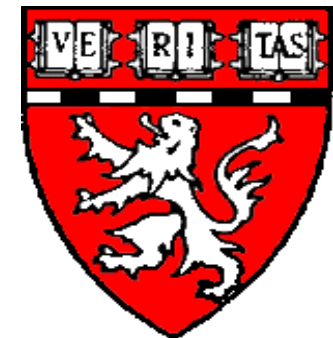


Communicating with patients about their concerns, preferences and expectations

Karen Sepucha, PhD
Massachusetts General Hospital
Harvard Medical School
April 1, 2010



Shared Decision Making

Interactive process between patient
(and family) and clinician(s)

- Engage patient in decision making
- Accurate information about options and outcomes
- Tailor treatments to patient's goals and concerns



(Charles C, Soc Sci Med 1997; 44:681; Mulley A. Med Care 1989)

Key questions

How are we doing?

How can we improve?

How do we make it happen?



DECISIONS Study

Nationally representative sample of 3,010
English speaking adults 40+

- **Surgery**
 - Back surgery, knee/hip replacement, cataracts
- **Cancer screening**
 - Prostate, colorectal, breast
- **Medications**
 - Hypertension, hyperlipidemia, depression

What Did Patients Know?



For 7 out of 9 decisions, fewer than half could get more than one of the 4-5 knowledge questions right.



Fagerlin et al. MDM in press

What DECISIONS Tells Us



- Patients not well-informed
- Providers discuss both the pros and cons about half the time
- Providers take patients' views into account about half the time



Zikmund Fisher et al. MDM in press

Poor quality decisions



Not sharing the right information

Not asking patients what they care about



à Study at 4 academic medical centers (n=445),
10-20% of women did not get breast cancer
surgery that matched their goals and concerns

Sepucha and Barry, Cancer 2009
Lee et al SABCS, 2009

Key questions

How are we doing?

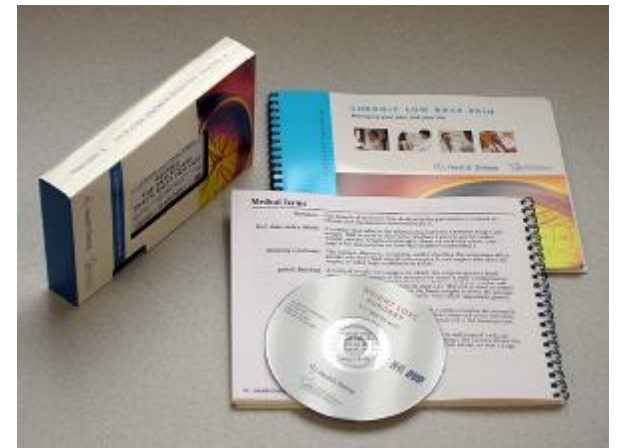
How can we improve?

How do we make it happen?

Patient Decision Aids

- Tools designed to help people participate in decision making about health care options.
- Provide accurate information on the options and outcomes
- Help patients clarify and communicate their personal preferences.
- Guidance in steps of decision making

The International Patient Decision Aid Standards (IPDAS) Collaboration



Decision Aids Work

In 55 randomized controlled trials addressing 23 different screening or treatment decisions, use has led to:

- Greater knowledge
- More accurate risk perceptions
- Greater comfort with decisions
- Greater participation in decision-making
- Fewer people remaining undecided
- Fewer people choosing major surgery



Our current system creates

- Ethical issues
- Patient safety issues
- Resource issues

that shared decision making
addresses.

Key questions

How are we doing?

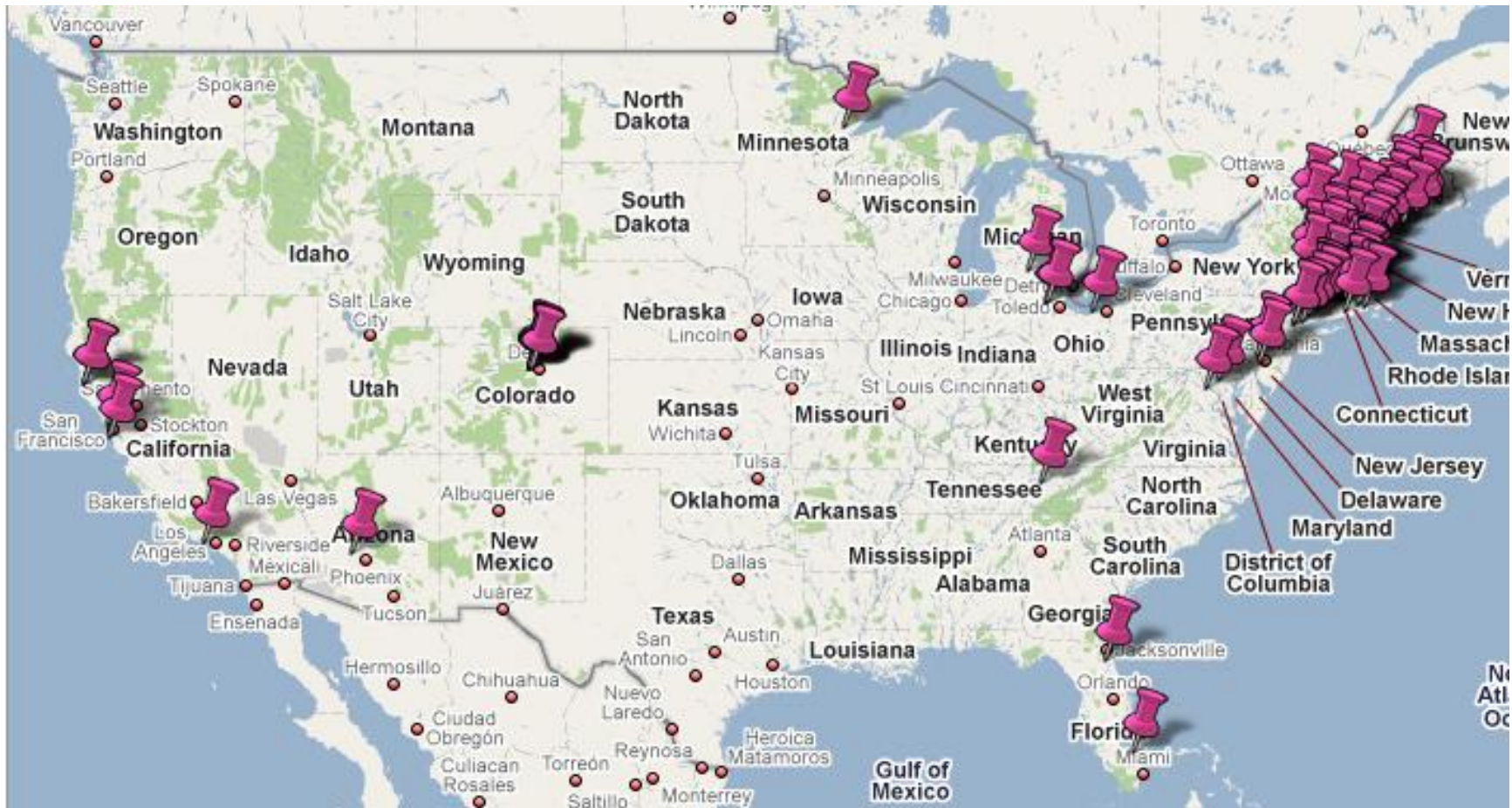
How can we improve?

How do we make it happen?

Demonstration Sites	Primary Care	Specialty Care
---------------------	--------------	----------------

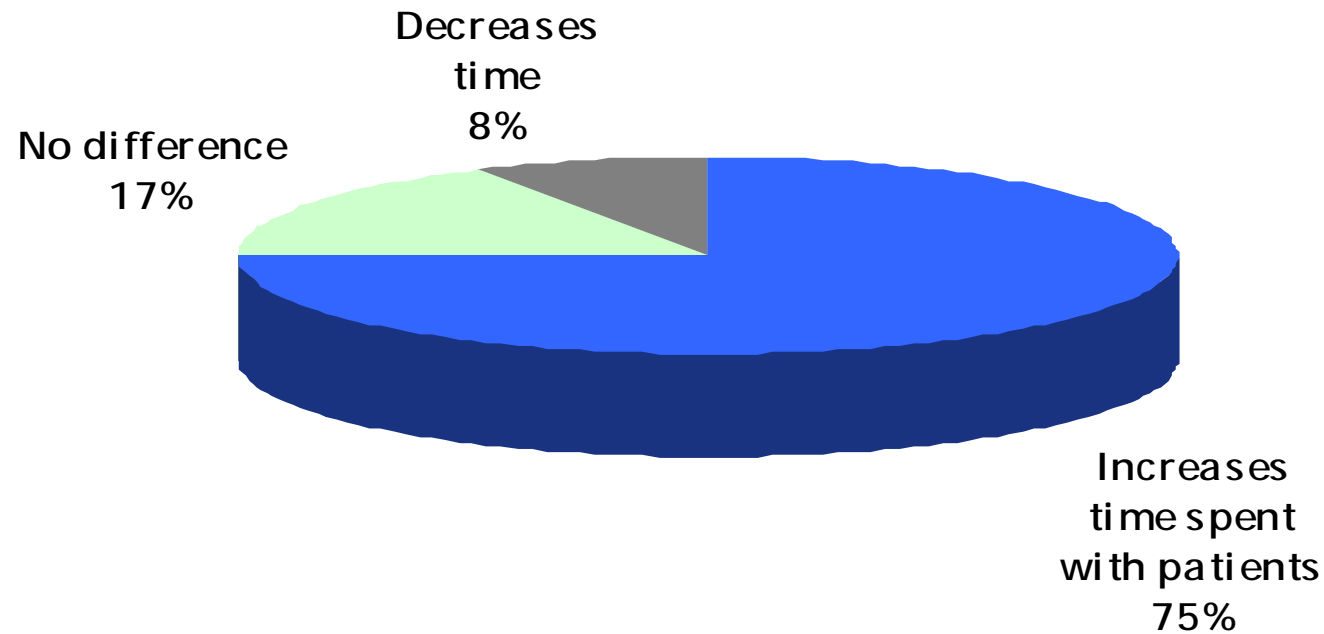
Dartmouth Hitchcock Medical Center	X	
White River Junction VA	X	
Massachusetts General Hospital	X	
University of North Carolina	X	
Maine Health	X	
Mercy Clinics Inc.	X	
Stillwater Medical Group	X	
Oregon Rural Practice Based Research Network	X	
Palo Alto Medical Research Foundation	X	X
Group Health Cooperative	X	
Everett Clinic	X	X
Multi-Care Health System	X	X
Virginia Mason Medical Center	X	X
Allegheny General Hospital - Breast Center		X
Carol Milgard Breast Care Center		X
University of California San Francisco - Breast Center		X
DHMC - Breast Center		X
DHMC - Urology		X
DHMC - Orthopedics		X
DHMC - Spine Center		X
DHMC - Cardiology		X
Mackey Family Practice	X	
Peace Health (Oregon)	X	
Mercy Cancer Center (Oklahoma)		X

Breast Cancer Centers using decision aids



Silvia K et al Health Expectations, 2008; Silvia K et al. Health Expectations 2006

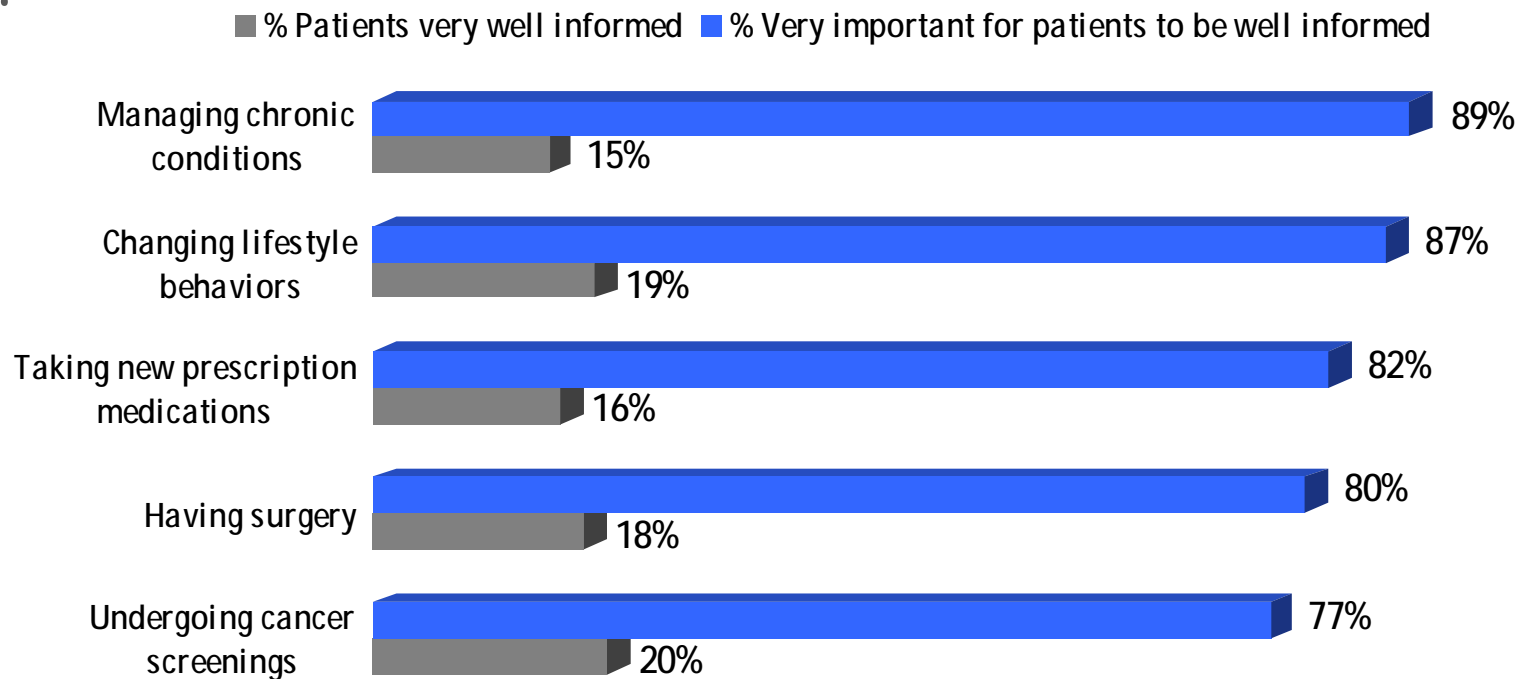
When patients come to you with information gathered on their own, does it generally increase or decrease the time you spend explaining what they need to know?



Primary Care Physician Survey
Lake Research Partners
n=402

1. How important do you feel it is for your patients to be well informed...

2. How well informed do you feel most of your patients are...



Primary Care Physician Survey
Lake Research Partners
n=402

Measurement and standards

DECISION QUALITY

Policy Support For Patient-Centered Care: The Need For Measurable Improvements In Decision Quality

Documenting gaps in patients' knowledge could stimulate rapid change, moving decisions and care closer to a patient-centered ideal.

by **Karen R. Sepucha, Floyd J. Fowler Jr., and Albert G. Mulley Jr.**

ABSTRACT: The phenomenon of practice variation draws attention to the need for better management of clinical decision making as a means of ensuring quality. Different policies to address variations, including guidelines and measures of appropriateness, have had little demonstrable impact on variation itself or on the underlying quality problems. Variations in rates of interventions raise questions about the patient-centeredness of decisions that determine what care is provided to whom. Policies that support the development and routine use of measures of decision quality will provide opportunities to measurably improve

- No decision made in the face of avoidable ignorance
- Reward tailoring treatment to patients' goals and concerns

Summary

- § Quality of decisions is variable, often poor
- § Expecting providers to inform patients and tailor treatments to patients' preferences is risky
- § Shared decision making, supported by decision aids, works and is acceptable to patients and providers, and it is happening (just not enough)
- § Decision quality measures and decision aid that meet standards will support efforts to expand