

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

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IOM Principles for 21st Century
Desired Consequences

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

Crossing the Quality Chasm, 2001

Question: Defining PHRs?

Outline

- What do *patients* want?
- What don't they want?
- What do they love?

Deriving a PHR Definition
based on Patients' Perspectives

Wants - Fears + Loves = Attributes of a PHR

What do patients want?

When all else fails...

... ask the patients!



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

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

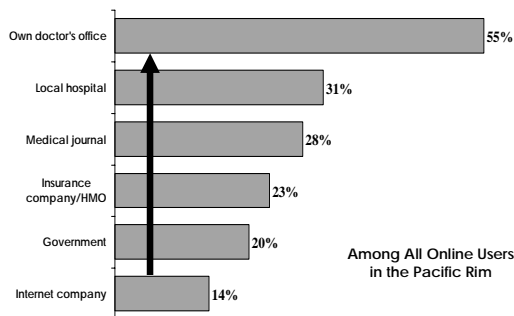
Patient Information Needs

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

Markle Survey *Connecting for Health, 2003*

- Would use functions in PHR:
 - 75% Email my doctor
 - 69% Track immunizations
 - 69% Note mistakes in medical record
 - 65% Transfer information to specialists
 - 63% Access test results
 - 62% Track medications

Online survey of 1,246 consumers

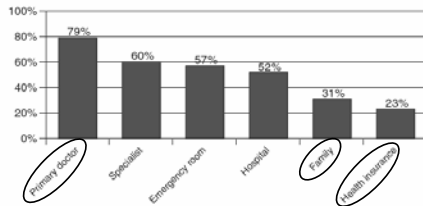
PHR Attributes *Wants, Fears, Loves*

- | | |
|--|---|
| <p style="text-align: center;">Wants</p> <ul style="list-style-type: none"> ➤ 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... | <p style="text-align: center;">Wants</p> <ul style="list-style-type: none"> ➤ Secure communication with doctors ➤ Transfer information to doctors |
|--|---|

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*

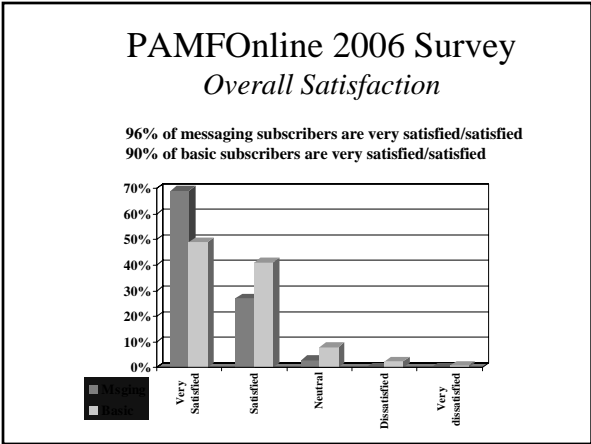
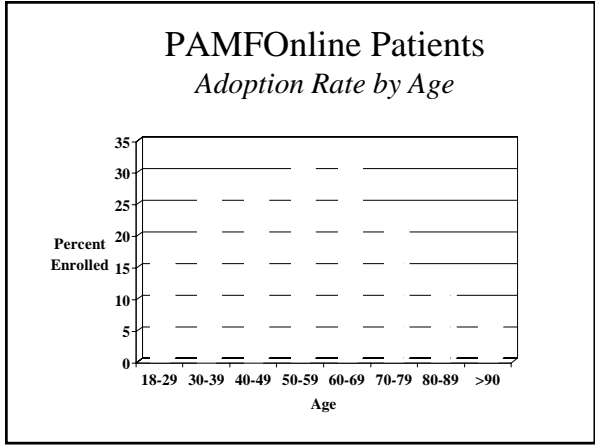
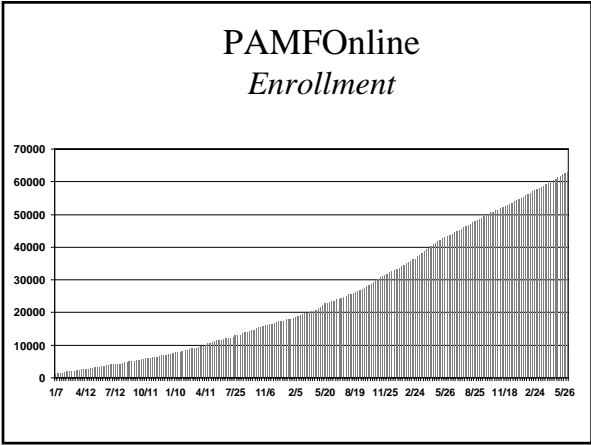
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|--|---|

PHR User Experience – Loves

"Try it; you'll like it."

PAMFOnline Demo

A PHR System



- ### PHR Attributes Loves
- Tools for managing health conditions (e.g., graphs, health information resources)
 - Online access to their physician
 - Knowledge and encouragement to take active role in own health

Deriving a PHR Definition

From Wants, Fears, and Loves

- Immediate, anytime, anywhere access to information from their medical record that is secure and privacy protected
- ...linked to interpretations, advice, and endorsed material from their physician
- ...providing secure online communication with their physicians
- ...and tools for managing their health condition
- ...with convenient self-services
- ...hosted by a trusted source (e.g., their doctor)

Policy Implications

For PHR Adoption

- National leadership needed
 - Educate public on benefits (and potential risks)
 - Uniform protection for personal health information
 - Reimburse online care
- National data standards for PHR consistent with EHR standards
- Research and evaluation

Summary

PHRs Bridge a Missing Link

- Personal health records can bridge the information gap between consumers and their health care team...
- If we meet their expectations for
 - Information transparency and completeness
 - Tools for managing health
 - Online connection with physicians
 - Privacy and security