

# Uninformed Decisions

Jack Fowler

Foundation for Informed Medical  
Decision Making

# How are decisions made in America?

- They are driven by physicians
- Patients have very little information
- Patients have very little input

# This isn't new

- In 1982, a Presidential Commission on Ethics in Medicine declared that it was **unethical** for patients to be given treatments who were not prepared to have an informed opinion about whether or not it was a good idea.

# It seems pretty pervasive

- There have been 55 randomized control trials comparing patients who are exposed to decision aids with those in “usual care”
- Essentially without exception, “usual care” patients were less informed—
  - And usually they were really uninformed

# Patient perspective on medical decisions

- We funded the University of Michigan to collect the data

# National Survey of Medical Decisions

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- Telephone interviews with 3,010 persons 40 and older
- Screened for discussions in the past two years related to nine common medical decisions
- Detailed questions on up to two conditions, among those who had a discussion
- A medical decision was defined as having taken action (screened, initiated medication, had surgery) or having discussed taking such action with a health care provider in the last 2 years

# National Survey of Medical Decisions

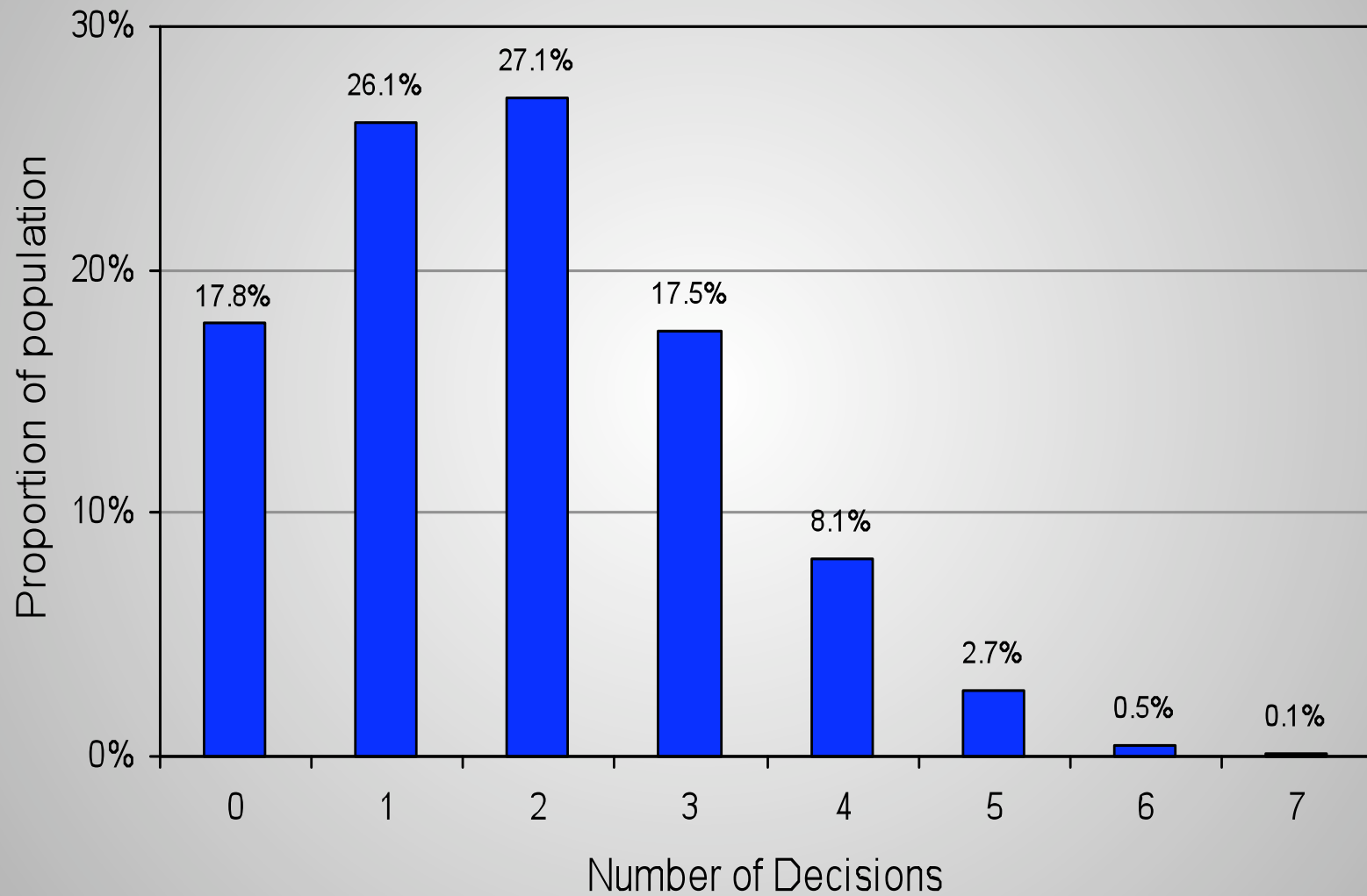
- Cancer screening tests:
  - Colorectal cancer
  - Breast cancer (mammography)
  - Prostate cancer (PSA testing)
- Prescription medication decisions:
  - Hypertension
  - High cholesterol
  - Depression
- Surgical interventions:
  - Knee/hip replacement
  - Cataracts
  - Lower back pain

# How Often do Americans Make Medical Decisions?

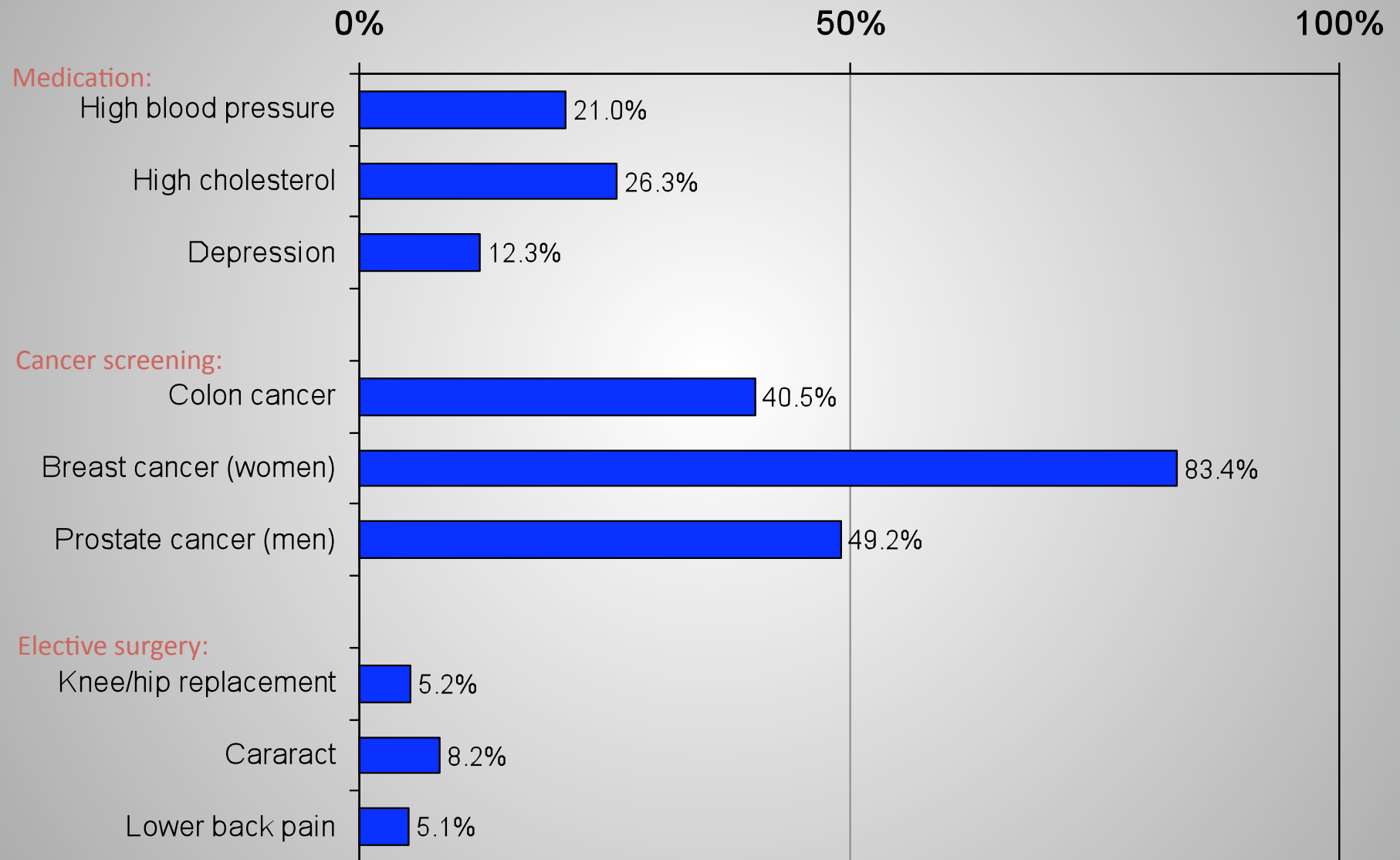
- Very frequently!
- 51% of adults 40+ are currently taking prescription medications for high blood pressure, high cholesterol, and/or depression
- In the past two years...
  - 56% discussed starting or stopping meds for HBP, cholesterol and/or depression
  - 72% discussed a screening test for cancer
  - 16% discussed one of the 4 surgical interventions



# Number of Decisions in Past 2 Years

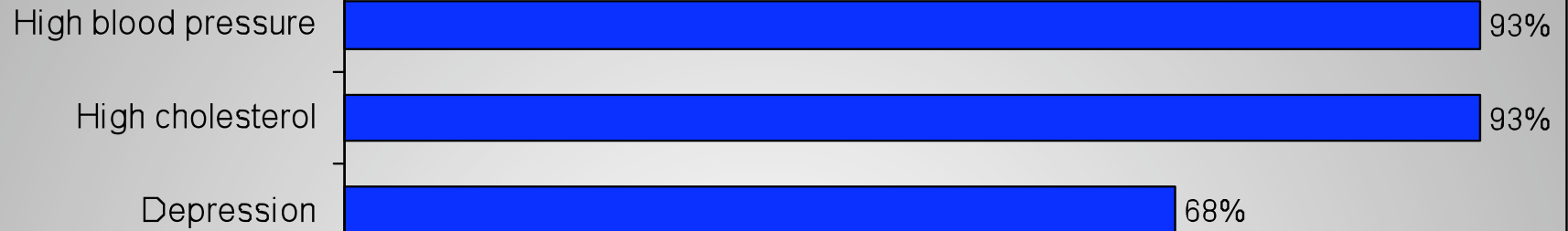


# 2 Year Prevalence of Medical Decisions

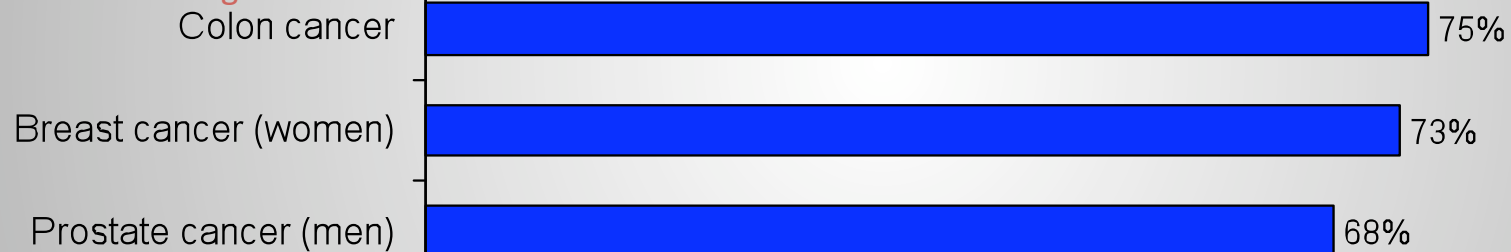


# Discussions Initiated by HCP

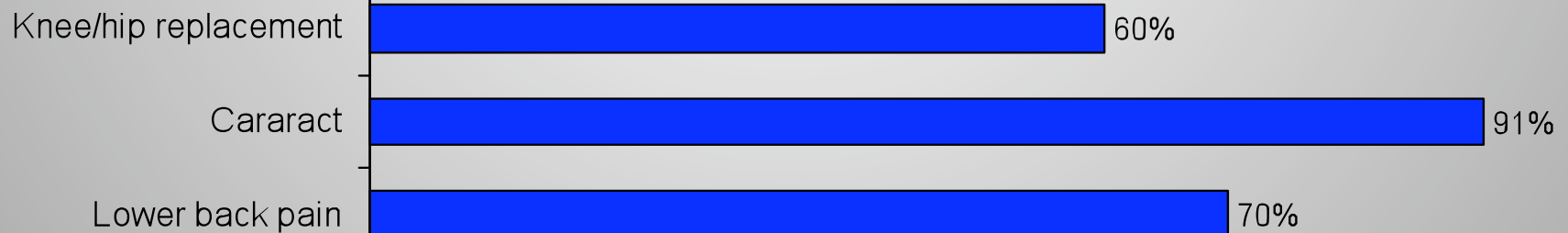
## Medication Initiation:



## Cancer screening:



## Elective surgery:



# What Did the Physicians Recommend?

## **Surgical decisions**

- about 65% of recommendations were to do it

## **Medication decisions**

- over 90% of recommendations were to take it

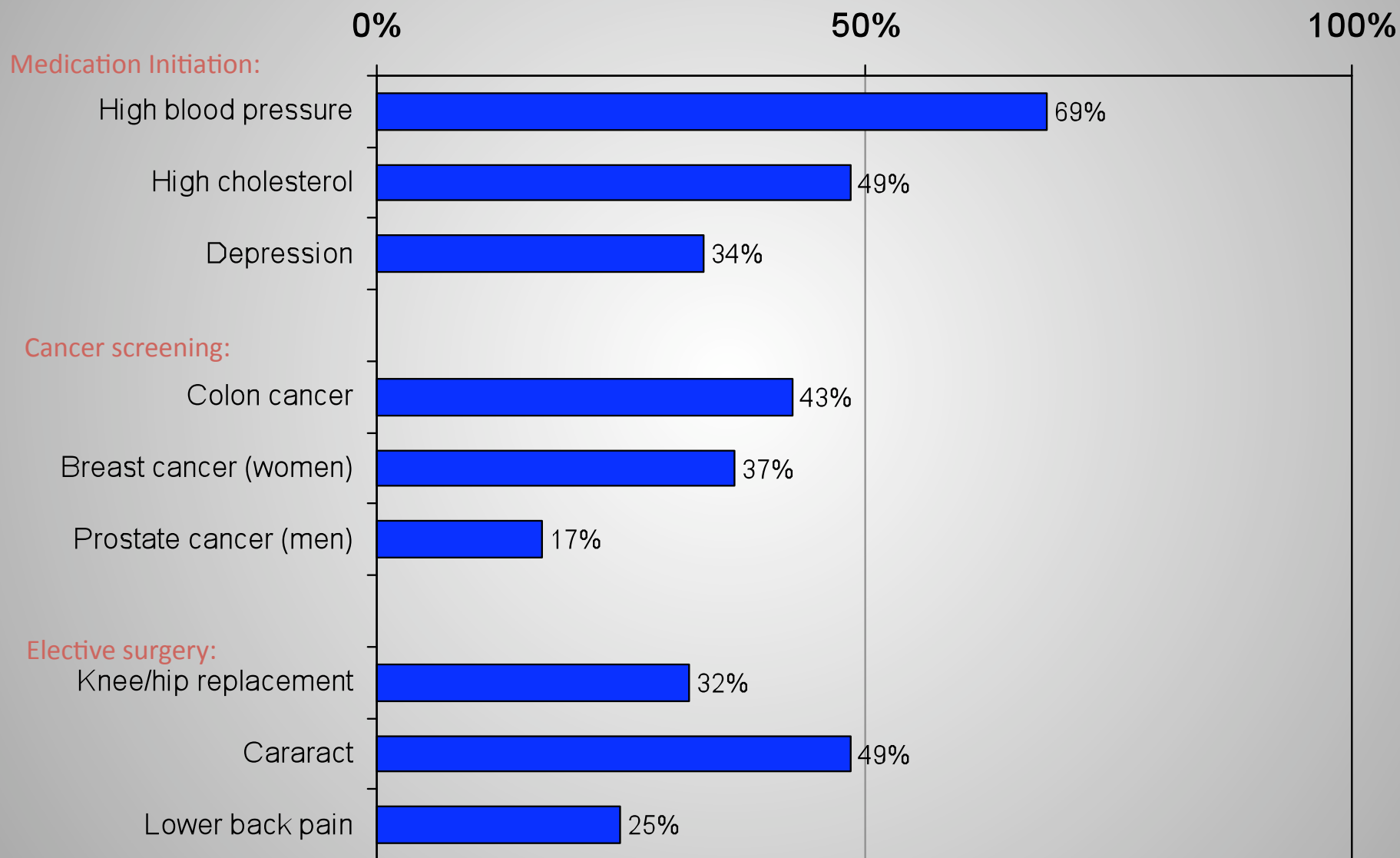
## **Cancer screening (including PSA testing)**

- about 95% of recommendations were to do it

# How Much do Patients Know about their Conditions and Treatments?

- Not so much!
- We had clinical experts specify 4-5 key items they thought a patient faced with each of the decisions should know like:
  - diagnosis and death rates
  - key side effects
  - duration of medication
  - etc.
- For all decisions except high blood pressure:
  - on average patients answered half or fewer of the questions correctly

# Mean proportion of knowledge items answered correctly



# Where Else Do Patients Get Information?

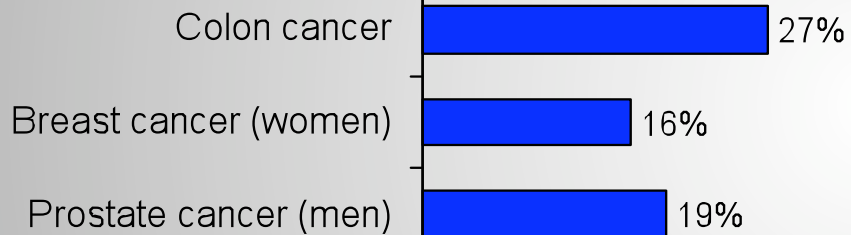
- Does it matter that patients don't have detailed discussions with providers if they can get the information elsewhere?
- Specifically, does the Internet substitute for busy providers?
- While about 60% of those 40+ go online at least occasionally (Pew Internet Project), 31% report using the Internet to look for medical information (HINTS)
- In the DECISIONS survey, only 28% of patients 40+ made use of the Internet for information specific to one of the decisions

# Use of the internet for information on decisions

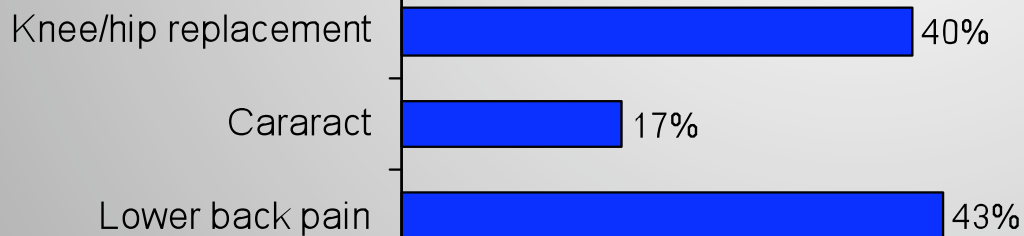
## Medication:



## Cancer screening:



## Elective surgery:



0%

50%

100%



# National Survey of Medical Decisions: Summary

- Important medical decisions are very prevalent
- Patients report that many decisions are made in ways that omit key elements of informed decision making
  - They almost always involve a recommendation from a doctor—and often little input from patients
  - That recommendation is almost always to get more treatment or tests
  - Discussions emphasize pros of treatment rather than cons
  - And doctors are clearly the most important sources of information for patients

# And worst of all

- Patients who actually do these things (take meds, get screened, have surgery)
  - Think they are pretty well informed
  - And in fact are usually quite poorly informed

# Why does it work this way?

- 1. Tradition—there is a history of delegating decisions to doctors (that doctors and many patients think is fine)
- 2. Time—most doctors say they get 15 minutes with patients in a typical visit—they don't have time for much discussion
- 3. Incentives—they also usually do not get paid to spend extra time talking

# What do physicians think about decision making?

- The Foundation funded an Internet-based survey (Harris Interactive) of 400 primary care physicians to find out

# Goal

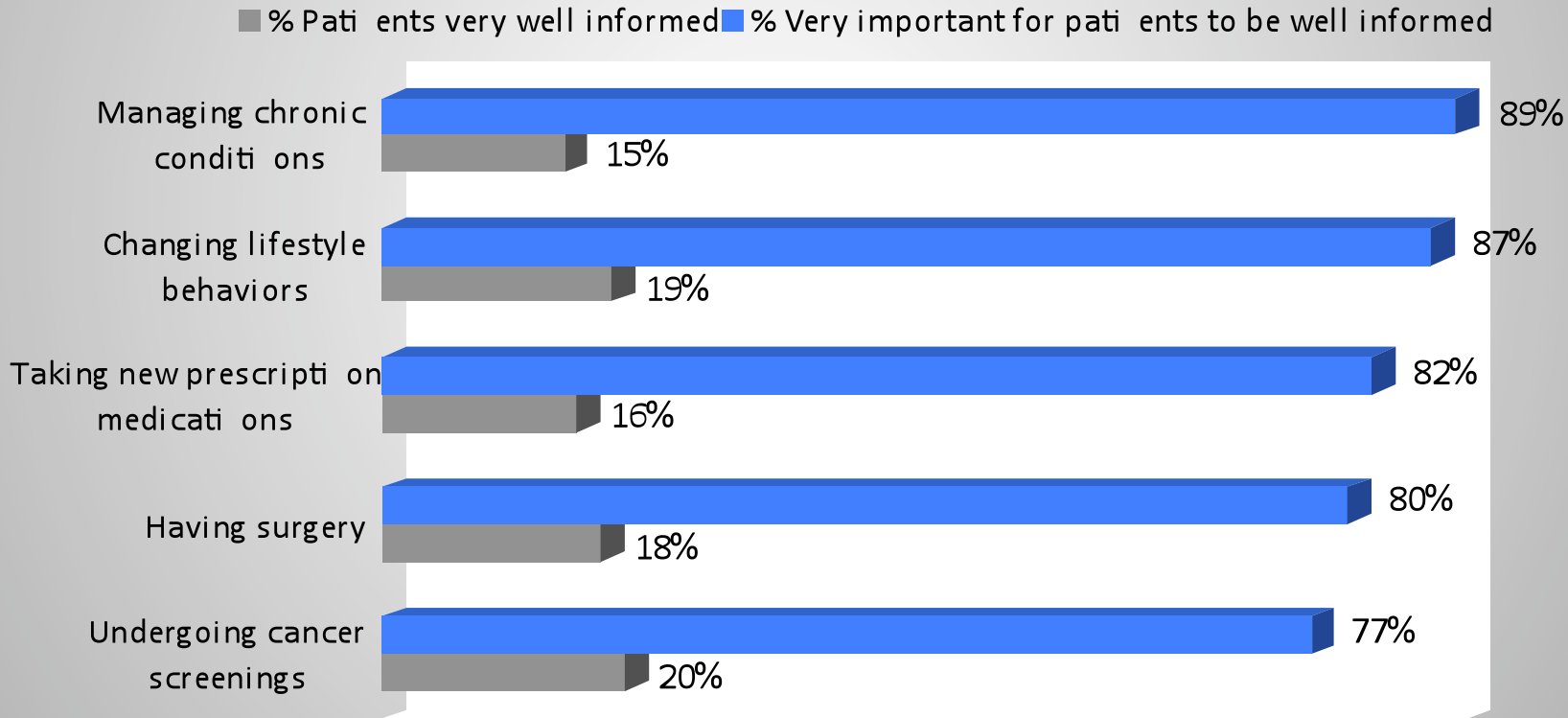
- After seeing the data from the patients, we wanted to get the perspective of doctors on why decisions are made the way they are
- Is it already the way doctors like it?
- If not, what are the barriers to a better decision making process?

# Do PCPs Think Patients Are Well Informed?

- Generally not
- Answers square fairly well with Michigan data?
- 15%-20% say patients are “very well informed” (depending a little on the topic)

# Figure 3: Importance of Well Informed Patients vs. Reality of Most Patients

How important do you feel it is for patients to be well informed when making decisions about:  
In general, how well informed do you feel most of your patients are when making decisions about:



# Do PCPs Think Patients Should Be Informed?

- Generally “yes”
- Widespread agreement that patients should be informed
- 87-89% - lifestyle changes & managing chronic conditions
- 77-82% for screening tests/meds/surgery



# Shared Decision-Making?

- When we defined shared decision making, 52% said it seemed like a “very positive” process

# Importance of Shared Decision-Making

- 80-81% very important for changing lifestyles and managing chronic conditions
- 62-64% very important for meds and cancer screening
- Surgery was in between

# Frequency of Shared Decision-Making

- Overall, about half the respondents reported that it was routine (higher than one would have thought from the patient survey data)
- 58% - for lifestyle changes
- 42-43% - for medications & cancer screening
- 31-33% - for imaging & referrals to specialists

# Barriers to Shared Decision-Making

- Two answers dominated everything else—
- Not enough time 45%
- Patients have difficulty understanding what they need to know 38%

## Those (25%) who saw controlling the decisions as no issue

- Were the most positive about shared decision making
- Thought it was most important
- And reported doing it the most.

## Table 9: Perception of SDM by Preference for Patients Relying on Own Advice

How much of a barrier is each of the following to engaging patients in a shared decision-making process? *I prefer patients rely on my recommendations.*

	<b>Large/ moderate barrier</b>	<b>Small barrier</b>	<b>Not a barrier</b>
SDM sounds very positive	37%	52%	70%
Somewhat positive	51	43	26
Neutral or negative	11	5	4

# Conclusions

- 1.) Physicians favor informed patients, at least in principal.
- 2.) Patients digging up information on their own is not popular; majority of physicians see it as a negative.
- 3.) Physicians need patients to receive information they respect to be positive about “informed” patients.

# Conclusions

- 4.) Shared decision-making is seen as particularly valuable in areas where patients have control anyway: lifestyle changes and chronic condition management.
- 5.) Physicians who are less interested in giving up control are less likely to be enthusiastic supporters of shared decision making.



# What is wrong with delegating decisions to physicians?

- Some research by Karen Sepucha illustrates one important aspect of the problem

## Example: Early Stage Breast Cancer

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- NIH Consensus conference of 1990 concluded that, “breast conservation treatment...is preferable because it provides survival equivalent to total mastectomy...while preserving the breast.”

# Provider perspective: key facts

## Mastectomy

Survival same

Lose breast



## Lumpectomy

Survival same

Keep breast

## Cancer: Finding It And Treating It

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To the Editor:

Re "Lumpectomies Seen as Equal  
in Benefit to Breast Removals"  
(front page, Oct. 17):

Regardless of the global outcomes  
of studies, a woman's choice of treat-  
ment for breast cancer will remain  
an intensely personal one.

The mastectomy that I chose to  
undergo seven months ago felt a lot  
less invasive than the prospect of six  
weeks of daily radiation treatments,  
not to mention the 14 percent risk of  
local recurrence.

ANN J. KIRSCHNER  
Brooklyn, Oct. 17, 2002

# What are the Key Facts and Goals?

## Mastectomy

## Lumpectomy

Same

Survival

Same

Lose breast

Cosmetics

Keep breast

Low (1-5%)

Recurrence

Slightly higher  
(5-15%)

Not common

Radiation

6+ weeks

Rare (unless  
reconstruction)

Additional surgery

Common 20-50%

# Validating Key Facts and Goals

- Mailed survey to determine accuracy, importance and completeness of items
- Providers AND patients in sample
  - How important was each item?  
(Not at all; Somewhat; Very; Extremely)
  - Pick top three
  - Anything missing?

# So what is the problem with delegating decisions?

- The physician is very likely to have different ideas about what is important to the patient than the patient does
- And, currently, the physician is not that likely to ask patients what is important to them

# My goal:

- That it would become the standard for medical care in the US that no one would do anything medical to a patient until that patient:
  - 1. Knew the alternatives
  - 2. Understood the pros and cons of those options
  - 3. Was given a chance to have a voice in which options were chosen



# Until then--

- Uninformed decisions will continue to be the norm in the US
- And medical care will cost more and serve patients less well than it should.

**THANK YOU!**