy
- 15 sites (14 hospitals and 1 MCO) publish data
 - Demographics
 - Date of encounter, reason for encounter
 - ICD9 and CPT codes
 - Lab results
 - Imaging results (reports only)
 - Dictated reports (discharge summaries, H&P, Operative Reports, ER Reports, etc.)
- By end of the year we will have data from 4 community health clinics and a 300+ physician practice

Where are we today?

- The initial focus is on providing improved care in the Emergency Department
 - Two emergency departments are accessing the patient data from all 15 publishers
 - Third emergency department will begin using on December 13th
 - Two more emergency departments will begin using the system the first quarter of 2007
- We have spent a tremendous amount of time addressing Patient Privacy issues –it is the number one concern of all parties involved in the project
- Our goal is to understand the challenges, issues, problems, etc. from a technical and policy perspective. In addition we are trying to understand what the market really requires.
 - The policy challenges have been numerous but the process of addressing them has created an incredibly educated community and a cohesive community that is focused on doing the right thing
 - The technical challenges to date have been manageable but they increase with every implementation from both the publisher side and the user side

Is there a role for the Consumer in a Health Data Exchange?

- Absolutely it is the right thing to do to allow the consumer access to his/her records BUT...
- Saying what is the right thing to do and making it happen are at least two different things...

What are some of the challenges?

- Authentication – how can a system know that a user is who they say they are?
 - Today in the MidSouth eHealth Alliance we “know” all of our users and use SecurID Tokens to authenticate
 - We are already concerned about Identity Management process and how to scale them
- With whom will the patient have a relationship with in the future – the provider or the exchange?
 - Today, it is very important to the Participants in the MidSouth eHealth Alliance to maintain the patient relationships and that the MidSouth system be viewed as a “tool” for better care that the Participants provide.
- How to reconcile a Health Data Exchange PHR with a plan’s or a provider’s PHR?
 - Several of the Participants in MidSouth are looking at developing a PHR for their patients – how will the PHR’s be updated and reconciled?
 - The Plans in the region are providing PHRs.
- Developing the appropriate policy and legal framework to accommodate and document the above. Who is responsible when things “go wrong”?
 - The MidSouth has a policy and legal framework based on the Connecting for Health Framework (CFH) that includes user agreements, registration agreements, framework for managing policy, etc.

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Health Information Technology

Consumer Principles

As Applied to the MAeHC

Pilot Program

**By Lisa Fenichel, M.P.H.
E-Health Consumer Advocate
Health Care For All
December 2006**

National HIT Principles: Background

- Five principles submitted on April 6, 2006, to HHS Secretary Michael Leavitt.
- Crafted by national consumer advocacy groups, convened by the National Partnership for Women and Families, and signed by 20 groups including: **AARP, AFL-CIO, Consumers Union, Health Privacy Project, March of Dimes, Service Employees International Union, United Steelworkers International Union, and HCFA.**

National HIT Principles

- Individuals should be able to access their personally identifiable health information conveniently and affordably.
- Individuals should know how their personally identifiable health information may be used and who has access to it.
- Individuals should have control over whether and how their personally identifiable health information is shared.
- Systems for electronic health data exchange must protect the integrity, security, privacy and confidentiality of an individual's information.
- The governance and administration of electronic health information networks should be transparent, and publicly accountable.

1. Individuals should be able to access their personally identifiable health information conveniently and affordably.

- MAeHC is not requiring a patient portal, though North Adams would like to include one, if possible.
- Otherwise, access to copies and ability to supplement and edit records have not changed from current practice.
- Conclusion: MAeHC does not yet meet Principle 1 standards.

2. Individuals should know how their personally identifiable health information may be used and who has access to it.

- MAeHC has developed and distributed patient permission forms and consumer education literature in one community so far.
 - These first documents stimulated discussion about gaps in descriptions both of sensitive information exchange and of possible (though remote) PHI security risk.
- Access to PHI will be limited to authorized individuals or entities.
- Consumers will be able to request a printout audit of those who accessed their medical records.
- Conclusion: MAeHC meets Principle 2 standards for PHI access and auditing and is actively working with HCFA and other stakeholders to address information gaps in forms and literature.

3. Individuals should have control over whether and how their personally identifiable health information is shared.

- MAeHC requires opt-in for sharing PHI on the e-health network.
- Opt-in is for all PHI or none, though it might be possible to flag or block sensitive information.
- MAeHC will not make any PHI commercially available.
- Conclusion: MAeHC exceeds Principle 3 standards with opt-in.

4. Systems for electronic health data exchange must protect the integrity, security, privacy and confidentiality of an individual's information.

- MAeHC has planned strong security safeguards, including monitoring systems, auditing procedures, and security certification requirements.
- It is unclear whether and when individual patients will be informed of security breaches or privacy violations.
- Conclusion: MAeHC partially meets Principle 4 standards.

5. The governance and administration of electronic health information networks should be transparent, and publicly accountable.

- MAeHC is not a public entity, though its networked communities are accountable to themselves and to the MAeHC.
 - Certain MAeHC subcommittees include public members.
- CCCs should give consumers equal footing with other stakeholders, making networks accountable and transparent to consumers.
 - Brockton and North Adams, among three CCCs, are active.
- Conclusion: MAeHC partially meets Principle 5 standards.

Key HCFA Recommendations

- Engage consumers through CCCs to be stakeholders in pilot design and implementation.
- Include patient portals in all three communities.
- Create selective opt-in option to protect sensitive information.
- Immediately notify consumers of PHI security breaches/ privacy violations and offer remedies.
- Have clear, transparent consumer information easily available (handouts, website, newspaper, hotline) and appropriately translated.

Health Care For All

- For more information, contact E-Health Consumer Advocate Lisa Fenichel: lfenichel@hcfama.org, 617-275-2868.
- Also, check out E-Health web pages on the HCFA Website, www.hcfama.org, by clicking on Policy and Advocacy, and then E-Health.

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