The Missing Link: Bridging the Patient-Provider Health Information Gap

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IOM Principles for 21st Century
What's the Gap?

"Patients should have unfettered access to their own medical information and to clinical knowledge."

Crossing the Quality Chasm, 2001

Possible solution: Personal Health Record (PHR) system

Outline

- What do *patients and consumers* want?
- What don't they want?
- What do they love?
- Creating *sustaining* value for consumers

Deriving a PHR Definition based on Patients' Perspectives

Wants - Fears + Loves = CSF for PHRs

What do patients want?

Patient Education Focus Groups
Methodology

- Independent market research firm
- Random selection of patients seen within 2 months in 5 clinics
- 24 patients in 2 focus groups
- One-way mirror

Tang, et al. JAMIA 1998; 5:563-570

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Patient Information Needs
Focus Group Results - Themes

- Patients *do* seek information about diagnosis and treatment plan (including alternatives)
  - Friends, relatives
  - Libraries, Internet, pharmacy inserts

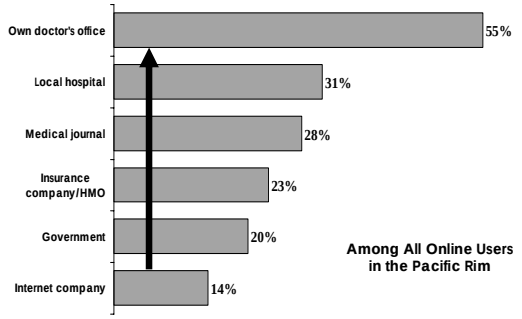
Tang, et al. JAMIA 1998; 5:563-570

Patient Information Needs
Focus Group Results – Themes II

- Patients prefer custom-tailored information
  - *Their* own data (lab results, findings)
  - Information on *their* problem and possible solutions
- Need for their physician endorsement
  - Physician endorse material as relevant to them
  - Physician should briefly review with them

Tang, et. al., JAMIA 1998; 5:563-570

Preferred Source for eHealth Information



Cyberdialogue, 2000

Patient Information Needs
Focus Group Results – Themes III

- Timing should be when the *questions* arise
  - Not in the exam room!
  - At home, with friends and family

Tang, et. al., JAMIA 1998; 5:563-570

Desired Online Services
Harris Interactive Poll, 2006

- **"Which of the following technologies would you like to have access to when seeking care from a doctor or hospital?"**
  - 77% Reminders about being due for visit or care
  - 75% Make appointments online
  - 74% Email directly with my doctor
  - 67% Receive test results
  - 64% Access my electronic medical record
  - 57% Send home monitoring results to my doctor

Online survey of 2,624 consumers

PHR Attributes
Wants, Fears, Loves

Wants
- Information about them…
- Related to their visits…
- Available 24x7…
- Reviewed and interpreted by their physicians…
- Linked to endorsed resources for further study…
- Accompanied by tools for managing chronic diseases…

Wants
- Secure communication with doctors
- Transfer information to doctors

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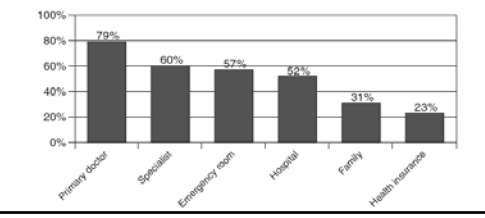
Markle Online Survey
June, 2003

- 91% Very concerned about privacy and security

Based on responses to the question, "If you kept your medical records online, how comfortable would you feel having the following people access your records *only after you have given your explicit permission.*"



Markle Focus Groups
Concerns

- From six focus groups (35 consumers):
  - "People trust their doctor to host, manage, and access their PHR. People do not want their PHR maintained by their insurance company, their employer or the government…"

Connecting for Health, 2003

PHR Attributes
Wants, Fears, Loves

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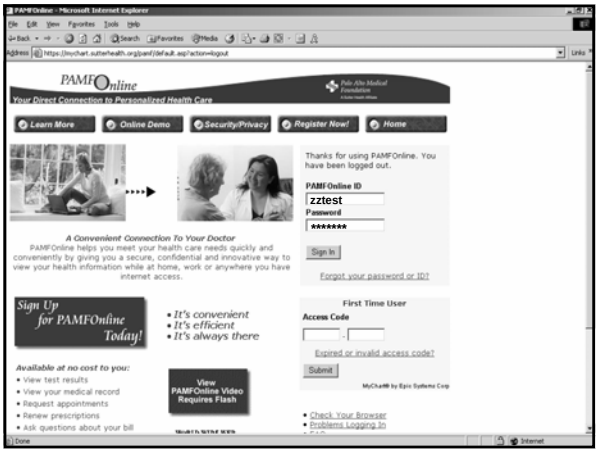
Wants
- Secure communication with doctors
- Transfer information to doctors
- Hosted by their doctors…

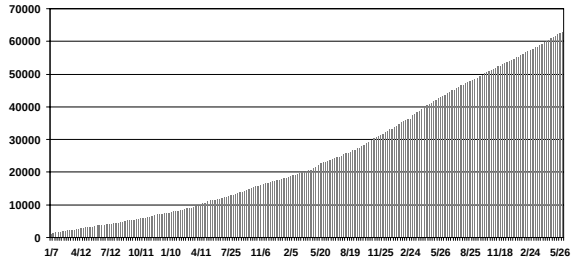
Fears
- Privacy and security
- Not shared or hosted with employer or insurer

PHR User Experience – Loves

"Try it; you'll like it."



PAMFOnline
Enrollment



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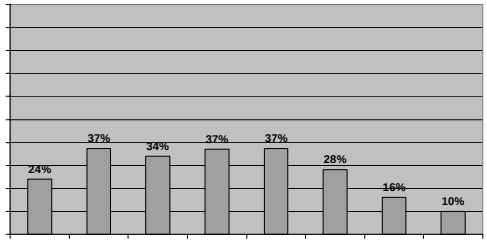
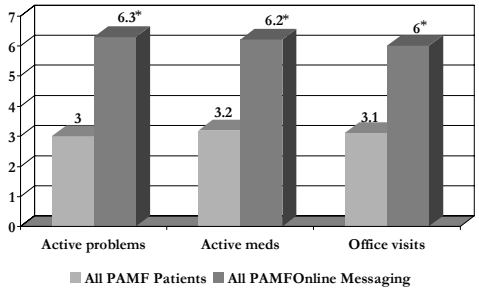
PAMFOnline Patients
Adoption Rate by Age



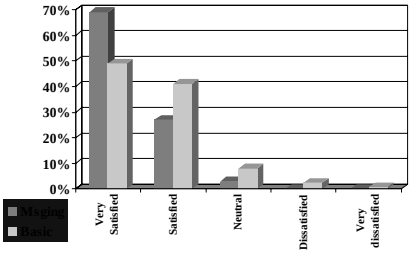
Patient Profile
Baseline



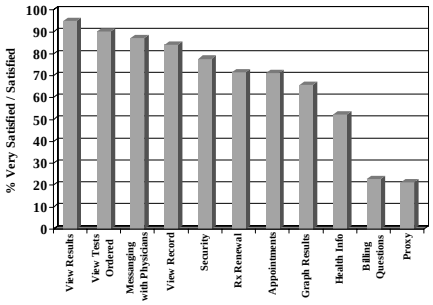
*All differences p<0.0001 by t-test

PAMFOnline 2006 Survey
Overall Satisfaction

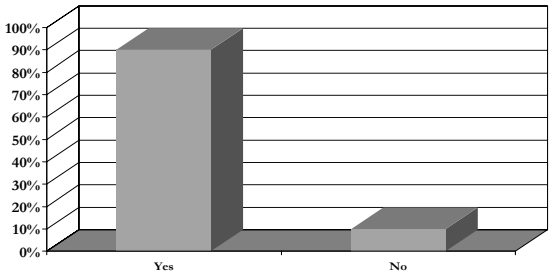
96% of messaging subscribers are very satisfied/satisfied
90% of basic subscribers are very satisfied/satisfied



PAMFOnline 2006 Survey Results
PAMFOnline Messaging Patients



2003 Physician PAMFOnline Survey
"Are you satisfied with PAMFOnline?"



Physicians with 100+ PAMFOnline patients

PAMFOnline Enrollment
By Physician

Active >= 18yrs	APL >=18yrs	% Active >= 18yrs
1417	2293	62%
1104	1926	57%
1093	1519	72%
1035	1599	65%
997	1533	65%
995	2006	50%
911	2558	36%
850	1787	48%
833	1762	47%
828	1332	62%
756	1273	59%
755	1503	50%
743	1888	39%
737	1787	41%
734	1523	48%

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Employer Adoption
Example of Sustaining Value

- PAMF-Cisco pilot of PHR for employees
  - Cisco collaborators: Jeff Rideout, MD, Sharon Gibson, IBSG
- Employer sponsor of online physician messaging
- Employee survey results
  - 87% spent less time away from work (1-10+ hrs)
  - 72% saved 1 or more office visits
  - 61% would prefer online interaction as the primary communication method
- ROI 4.5 : 1 (primarily productivity savings)

Differentiating Wants from Needs
Choosing the "Right" Use Model

- What consumers (think they) "would like"
- What _____ "wants consumers to like"
- What consumers "love to use" [fills a need]

- Which perspective will lead to sustaining value and a supportable business model?

Sustaining Value Proposition
Critical Attributes

- Comprehensive patient information
  - Integrated delivery system
  - Interoperable EHR/PHR
- Connections with health care team
- Trust
  - Privacy
  - Clinical competence and accountability
- Physician adoption
  - Efficient workflow
    - Integrated with EHR
    - Integrated with communication workflow
  - Reimbursable professional activity

Motivating Adoption
Who, then What

Who

- Physicians
  - EHR adoption
  - Reimbursable online care
- Patients
  - Participating physicians
  - Awareness and understanding (induce consumers to "try it")
    - Understand value
    - Trust privacy protection

What

- HHS Leadership
  - Incentives (e.g., P4P)
  - Standards
  - Certification
- Ensure privacy protection
- DTC education by trusted sources
  - PSAs
  - Professional societies
  - Consumer associations

AMIA gotEHR?
AMIA Campaign to Accelerate Adoption

- Goal: Explore consumer approach to accelerating adoption of EHRs and PHRs
- AHRQ-funded organizational workshops
  - AMIA, AHRQ, ONC, CMS
  - Aug, 2004 Workshop on social marketing
    - Kathy Crosby (Ad Council), Bill Smith (Academy for Educational Development), David Lansky, Janet Dubow (AARP)
    - Need "experience of care" message; "petting zoo"
    - Does problem/solution impact a large population?
    - Actionable?

AMIA gotEHR?
2nd Workshop

- October, 2004
  - Strategic framework around 3 P's
    - Public / consumers
      - Raise awareness about the vision
      - Target a market segment e.g., Medicare population
    - Providers
      - Promote adoption of EHRs
      - Promote PHRs to enhance patient relationships
    - Policy Makers
      - Educate about barriers, reimbursement mechanisms
      - Consider legislative stimulus

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AMIA gotEHR? Initiative

Status

- Public / consumer
  - PHR principles (with AHIMA)
  - AMIA partnership with PBS to develop documentary including EHRs: *Healthy Bodies*
- Providers
  - 10x10 program (train 10,000 healthcare professionals by 2010)
- Policy makers
  - Working with Carper's staff on PHRs for federal employees

Summary

PHRs Bridge the Information Gap

- PHRs bridge the information and knowledge gap between consumers and their health care team
- Critical success factors
  - Physician adoption of EHRs
  - PHRs integrated or interoperable with EHRs
  - Online connectivity with physicians, health care team, and caregivers
  - Privacy protection
  - Educated consumer on value and use of PHRs

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