

Shared Decisions through Transparency

Personal Health Record Systems

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Outline

- Driving towards *patient*-centered care
- Patients' need for information
- Tools for patients
- Using information transparency to transform health care delivery

IOM Principles for 21st Century *Transparency*

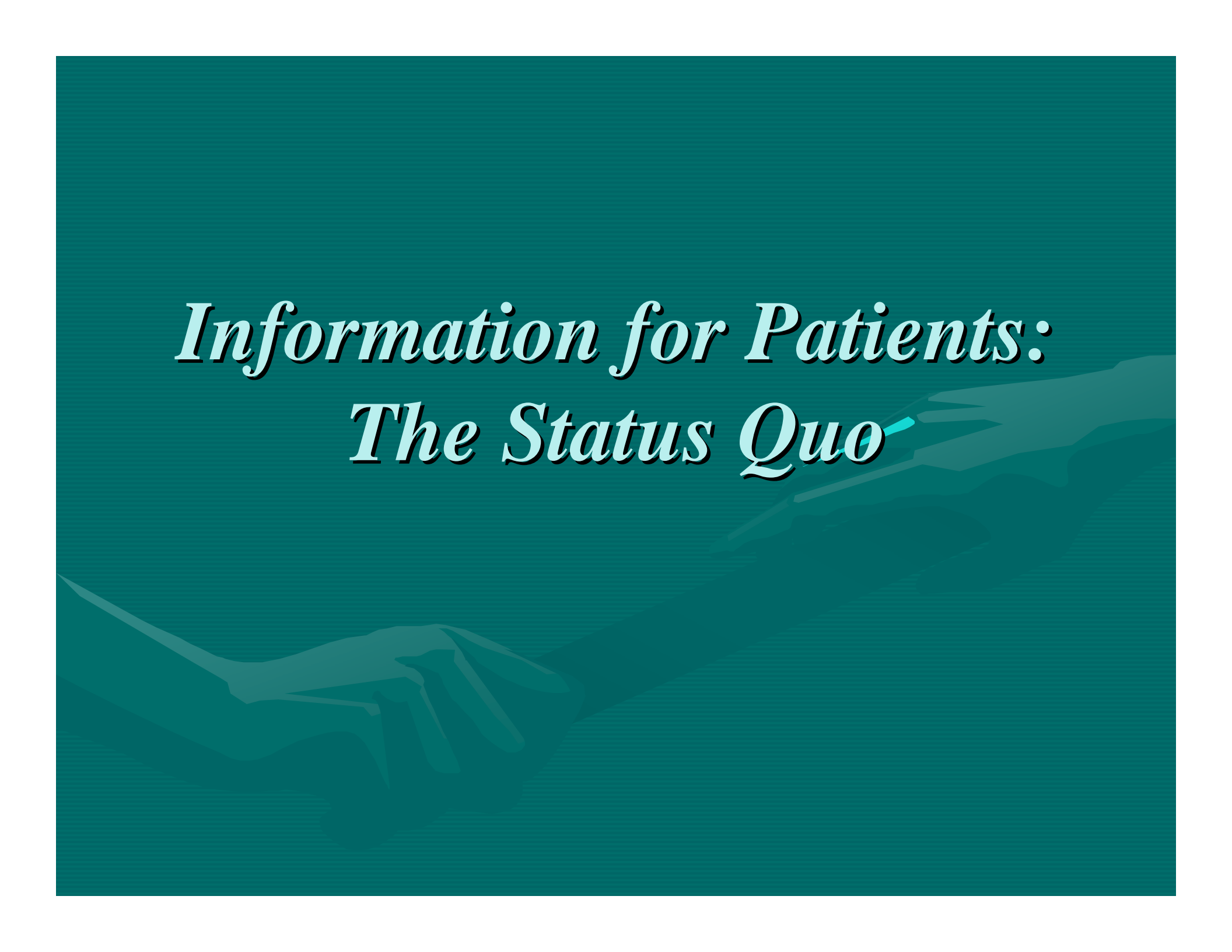
“Patients should have unfettered access to their own medical information and to clinical knowledge.”

Crossing the Quality Chasm, 2001

Shared Decision Making

Engaging Patients

- Shared Decision Making – involving patients as active participants in decision making by providing:
 - Data
 - Knowledge
 - Tools



*Information for Patients:
The Status Quo*

Ethnography at Northwestern

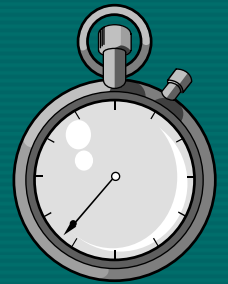
The Status Quo



Time Allocation Methodology

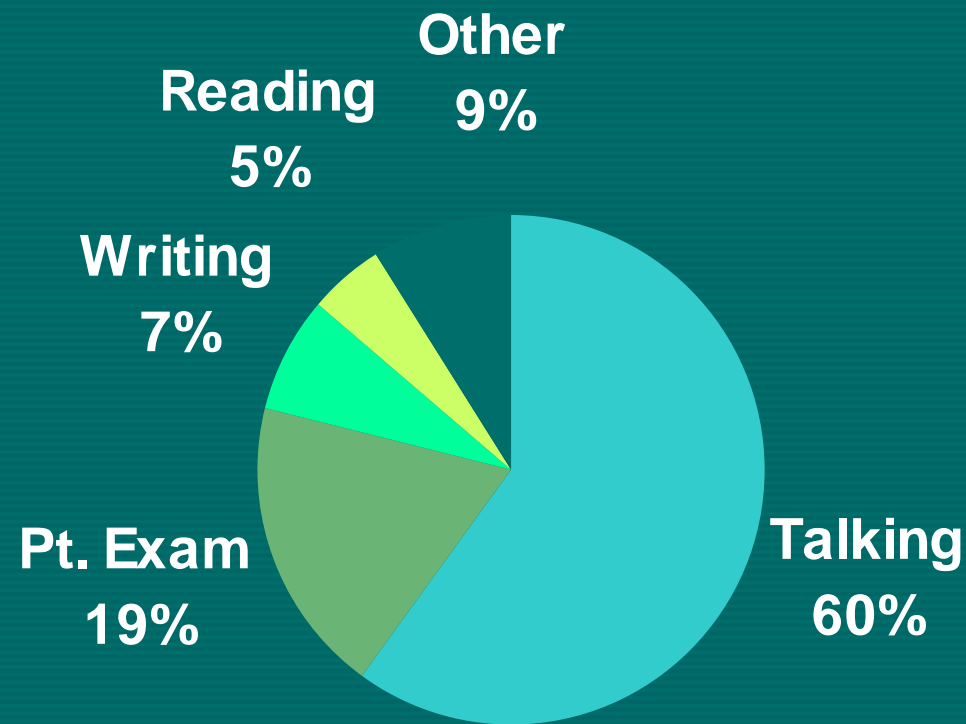
In Office

- 38 clinicians shadowed for 2 hours
- Activities recorded at 1 minute intervals
- 159 encounters observed
- 4541 observed minutes



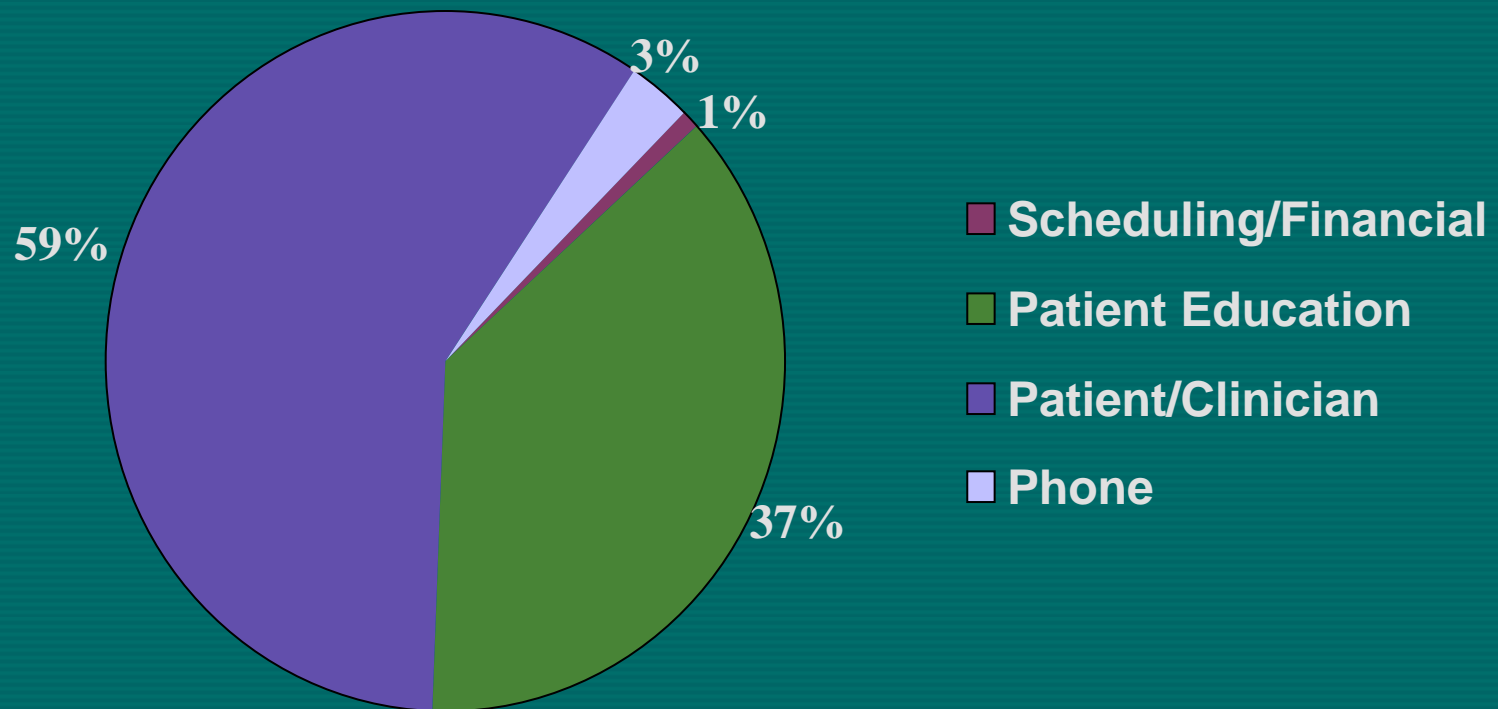
Information Activities During Encounter

Average Distribution Across Sites



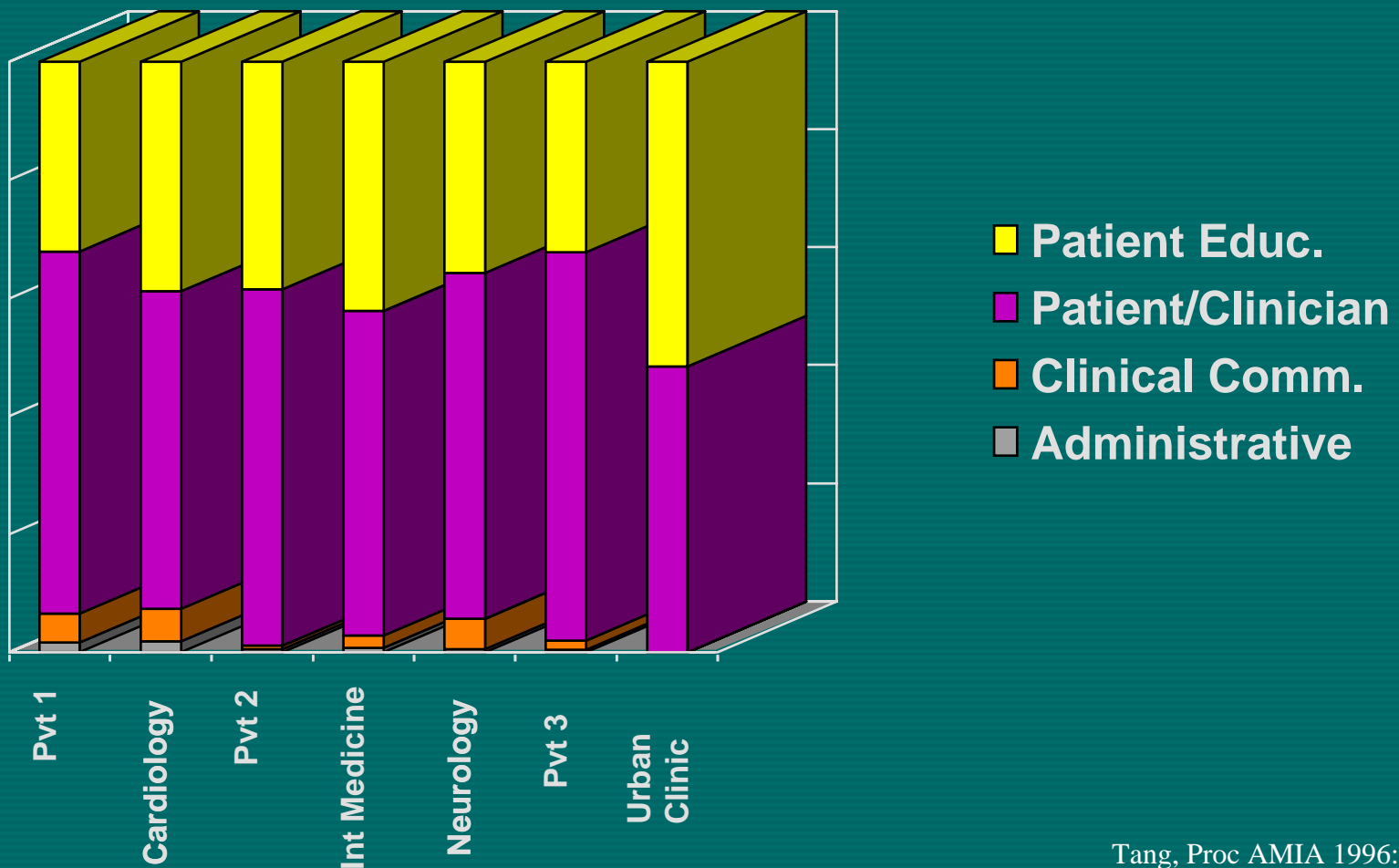
Sub-Categories of Talking

Average Distribution Across All Sites



Observed Talking Activities

Subcategories, All Sites



Outcome of Patient Education?

Understanding of Diagnoses

- 57 Mayo internists; 458 visits, 2.7 prob/visit
- Post-visit questionnaires to MD and patient
 - Major health problems and other problems
- Patients failed to report 68% of problems
- Missed 54% of “most important health problem” according to MDs

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

Patient Information Needs

Focus Group Results - Themes

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

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

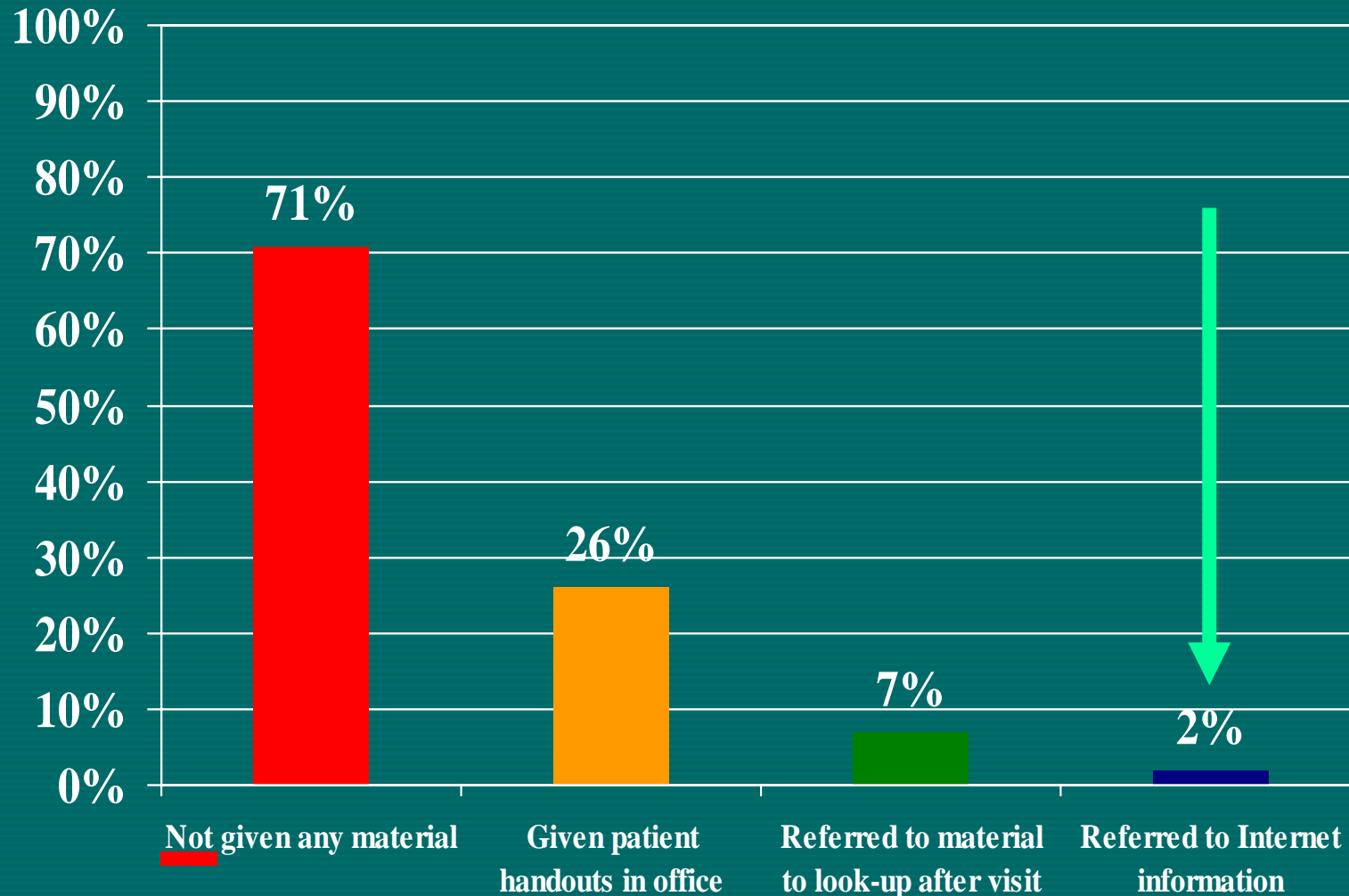
Patient Information Needs

Focus Group Results – Themes III

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

Assumption?

Information Given at Last Office Visit



*Percentages do not add up to 100 percent due to total mentions

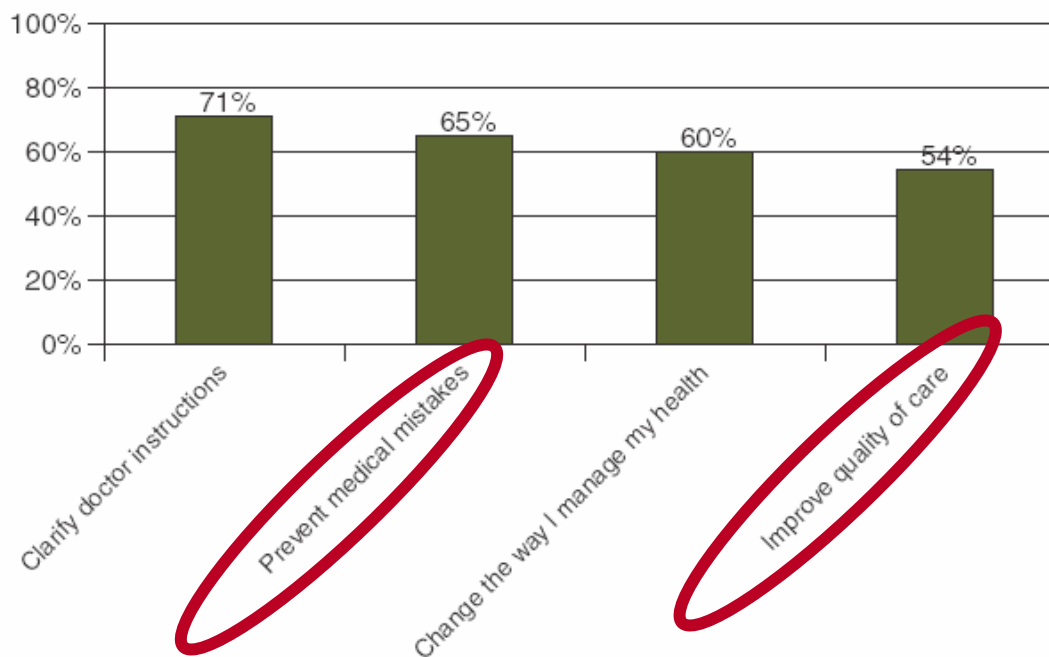
VHA, 1999 *Clinical Office Practice*

Patients' Self Defense

Personal Health Record Systems

40% of survey respondents keep medical records at home

Based on responses to the question, "I think that having my health information online would..."



Markle Foundation, Connecting for Health survey
June, 2003

Change the Assumption

LOS ALTOS INTERNAL MED
PALO ALTO MEDICAL FOUNDATION

Summary of Your Visit Today

Patient
ZZTEST, LIBBY MR # 2566680 DOB 12/03/1945 F

Date Time Clinician Seen Today Clinic/Dept
09/27/01 8:36 AM Paul C. Tang MD SH/LAINT

During your visit today, we recorded the following information about you:

<u>Temperature</u>	<u>Pulse</u>	<u>Respiration</u>	<u>Blood pressure</u>
102 degrees	88/minute	18/minute	130/80

Prescriptions as of 09/27/2001	Disp	Refills	Start	End
LISINOPRIL TABS 10 MG OR Class: Historical Sig: Take 1 by mouth each day.	30	6	9/27/2001	
ATENOLOL TABS 50 MG OR Class: Historical Sig: Take 1 tab daily	30	6	9/27/2001	
ASPIRIN TABS 81 MG OR Class: Historical Sig: Take 1 tab daily	30	6	9/27/2001	
LIPITOR TABS 10 MG OR Class: Historical Sig: Take 1 tab daily	30	6	9/27/2001	

Return for Care: If symptoms worsen or fail to improve

Patient Instructions:

1. Please take the antibiotics until finished.
2. Please let me know how you are doing in a few days via PAMFOnline (www.pamfonline.org).
3. Call if symptoms worsen or persist

Pneumonia

Home treatment is a very important part of treatment for pneumonia. If you have pneumonia, follow your doctor's advice. Watch carefully for complications of pneumonia.

People with impaired immune systems are at high risk for complications from pneumonia. If you have an impaired immune system:

If you can, avoid contact with people who have respiratory tract infections,

Consequences?

Comments from a Focus Group

- “It **shows** that the doctors are **more organized**, more professional.”
- “It **shows** they are **paying more attention** to you.”
- “I **feel** like there is **more care** involved.”
- “I **feel** like they are professional, well organized. And I would **more likely stay** with them rather than going to a place that didn’t do something like this.”

Institute of Medicine

Providing Continuous Care

“Patients should **receive care whenever they need it** and in many forms, **not just face-to-face** visits.

... the health care system **should be responsive at all times** (24 hours a day, every day) and that access to care should be provided **over the Internet, by telephone, and by other means** in addition to face-to-face visits.”

Crossing the Quality Chasm, 2001

Delivering Continuous Care – Online

*Engaging Patients as Active
Participants*

- Learn More
- Online Demo
- Security/Privacy
- Register Now!
- Home



A Convenient Connection To Your Doctor

PAMFOnline helps you meet your health care needs quickly and conveniently by giving you a secure, confidential and innovative way to view your health information while at home, work or anywhere you have internet access.

*Sign Up
 for PAMFOnline
 Today!*

- *It's convenient*
- *It's efficient*
- *It's always there*

Available at no cost to you:

- View test results
- View your medical record
- Request appointments
- Renew prescriptions
- Ask questions about your bill

View
 PAMFOnline Video
 Requires Flash

WORLD WIDE WEB

Thanks for using PAMFOnline. You have been logged out.

PAMFOnline ID

Password

Sign In

[Forgot your password or ID?](#)

First Time User

Access Code
 -

[Expired or invalid access code?](#)

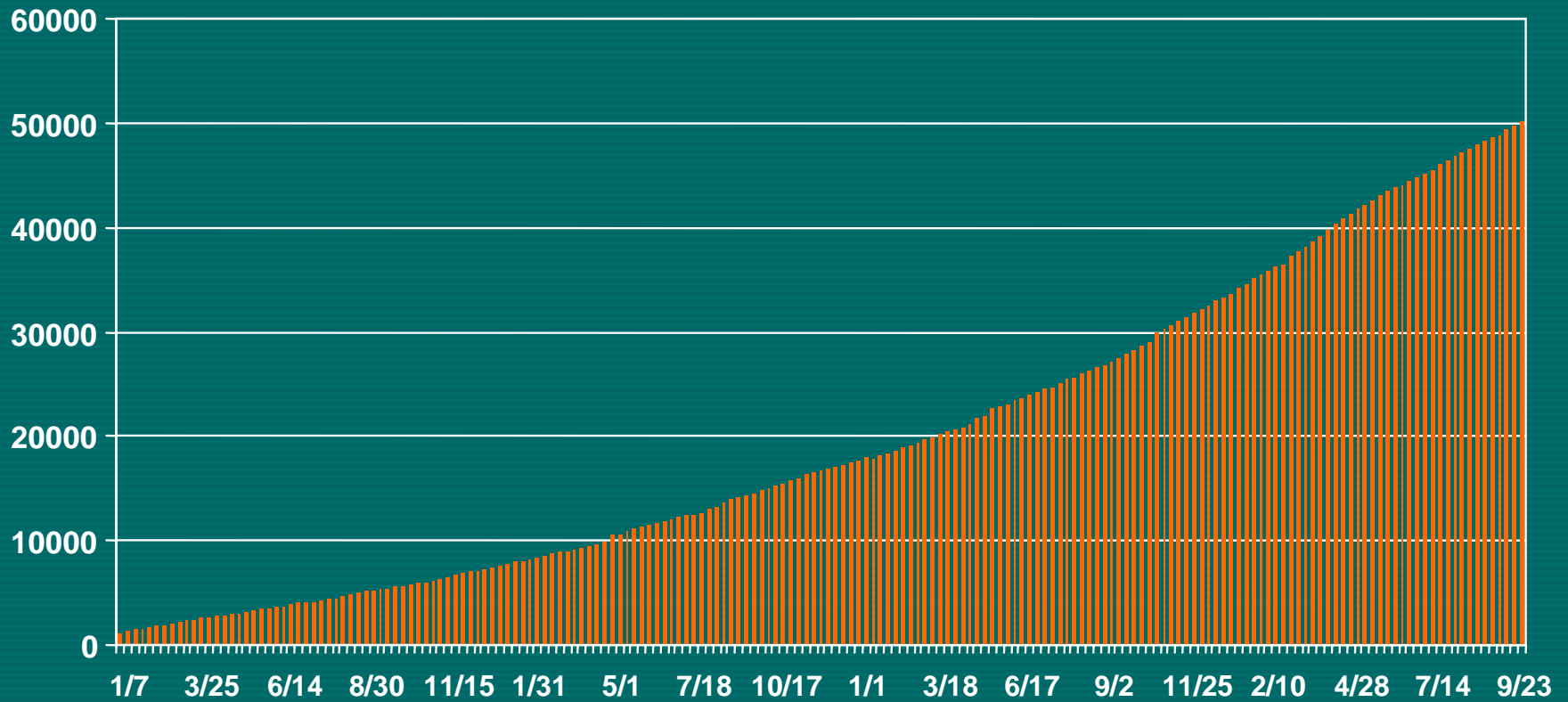
Submit

MyChart® by Epic Systems Corp

- [Check Your Browser](#)
- [Problems Logging In](#)

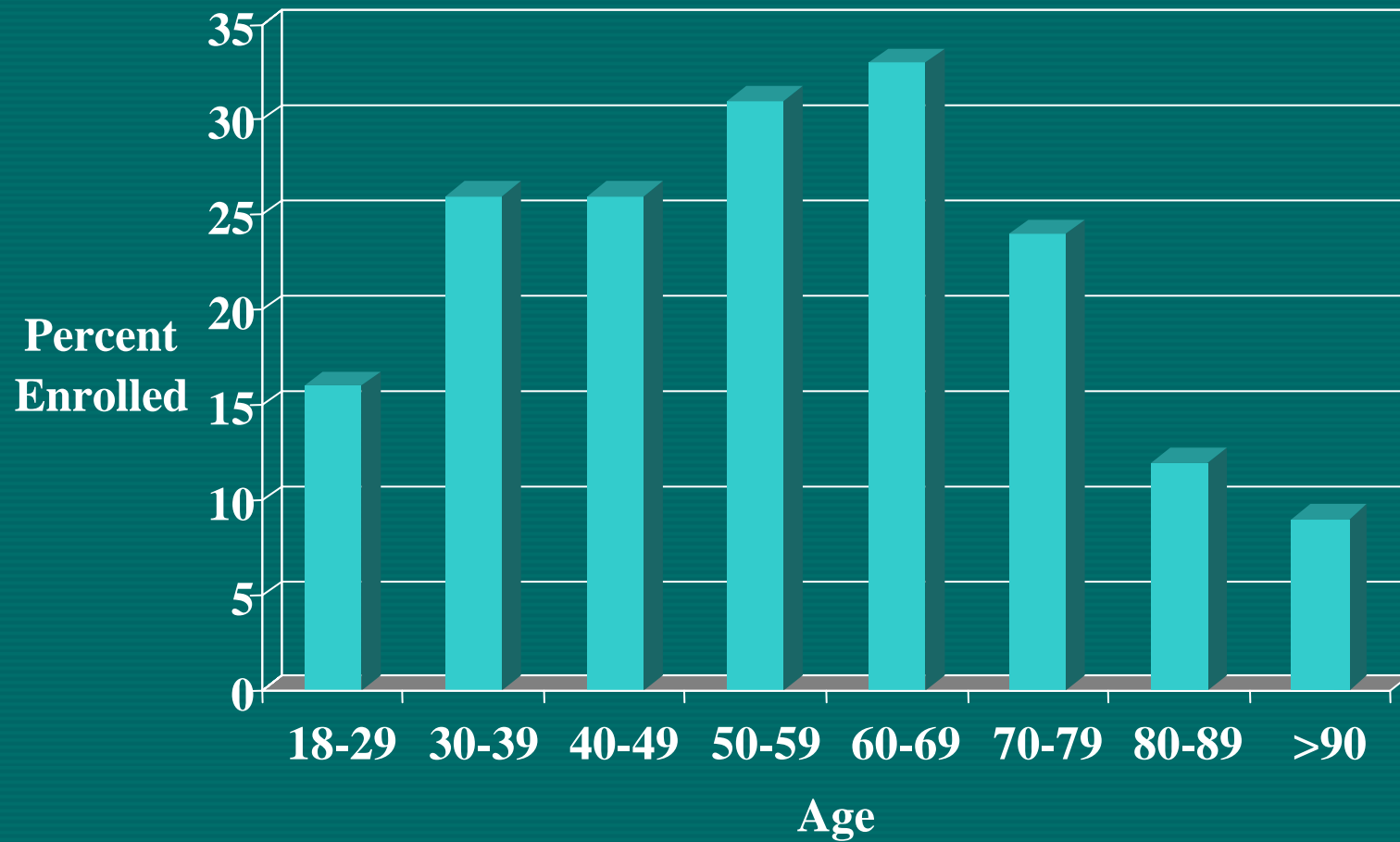
PAMFOnline

Enrollment



PAMFOnline Patients

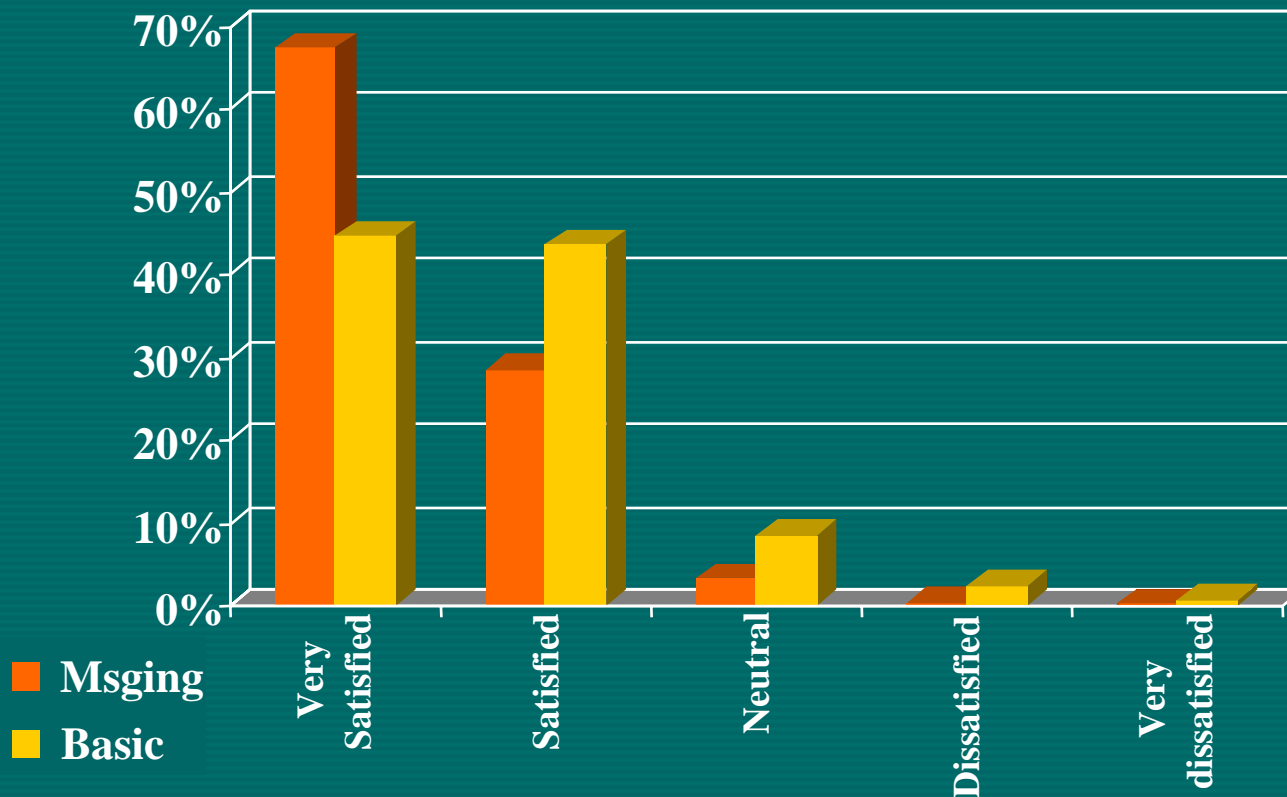
Adoption Rate by Age



PAMFOnline 2005 Survey

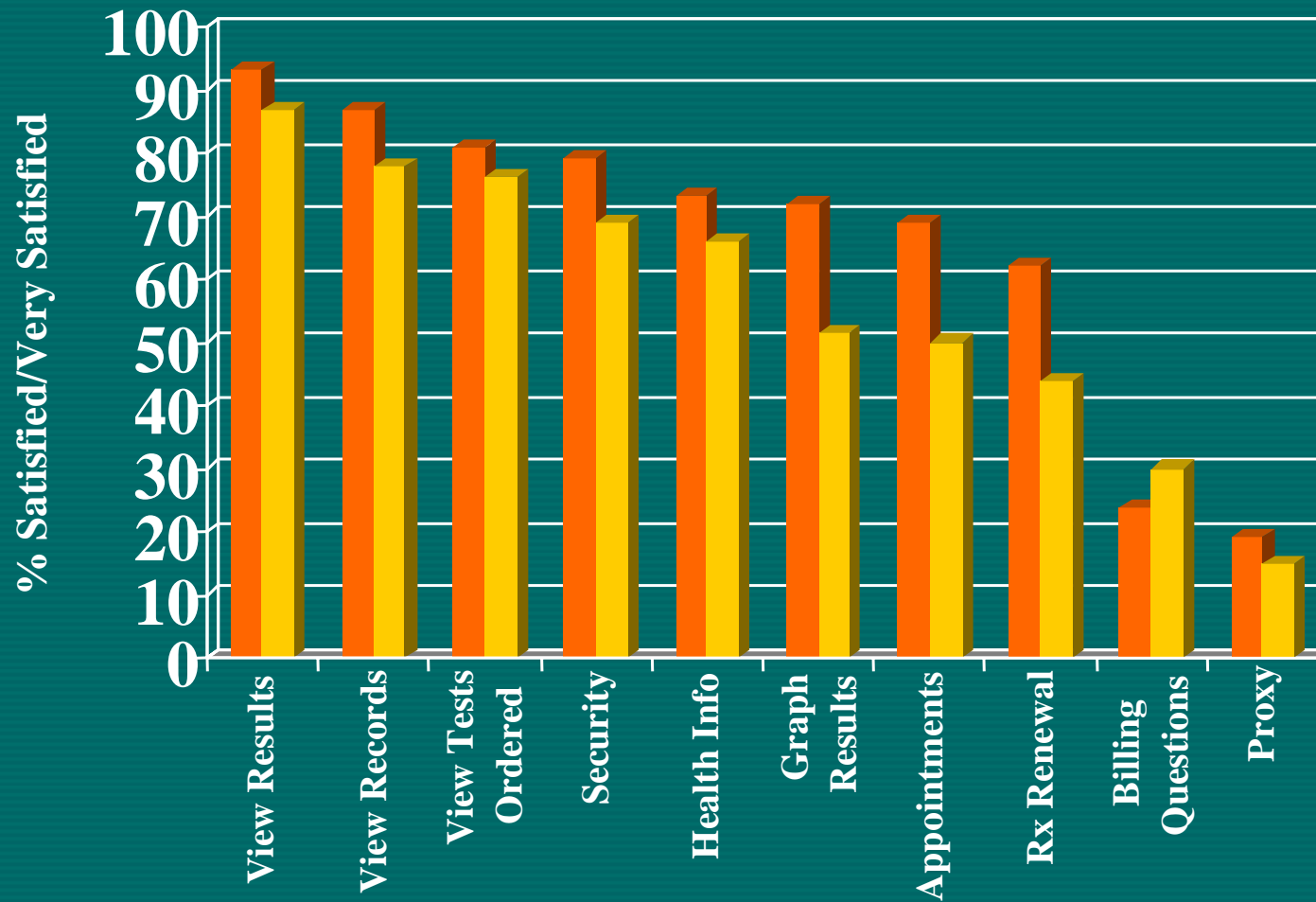
Overall Satisfaction

96% of messaging subscribers are very satisfied/satisfied
88% of basic subscribers are very satisfied/satisfied



PAMFOnline 2005 Survey

Features Satisfaction



PAMF Online Survey

What changes did you make?

“Seeing graph of test results against time helped me stick to my diet.”

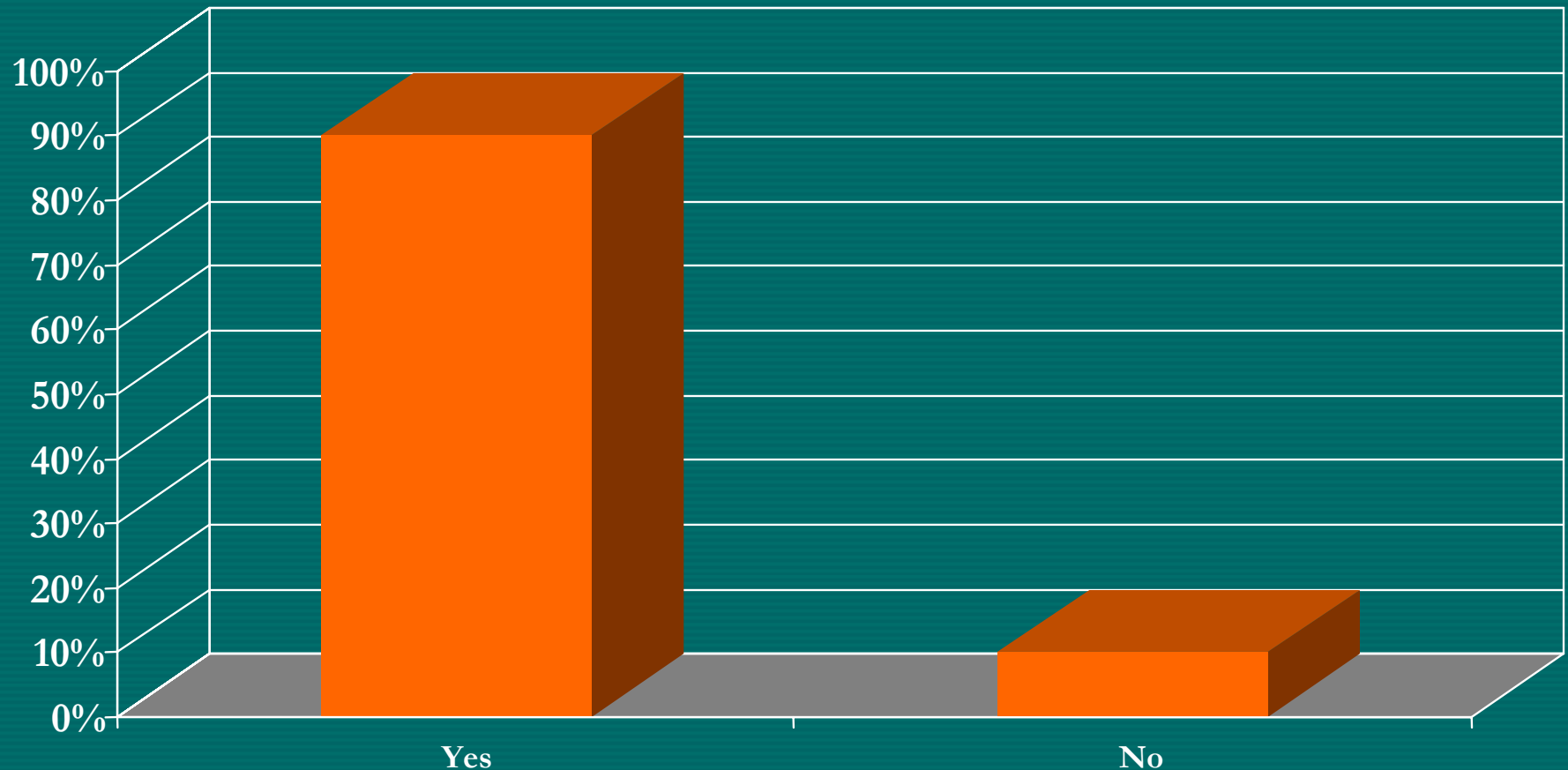
“I feel a stronger relationship with my doctor and more accountability to his advice as a result of having online access to test results and email communication with my physician.”

“Lost weight and started exercising more”

“I always check my lab results... I was able to tailor a diet specifically to adjust my blood lipids... I saw the improved test results 2 weeks ago. Not only was I hugely successful (Triglycerides from 333 to 85) but I lost 20 lbs, too. Having the lab results online was tremendously helpful.”

Physician PAMFOnline Survey

“Are you satisfied with PAMFOnline?”



Physicians with 100+ PAMFOnline patients

Patient Satisfaction Survey

Transforming Healthcare Relationships

“I can't tell you how great this system is. It **changes totally the dynamic of medical care** as far as I'm concerned.”

“Since I am **in my 80s...** the most **important** [factor] is the **savings in physical travel** to the clinic I am getting **a bit handicapped physically,** but as yet **not mentally.**”

“I can be current on test results and **be a team member in my own care...**”

“It's not just a website. **It's a good deed.**”

Summary

Achieving a New Standard of Care

- Driving towards *patient*-centered care
- Shared decision making requires:
 - Data
 - Knowledge
 - Tools
- Personal health record systems are tools for transforming care