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: Empowered Consumers, Personal Health Records and Emerging Technologies

2006

Latest Research
David Ahern - Health eTechnologies
Eric Dishman - Intel Corporation
Corey Angst - University of Maryland
Steve Ross - University of Colorado
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and Emerging Technologies

2006

Latest Research
Eric Dishman
Intel Corporation
Latest Research: PHRs

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CENTER FOR HEALTH INFORMATION AND DECISION SYSTEMS
Agenda

• Important research topics related to PHRs
• Studies of patient value
• Predictors of value
• Barriers to adoption
• Privacy research
• Path forward in research
What should researchers measure?

• Return on Investment (ROI)?
• Relationship Capital?
• Improved Health outcomes?
• Provider perceptions?
• “..the most profound impact of personal health records may lie in their ability to encourage patients to become more active in managing their own care.”¹

• “‘patient-empowerment’ - a key theme of the Nationwide Health Information Network”²

What Do Patients Value in a PHR?

- Patient-provider secure messaging
- Online refills
- Lab results
- Medication lists
- Disease Mngmt
- Empowerment


Studies of Patient Value

• Patient access to PHR enhances patient’s understanding of their conditions and improves communication with their physicians\(^1\)
• No negative relationships between clinician-patient as a result of system usage\(^1\)
• Patients feel increased ownership of their healthcare\(^2\)
• Patients are willing to be ‘empowered’\(^3\)
• Value of having records available to them over the Internet was very high\(^3\)


Predictors of PHR Use or Desire for Use

• **Convenience** is a strong predictor of desire for PHR\(^1\)
• **Compliance** is a predictor of PHR use\(^2\)
• **Connectedness** is a predictor of PHR use\(^2\)
• **Education** and **Knowledge of PHRs** were predictors of desire for PHR\(^3\)

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Effects of Patient Empowerment

- **Objective outcomes:**
  - Level of compliance with health treatments
  - Frequency of health care seeking behavior
  - Improvements in overall health

- **Subjective outcomes:**
  - Perceived satisfaction with health treatments
  - Perceived satisfaction with personal health
  - Perceived control over health treatments
  - Perceived responsibility for medical care
  - Level of optimism about personal health
  - Coping strategies adopted by the patient (e.g., active, confronting strategies vs. passive, denial strategies)
Will People Opt-Out?

• Privacy Concerns are an issue
• Will people relinquish some degree of privacy for the promise of better care?
• With properly crafted messages, most will¹

Barriers to Adoption

Concerns that Keep Me From Using/Endorsing PHRs

Barriers to Adoption

Does IT Adoption by Doctors/Hospitals Influence Your Decision of Which Doctor/Hospital to Choose?

- No, definitely not, 9%
- Yes, definitely, 8%
- Yes, probably, 10%
- It might, 30%
- No, probably not, 24%
- No, but it should, 30%
- Yes, probably not, 10%
- No, definitely, 9%


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Privacy Concerns

Types of Privacy Concerns

Findings: Trust in the PHR

How comfortable would you be if a PHR system was provided, sponsored, and/or maintained by:

- **Doctor**: 5.56 (5.65)
- **Hospital**: 4.64 (4.80)
- **Employer**: 2.47 (2.56)
- **Pharmacist**: 4.25* (3.57*)
- **Pharmaceut.**
- **Sp Int Grp**: 3.00 (2.85)
- **Insurer/Payer**: 3.97* (3.10*)

*Significant differences between groups.
Institution Level Adoption

Diffusion Rates of HIT in Hospitals

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</tr>
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</table>

- Eclaims
- CDSS
- CPOE
- PHR
- LIS
- PMS
- EMR
- EHR
- RadPACS

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Path Forward in Research

• Distal connections are dangerous
  ▪ Focus on intermediate steps
  ▪ What increases uptake
  ▪ What increases follow-through
  ▪ Are there attitudinal or perceptual benefits which can/will translate into objective value long term

• Research design
  ▪ Currently there are multiple pilot projects either underway (Dell, IBM, GM, GE, etc) or planned (RWJ, AHRQ) and they don’t have enough rigorous research tied to them
  ▪ Some PHR pilot programs are poorly designed
    ▪ Incentives aren't doing what they are supposed to (i.e. encouraging use rather than encouraging a single visit)
    ▪ Aren't sufficient funds to make the projects successful
  ▪ May conclude that the ‘empowered' consumer is not of value..why…because we didn't properly design a program or have the right metrics in place to assess their value.
Path Forward in Research

• We need to push for randomized controlled trials.
• We could accomplish a lot in a short period of time with a properly designed pseudo-experiment
• Need to work closely with not only vendors and employers but also groups who collect and aggregate outcomes data or Rx data (only way to assess objective value from a PHR).
• Need to move beyond medical informatics, medicine, and IS research in isolation and begin to cross disciplines. Each discipline brings new insights.
Connecting Americans to Their Health Care:
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2006

Latest Research
Steve Ross
University of Colorado Health Sciences Center
Patient-Accessible Electronic Health Records at University of Colorado Hospital

Steve Ross MD
University of Colorado Health Sciences Center

Connecting for Health Conference
Washington, DC 2006
Organization

- Simple patient portal
  - My Doctor’s Office
- Bare bones access to records
  - SPPARO
- Patient friendly access to records
  - Diabetes-STAR
- Future Plans at University of Colorado Hospital
I. My Doctor’s Office
My Doctor’s Office

- Administrative functions
  - Appointments
  - Referrals
  - Refills

- Secure electronic messaging

- Offered at no cost
My Doctor’s Office

- An easy win where installed
  - Improved patient satisfaction
  - 1 additional message daily for 250 patients enrolled

Lin CT, Ross SE. JMIIR (2005) 7:e47
II. SPPARO
SPPARO

- System Providing Patients Access to Records Online
- Access to test results AND clinical notes
- No translation or interpretation
- No explicit theoretical model
### CONGESTIVE HEART FAILURE BNP

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**Report Comments**

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### Basic Metabolic Panel

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<th>Result</th>
<th>Ref. Range</th>
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<th>Ref. Range</th>
<th>Result</th>
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<td>137</td>
<td>133-145</td>
<td>136</td>
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<td>136</td>
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<tr>
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<td>3.3-5.0</td>
<td>4.3</td>
<td>3.3-5.0</td>
<td>4.4</td>
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<td>26</td>
<td>22-29</td>
<td>26</td>
<td>22-29</td>
<td>23</td>
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<td>GLU R</td>
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<td>34 H</td>
<td>5-23</td>
<td>32 H</td>
<td>5-23</td>
<td>30 H</td>
</tr>
</tbody>
</table>
Dear Dr. [Name],

I had the pleasure of seeing your patient, [Patient Name], today in the Heart Failure Clinic at the University of Colorado Hospital. As you know, she is a 71-year-old female with a history of Adriamycin-induced cardiomyopathy. This is currently her four-month follow-up and she was last seen on 07/15/2003. Her last evaluation of pumping function was done on 04/08/2003. At that time, her left ventricle was of normal size. Her left ventricular systolic function was moderately reduced, with her left ventricular ejection fraction of approximately 53.8%. She had some diastolic dysfunction, moderate mitral regurgitation which was better from her previous echo done on 08/02/2002, and mild tricuspid regurgitation, which is considerably better from her previous echocardiogram. She also had right ventricular systolic elevated pressure, which was consistent...
SPPARO: Clinical Trial

- Design
  - Heart failure practice at University of Colorado Hospital
  - Control group: delayed intervention
  - Assessments over 6 months in 2003

- Enrollment
  - 25% of clinic patients from waiting room

- Use
  - Each month, ~ 20% logged in
  - ~1 login per clinic visit

Funded by the Commonwealth Fund
SPPARO: Outcomes

- Improvements
  - Adherence (general)
  - Self-efficacy (trend)
  - Patient satisfaction with doctor-patient communication (trend)

- No effect
  - Adherence (medication)
  - Health status
  - Utilization of health services

SPPARO: Patient Interviews

- Valued transparency
- Anecdotes of benefit
- Medical jargon sometimes hard to decipher…
- …But STRONG interest in candid, unvarnished record
  - “My life is at stake”
SPPARO: Doctor Interviews

- Soon became “invisible” in routine practice
- Changing documentation
  - None left information out
  - Some made small additions for patients
- No major problems
  - One patient request for annotation

- OK with the concept…
- …but “show me the quality”
III. Diabetes-STAR
Diabetes-STAR

- “Diabetes-System to Access Records”
- Added disease management system to
  - My Doctor’s Office
  - SPPARO
- Explicit use of constructs from behavioral science theories, specifically…
Summarize health information in graphical format

Emphasize key clinical information

_Awareness of risk of complications

_Self-care outcome expectancies

_Behavioral capability

_Confidence
Diabetes-STAR: Design of Goal-Setting

- Based on “Diabetes Priority Program” kiosk program*
  - Effective in improving diabetes self-care
  - Patients came early to appointments
  - Diet and exercise modules
    - Assessment
    - Guided goal setting
  - Gave printout to physician
  - Staff member follow up in 2 weeks
Choose category of goal (diet)
Choose specific goal
Identify obstacles
Identify strategies to overcome obstacles
Rate self-confidence
Automatic follow-up

My Goal: I will stop eating candy and high fat snack foods such as potato chips and tortilla chips.

Goal Due Date: 09/25/2005
Confidence: 7 (On a scale of 1-10, where 10 is very confident)

I don’t have time to cook so we buy a lot of fast food.

- Never “supersize” your order. Instead, minimize fat and calories by ordering a SMALLER size meal.
- Put $10 in a “vacation jar” on the nights you save money by cooking at home.

I have little or no self-discipline (especially when under stress).

- Keep healthy food in the front (at eye-level) of the fridge. Keep high fat food out of sight.
- Plan ahead for “high risk” eating situations.
Diabetes-STAR Compared with “Diabetes Priority Program”

- Similar design
  - Guided goal setting to improve self-care
  - Shared with physician

- But:
  - Provides personalized clinical information
  - Not tied to clinic visit
  - Goal-setting recommended, not required
  - Follow up by e-mail (not staff)
Outcomes: Recruitment

- Enrolled 10% of patients with diabetes
  - Representative demographics (age, education, race/ethnicity)
- Many with Internet access didn’t enroll
  - Not engaged in self-care? “Not my role”? 
  - Only limited, casual use of Internet?
  - Research, not standard care?

Funded by Robert Wood Johnson Foundation Health eTechnologies Initiative
Outcomes: Use Interactive → Patient Retention

D-STAR vs Control: p < 0.001
Outcomes: Use Interactive → More Use (Higher “Dose”)

Days used per 100 patients

Month after enrollment

D-STAR
Control

p < 0.001
Use of Diabetes-STAR Goal Setting

- Initially, very little goal setting
- Began monthly prompts for both groups, which mentioned goal setting in intervention group

<table>
<thead>
<tr>
<th>Category</th>
<th>Goals</th>
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<tr>
<td>Diet</td>
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<tr>
<td>Exercise</td>
<td>60</td>
</tr>
<tr>
<td>Adherence to Medications / Monitoring</td>
<td>20</td>
</tr>
<tr>
<td>Smoking</td>
<td>11</td>
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</table>
Use of Diabetes-STAR: Lessons

- Personalized (intervention) system did result in more frequent use

- Goal setting was less than expected
  - Logins: 3 month survey: Patients like reminders
  - No explicit expectations were set for goal-setting
  - Would prompting before appointments help?
Outcomes

- Self-care activities
  - No significant improvements in
    - Diet
    - Exercise
    - Adherence
    - Smoking

- Biological markers
  - No apparent improvements
Diabetes-STAR: Conclusions

- Program was designed well
  - Based on theoretical models
  - Usable

- So why did self-care improve with “Diabetes Priority Program”, but not with Diabetes-STAR?
  - Insufficiently directive?
    - Not enough goals set
  - Weak commitment / accountability?
    - Automated follow up vs. human follow up
  - Not immediately actionable?
    - Not integrated with office visit
IV. Future Plans
The Future of PHRs at University of Colorado Hospital

- Administrative portal / messaging
  - Little controversy in rollout
- Labs / Notes: allayed concerns
  - No deluge of messages
  - Problems (angry, worried, confused patients) are rare
- Persistent concerns
  - Rare problems can still be an enormous hassle
  - Primary care vs. specialty care
The Future of PHRs at University of Colorado Hospital

- Diabetes-STAR
  - Provide to all patients at UCH clinics
  - Send prompt 1 week before clinic appointment
  - Direct participant to set goal before appointment
  - Continue computerized follow up
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