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

Latest Research

David Ahern - Health eTechnologies
Eric Dishman - Intel Corporation
Corey Angst - University of Maryland
Steve Ross - University of Colorado

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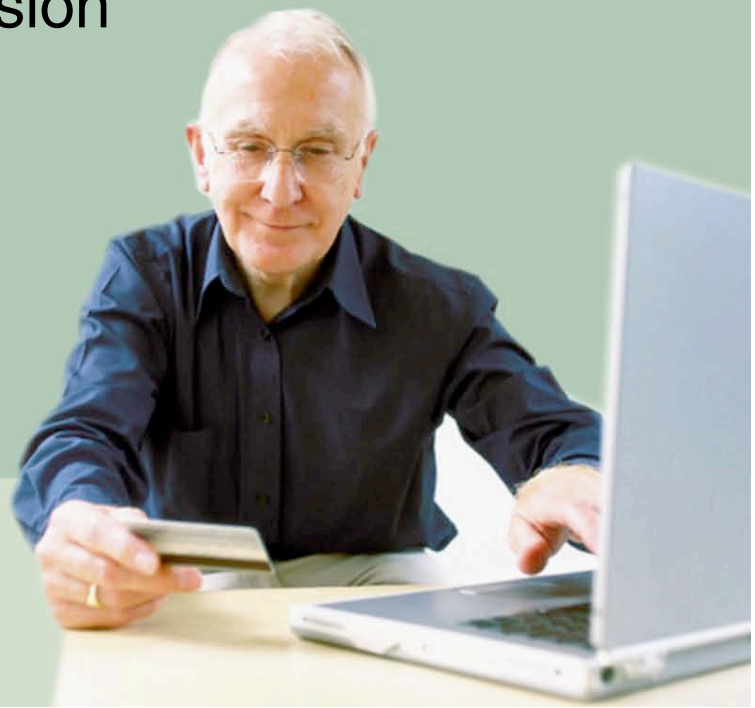
Corey Angst

Center for Health Information and Decision Systems, University of Maryland



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Latest Research: PHRs

Corey Angst, Associate Director, CHIDS
302.547.0487, cangst@rhsmith.umd.edu

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]

[1]Tsai CC, Starren J. Patient Participation in Electronic Medical Records. Journal of the American Medical Association 2001;285(13):1765.

[2]Masys D, Baker D, Butros A, Cowles KE. Giving Patients Access to Their Medical Records via the Internet: The PCASSO Experience. Journal of American Medical Informatics Association 2002;9(2):181-191

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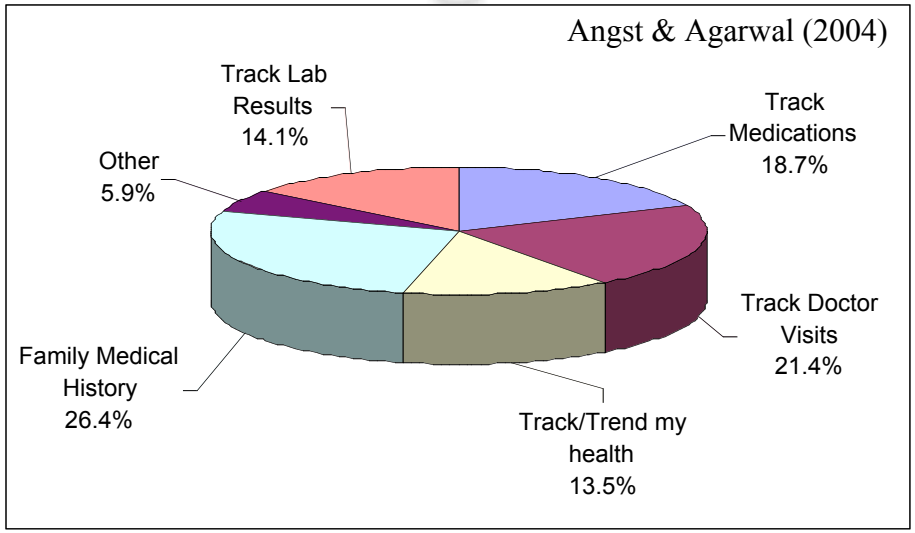
What Do Patients Value in a PHR?

- Patient-provider secure messaging[1]
- Online refills
- Lab results
- Medication lists
- Disease Mngmt
- Empowerment



[1]Lansky, D., Wald, J., & Flatley Brennan, P. (2005) "Overview of Personal Health Records," Connecting for Health Workgroup, Panel Discussion.

[2]Angst, C. M., & Agarwal, R. (2004) "Patients Take Control: Individual Empowerment with Personal Health Records," Center for Health Information and Decision Systems (Working Paper).

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]

[1]Cimino, J.J., Patel, V.L., & Kushniruk, A.W. (2001). What Do Patients Do With Access to Their Medical Records. *Medinfo*, 10(Pt 2), 1440-1444

[2]Cimino, J.J., Patel, V.L., & Kushniruk, A.W. (2002). The Patient Clinical Information System (PatCIS): Technical solutions for and experience with giving patients access to their electronic medical records. *International Journal of Medical Informatics*, 68(1-3), 113-127.

[3]Masys, D., Baker, D., Butros, A., & Cowles, K.E. (2002). Giving Patients Access to Their Medical Records via the Internet: The PCASSO Experience. *Journal of American Medical Informatics Association*, 9(2), 181-191.

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]

[1]Angst, C. M., & Agarwal, R. (Working Paper). "Getting Personal About Electronic Health Records: Modeling the beliefs of personal health record users and non-users," *Under Review.*

[2]Agarwal, R., & Angst, C. M. (2006). "Technology-Enabled Transformations in U.S. Health Care: Early Findings on Personal Health Records and Individual Use," In D. Galletta & P. Zhang (Eds.), *Human-Computer Interaction and Management Information Systems: Applications* (Vol. 5). Armonk, NY: M.E. Sharpe, Inc.

[3]Angst, C.M., Agarwal, R., & Downing, J. (Working Paper). "An Empirical Examination of the Importance of Defining the PHR for Research and for Practice," *Under Review*.

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)

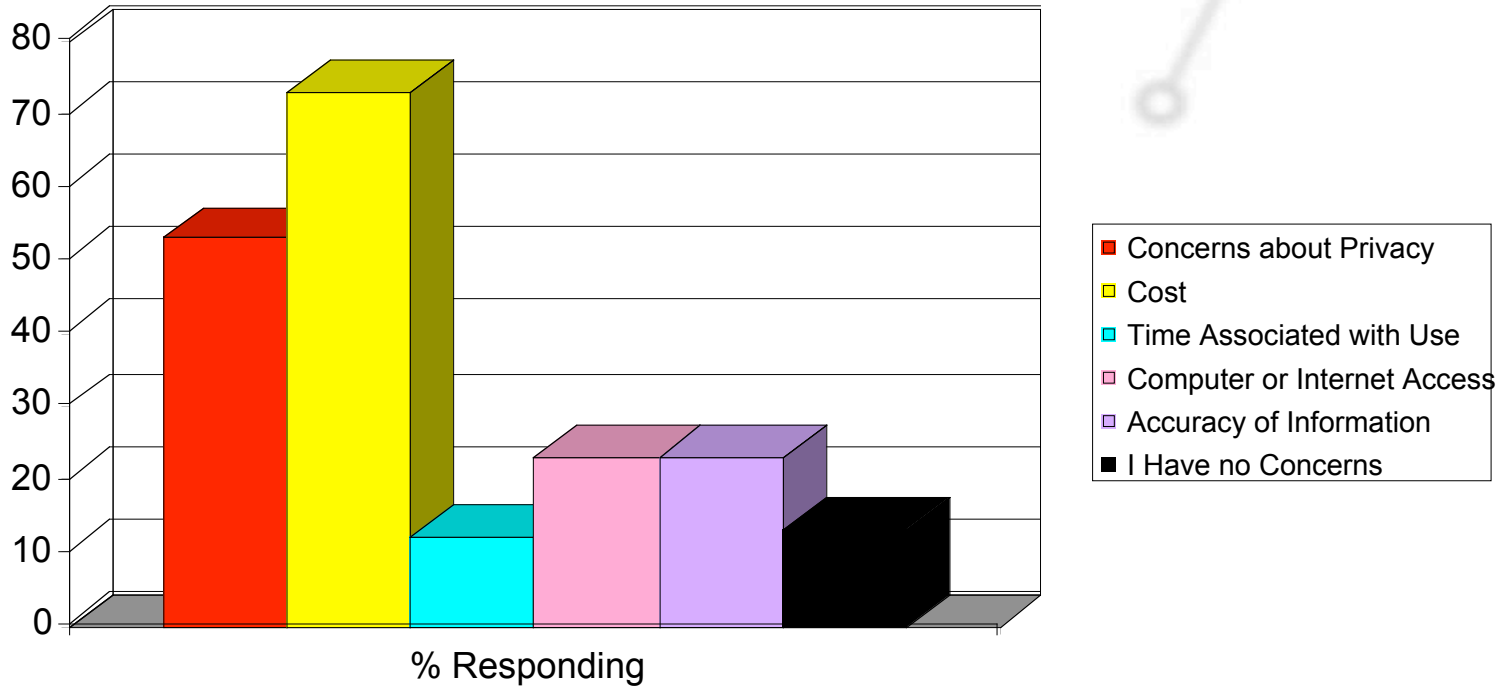
Will People Opt-Out?

- Privacy Concerns are an issue
- Will people relinquish some degree of privacy for the promise of better care?
- With properly crafted messages, most will[1]

[1]Angst, C.M., and Agarwal, R. (2006) "Digital Health Records and Privacy Concerns: Overcoming key barriers to adoption," *27th International Conference on Information Systems*, Milwaukee, WI, pp. 1-9.

Barriers to Adoption

Concerns that Keep Me From Using/Endorsing PHRs



[1]Angst, C.M., and Agarwal, R. (2006) "Digital Health Records and Privacy Concerns: Overcoming key barriers to adoption," *27th International Conference on Information Systems*, Milwaukee, WI, pp. 1-9.

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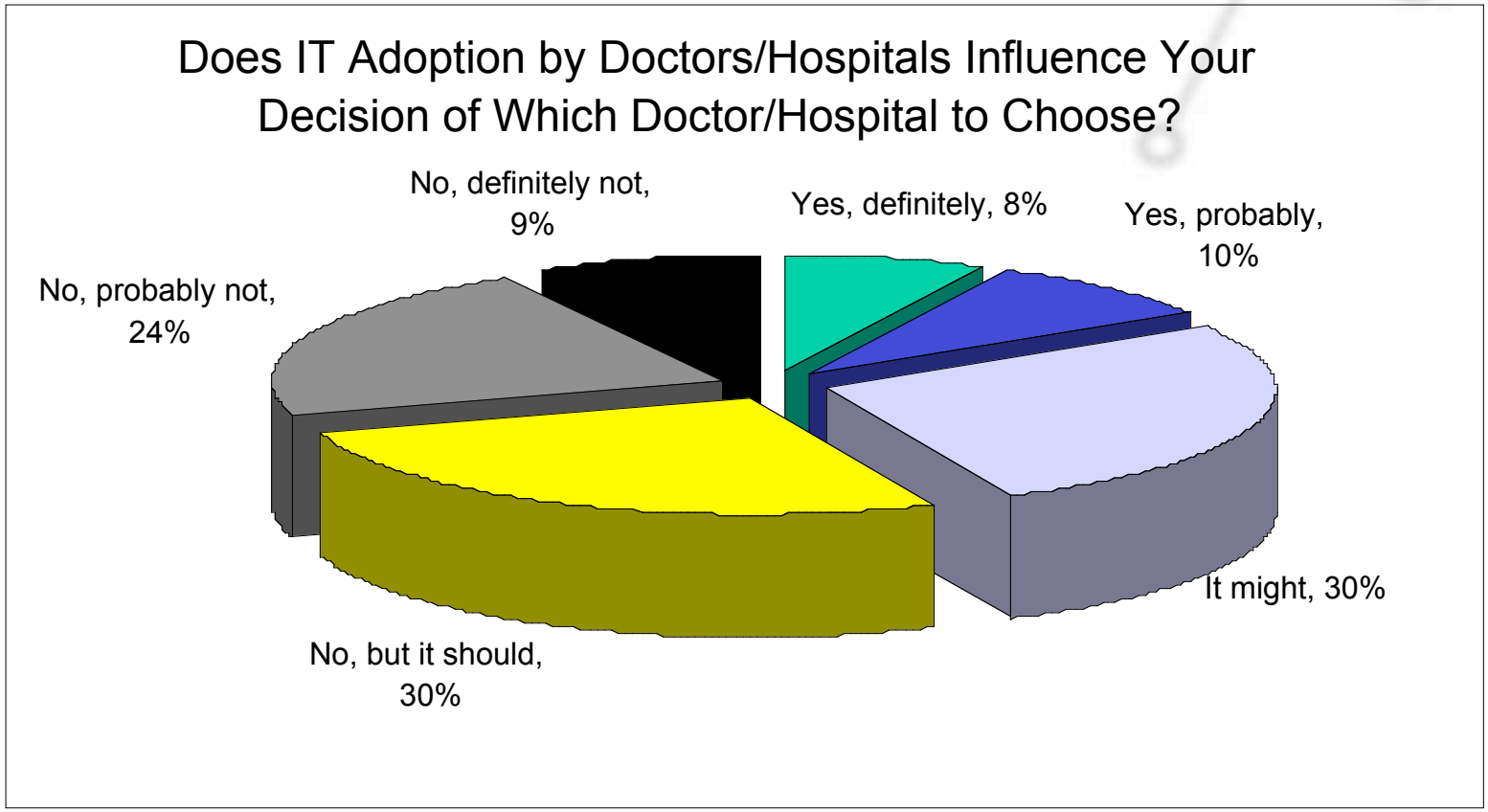
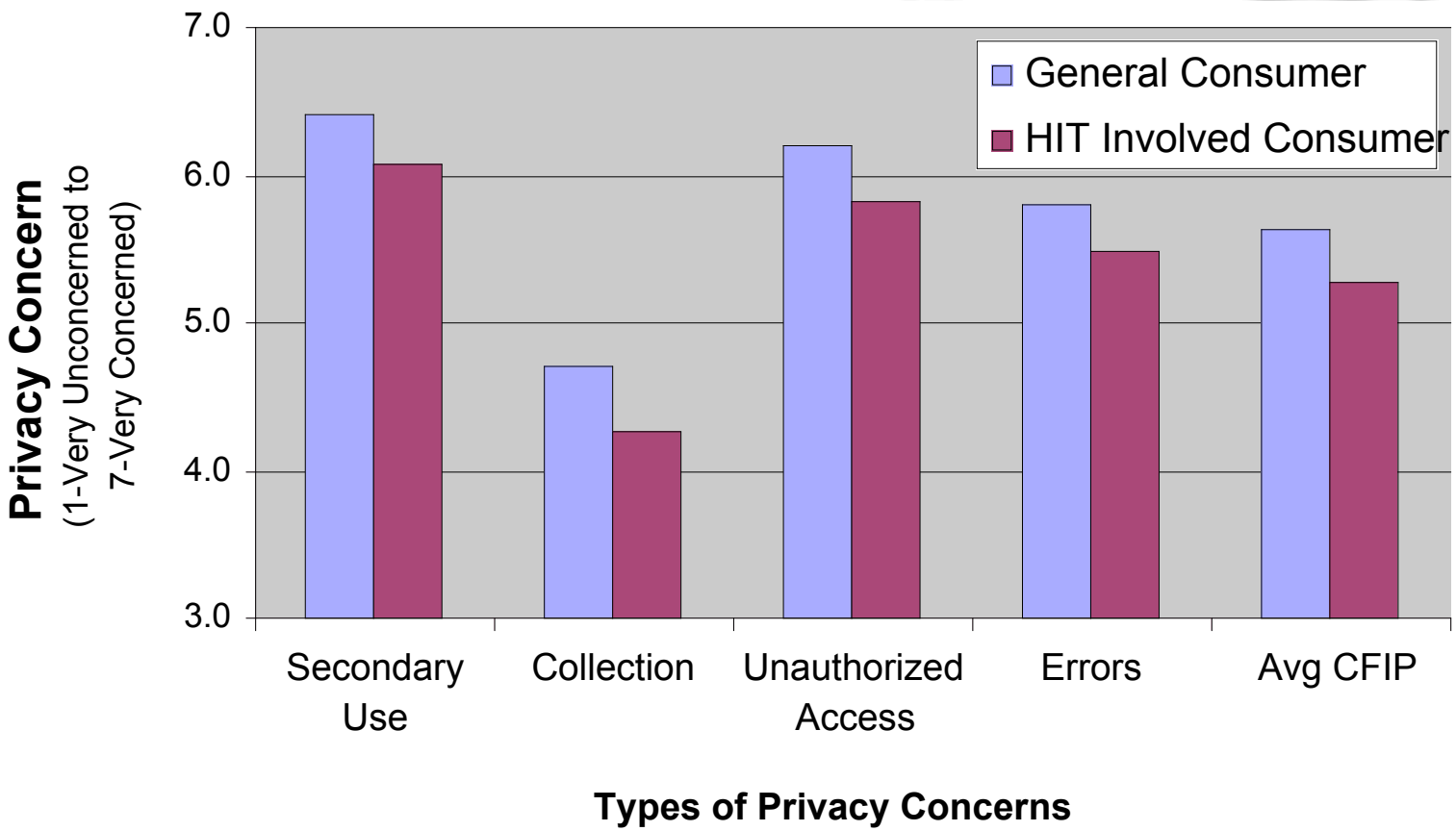
Barriers to Adoption



Angst, C. M., & Agarwal, R. (2006) "Barriers to EHR Adoption," Center for Health Information and Decision Systems (Working Paper).

Privacy Concerns



Angst, C. M., & Agarwal, R. (2006) "Barriers to EHR Adoption," Center for Health Information and Decision Systems (Working Paper).

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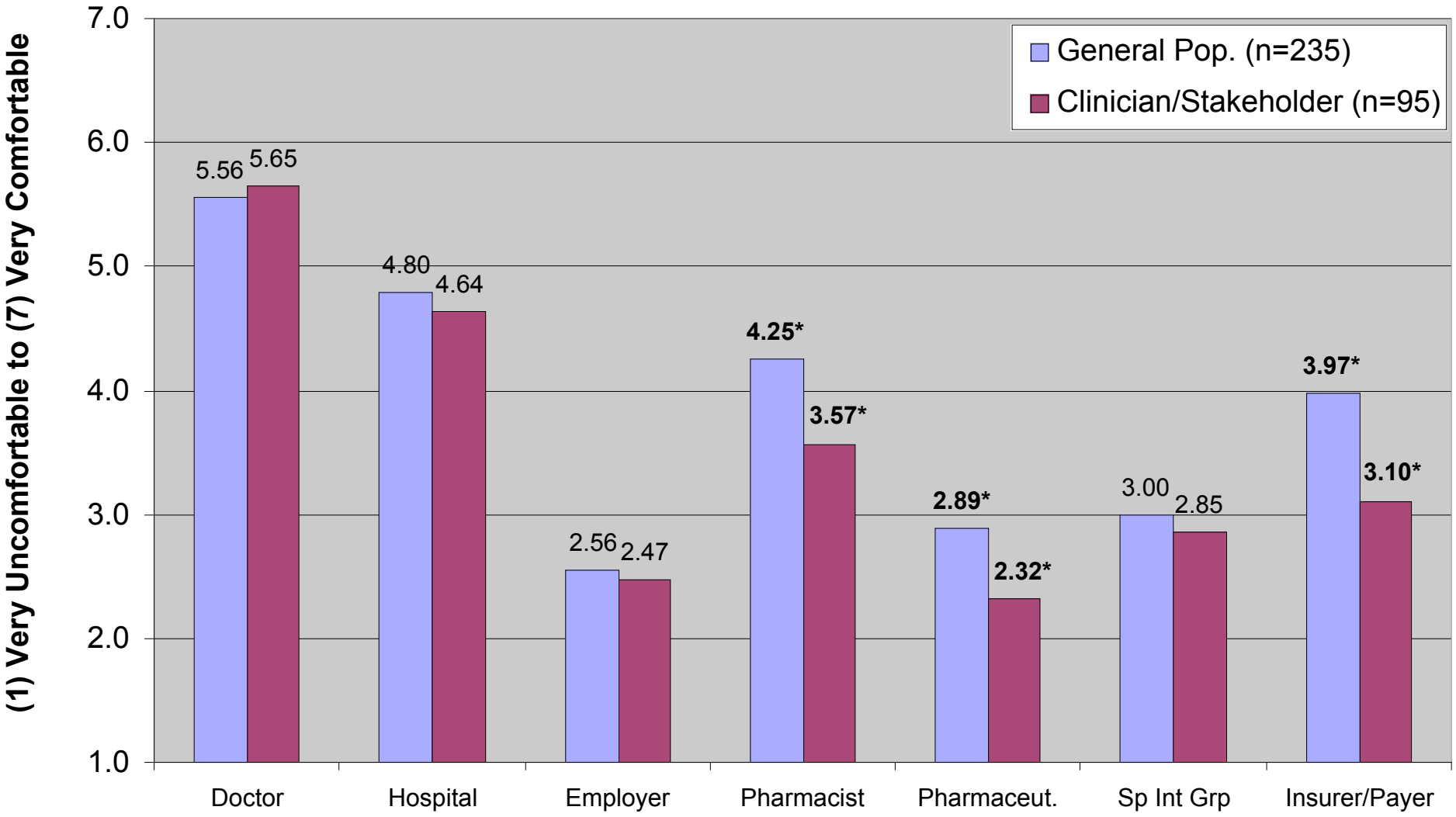
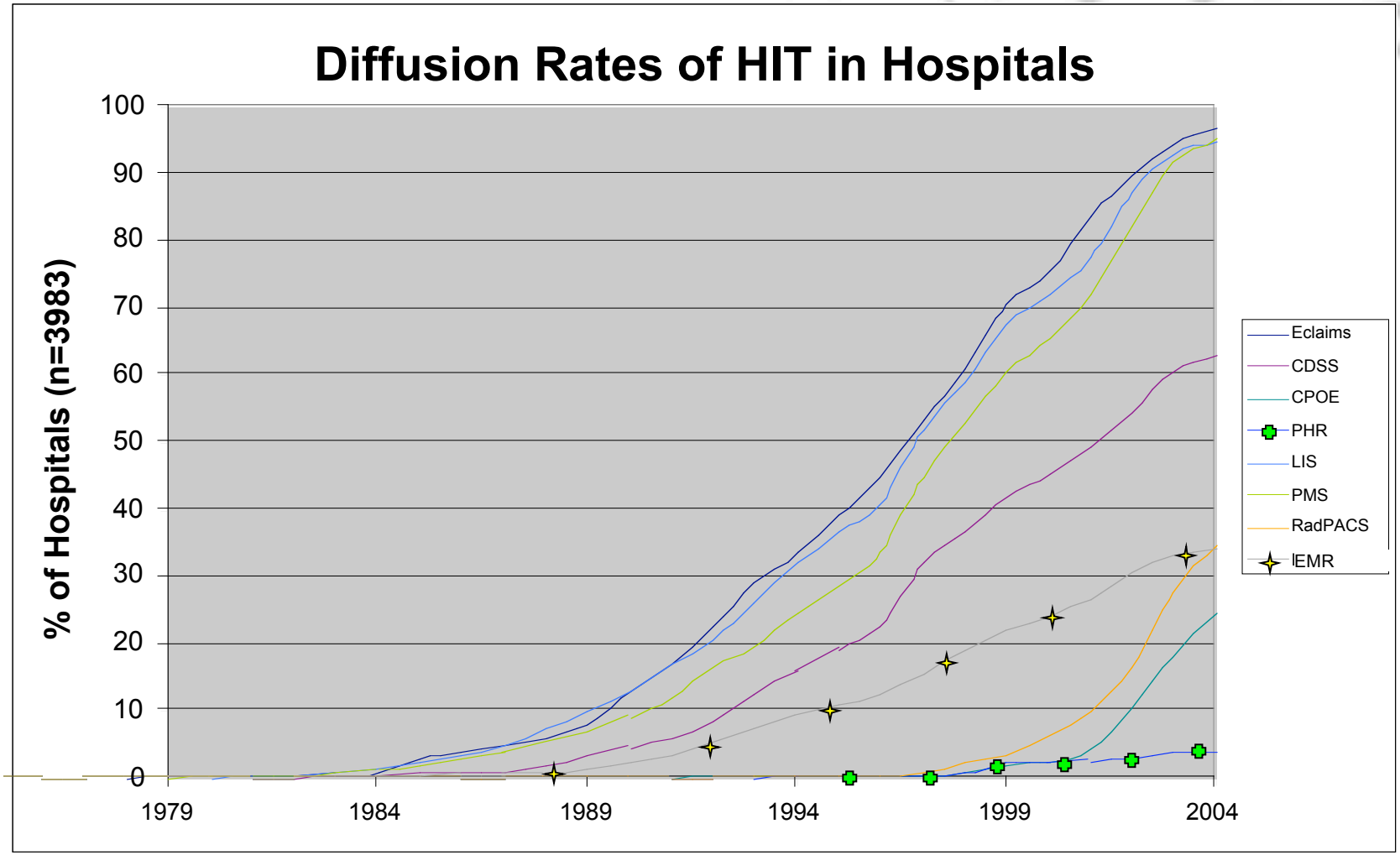
Findings: Trust in the PHR

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



Institution Level Adoption



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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.

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Steve Ross

University of Colorado Health Sciences Center

MARKLE FOUNDATION

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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

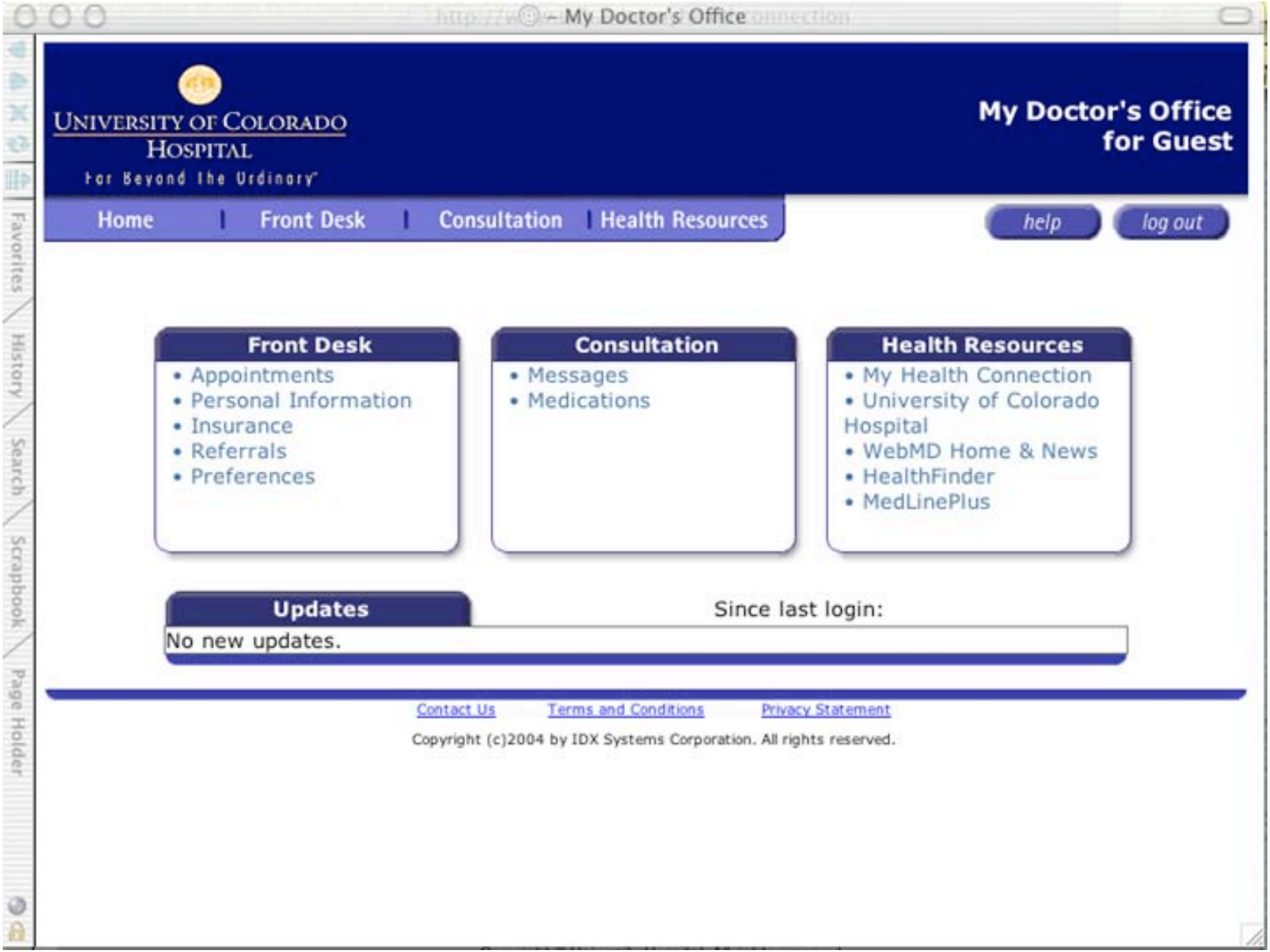
Organization

- 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
UNIVERSITY OF COLORADO HOSPITAL
For Beyond the Ordinary
My Doctor's Office for Guest
Home | Front Desk | Consultation | Health Resources
help
log out
Front Desk
• Appointments
• Personal Information
• Insurance
• Referrals
• Preferences
Consultation
• Messages
• Medications
Health Resources
• My Health Connection
• University of Colorado Hospital
• WebMD Home & News
• HealthFinder
• MedLinePlus
Updates
Since last login:
No new updates.
Contact Us
Terms and Conditions
Privacy Statement
Copyright (c)2004 by IDX Systems Corporation. All rights reserved.
Favorites
History
Search
Scrapbook
Page Holder

My Doctor's Office

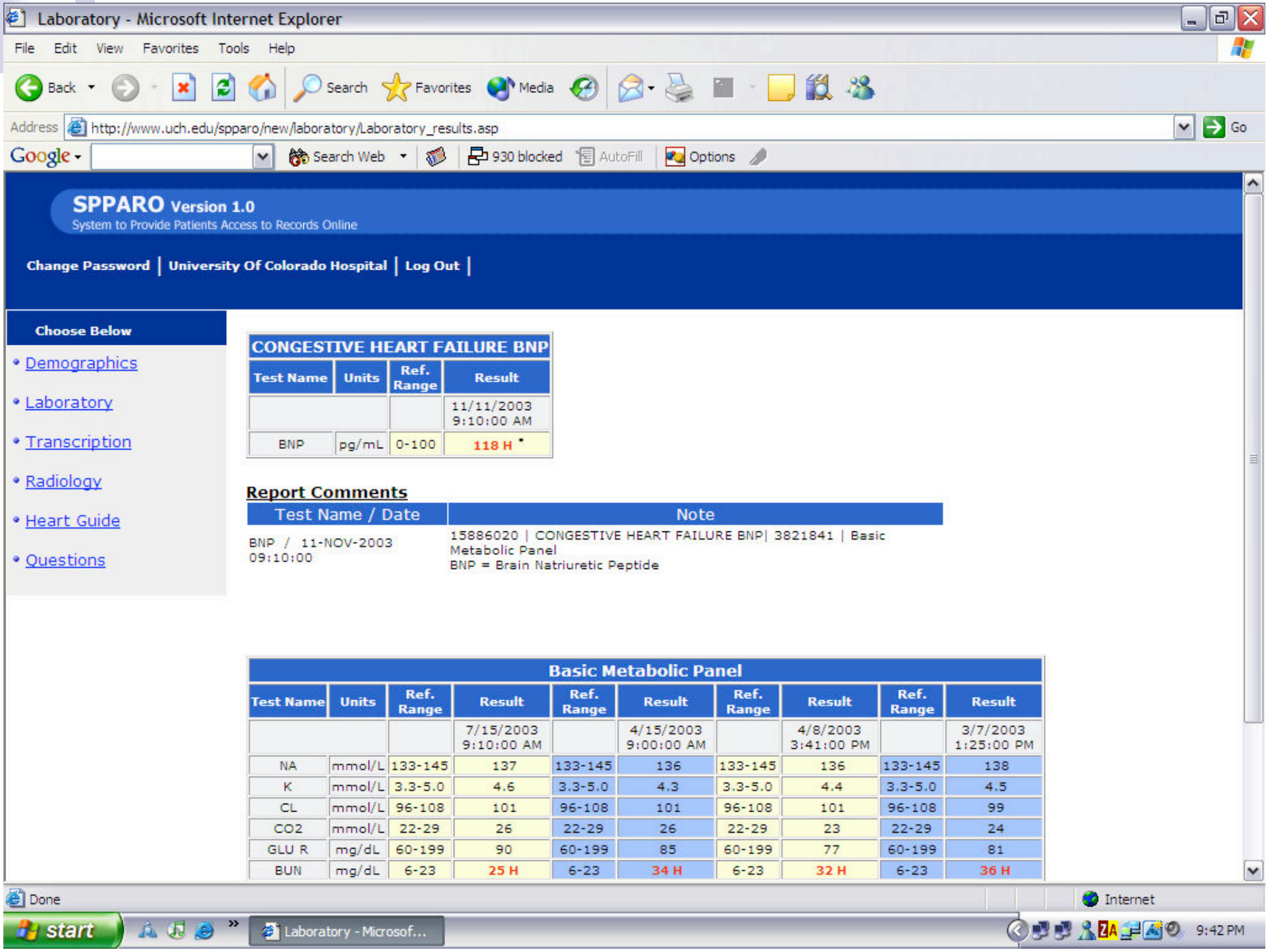
- An easy win where installed
  - Improved patient satisfaction
  - 1 additional message daily for 250 patients enrolled

Lin CT, Ross SE. JMIR (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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Google Search Web 930 blocked AutoFill Options
SPPARO Version 1.0
System to Provide Patients Access to Records Online
Change Password | University Of Colorado Hospital | Log Out |
Choose Below
Demographics
Laboratory
Transcription
Radiology
Heart Guide
Questions
CONGESTIVE HEART FAILURE BNP
Test Name | Units | Ref. Range | Result
11/11/2003 9:10:00 AM
BNP | pg/mL | 0-100 | 118 H
Report Comments
Test Name / Date | Note
BNP / 11-NOV-2003 09:10:00
15886020 | CONGESTIVE HEART FAILURE BNP| 3821841 | Basic Metabolic Panel
BNP = Brain Natriuretic Peptide
Basic Metabolic Panel
Test Name | Units | Ref. Range | Result | Ref. Range | Result | Ref. Range | Result | Ref. Range | Result
7/15/2003 9:10:00 AM | 4/15/2003 9:00:00 AM | 4/8/2003 3:41:00 PM | 3/7/2003 1:25:00 PM
NA | mmol/L | 133-145 | 137 | 133-145 | 136 | 133-145 | 136 | 133-145 | 138
K | mmol/L | 3.3-5.0 | 4.6 | 3.3-5.0 | 4.3 | 3.3-5.0 | 4.4 | 3.3-5.0 | 4.5
CL | mmol/L | 96-108 | 101 | 96-108 | 101 | 96-108 | 101 | 96-108 | 99
CO2 | mmol/L | 22-29 | 26 | 22-29 | 26 | 22-29 | 23 | 22-29 | 24
GLU R | mg/dL | 60-199 | 90 | 60-199 | 85 | 60-199 | 77 | 60-199 | 81
BUN | mg/dL | 6-23 | 25 H | 6-23 | 34 H | 6-23 | 32 H | 6-23 | 36 H
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Laboratory - Microsof...
9:42 PM

Transcription - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Search Favorites Media

Address http://www.uch.edu/spparo/new/transcription/Transcription_results.asp?MRN=

Google Search Web 930 blocked AutoFill Options

SPPARO Version 1.0
System to Provide Patients Access to Records Online

Change Password | University Of Colorado Hospital | Log Out |

Choose Below

- Demographics
- Laboratory
- Transcription
- Radiology
- Heart Guide
- Questions

Transcription Report Detail

Back to Report Listing
Printer Friendly Version

Referral Letters

THE SIGNED PAPER RECORD IS THE OFFICIAL FINAL MEDICAL RECORD. REVISIONS MAY BE MADE TO THE PAPER REPORT WHICH ARE NOT REFLECTED IN THIS ELECTRONIC REPORT. CLINICAL DECISIONS SHOULD BE MADE USING THE OFFICIAL FINAL MEDICAL RECORD REPORT.
UH No.:
Re:
MD

Dear Dr. L :
I had the pleasure of seeing your patient, , today in the Heart Failure Clinic at the University of Colorado Hospital. As you know, she is a pleasant -year-old female with a history of Adriamycin-induced cardiomyopathy. This is currently her four-month followup 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

Internet

start Transcription - Micros... 9:45 PM

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

Ross SE, Earnest MA, Lin CT. JAMIA (2004) 11:410-7, JMIR (2005) 7:e13

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

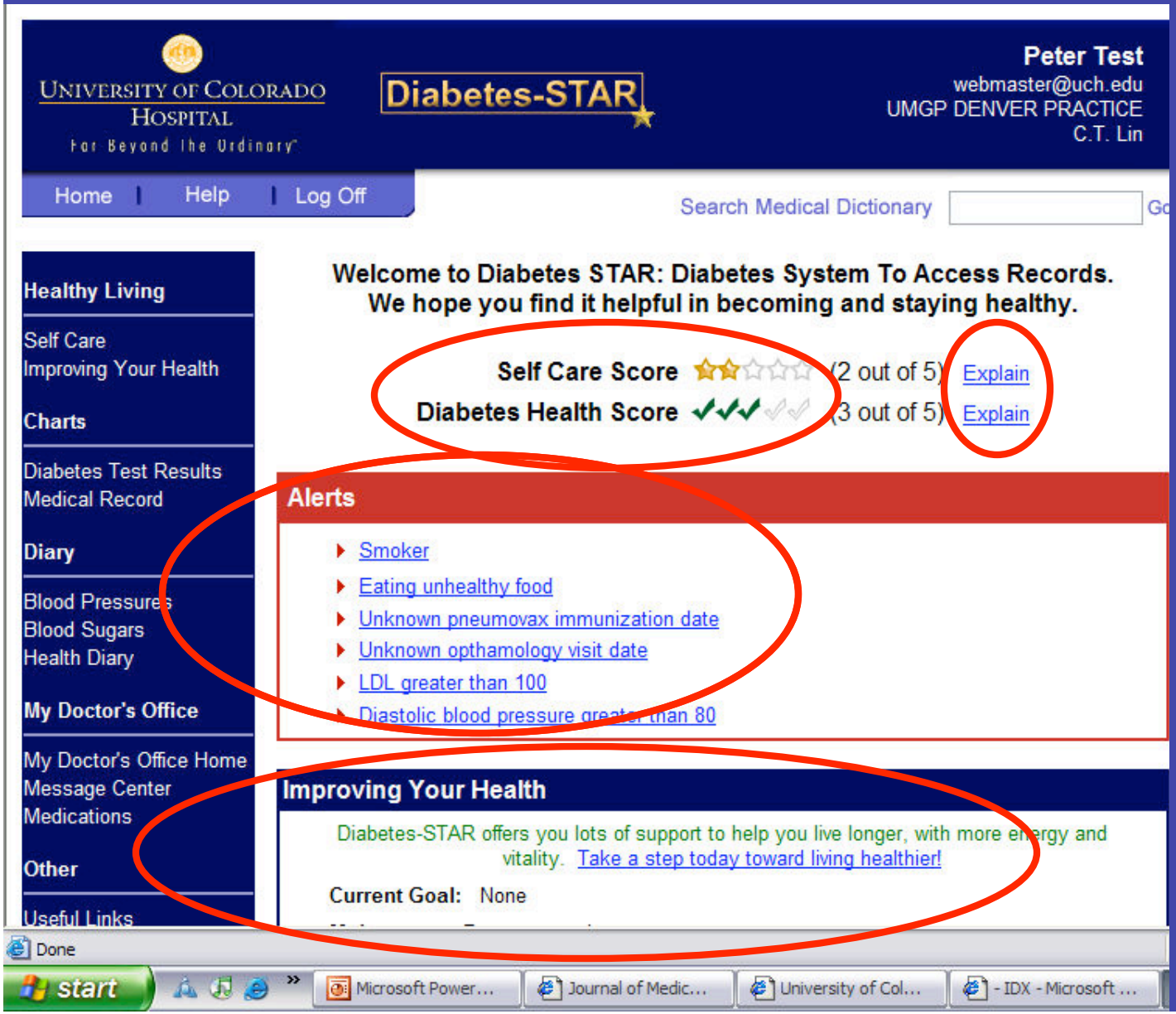
- OK with the concept…
- …but “show me the quality”

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…

Diabetes-STAR Interface



- 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

Diabetes-STAR Goal-Setting

- Choose category of goal (diet)
- Choose specific goal
- Identify obstacles
- Identify strategies to overcome obstacles
- Rate self-confidence
- Automatic follow-up

Diabetes-STAR Compared with "Diabetes Priority Program"

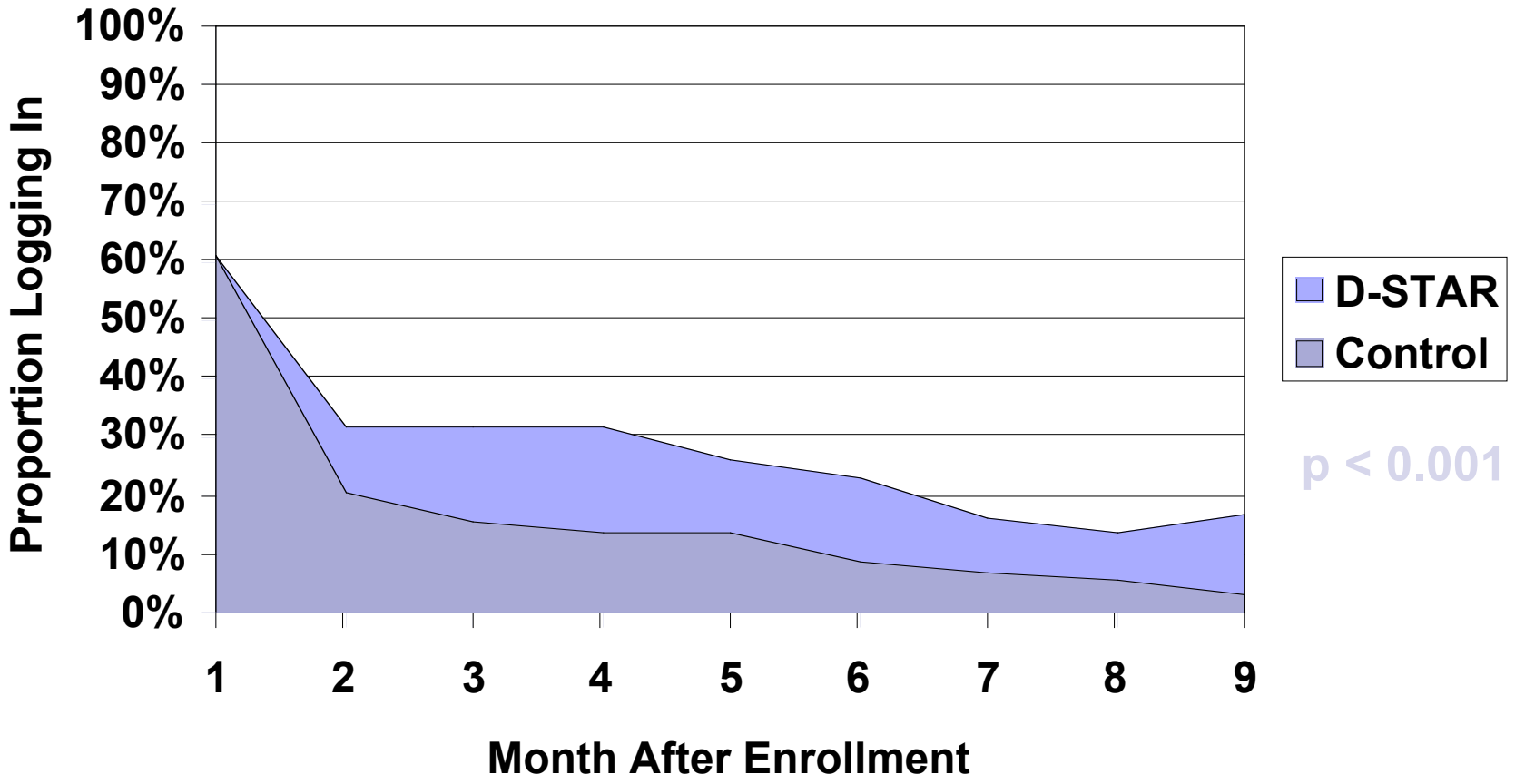
- Similar design
  - Guided goal setting to improve self-care
  - Shared with physician
- But:
  - Provides personalized clinical information
  - Not tied to clinic visit
  - Goal-setting recommended, not required
  - Follow up by e-mail (not staff)

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?

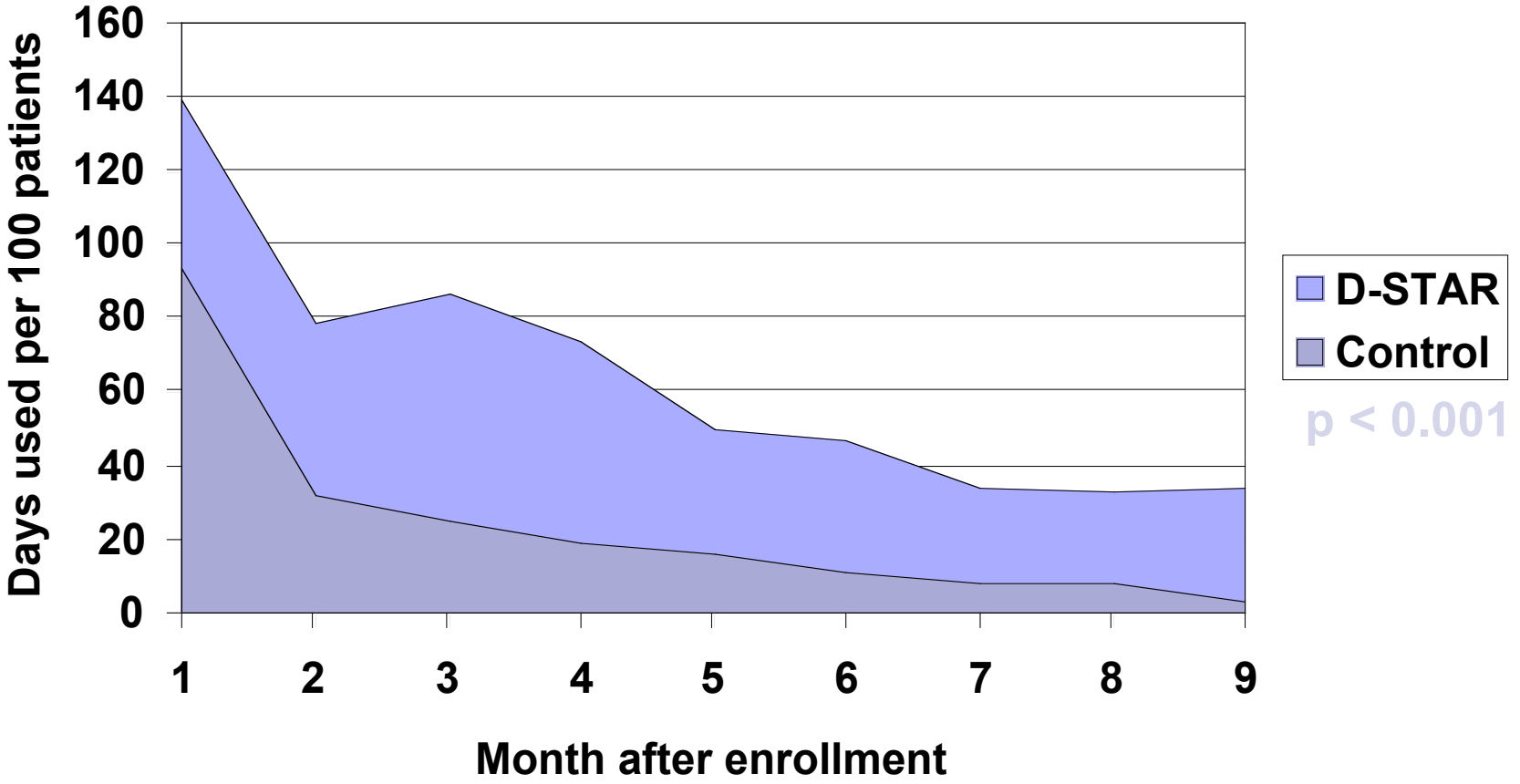
Funded by Robert Wood Johnson Foundation Health eTechnologies Initiative

Outcomes: Use
Interactive → Patient Retention



Outcomes: Use

Interactive → More Use (Higher "Dose")



Use of Diabetes-STAR Goal Setting

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

Diet	82 goals
Exercise	60 goals
Adherence to Medications / Monitoring	20 goals
Smoking	11 goals

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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