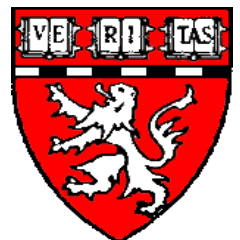# Decision Quality in Cancer Care

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Health Decision Sciences Center, MGH
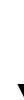## Harvard Medical School

Documenting the patients' voice...

Information

I have two small children and want to live as long as possible.

↓

What are my options? I want to do everything possible.

↓

What is the impact for each option on 10 yr survival? 20 yr?

Documenting the patients' voice...

Information

Involvement

I am concerned that my desire to forego treatment is discouraging and frustrating for you.

↓

I want to watch this recurrence and check it in 3 months. If it is growing then I will consider treatment.

↓

Your support is important to me. Are you willing to support me in this alternative?

Documenting the patients' voice...

Information

Involvement

Concordance

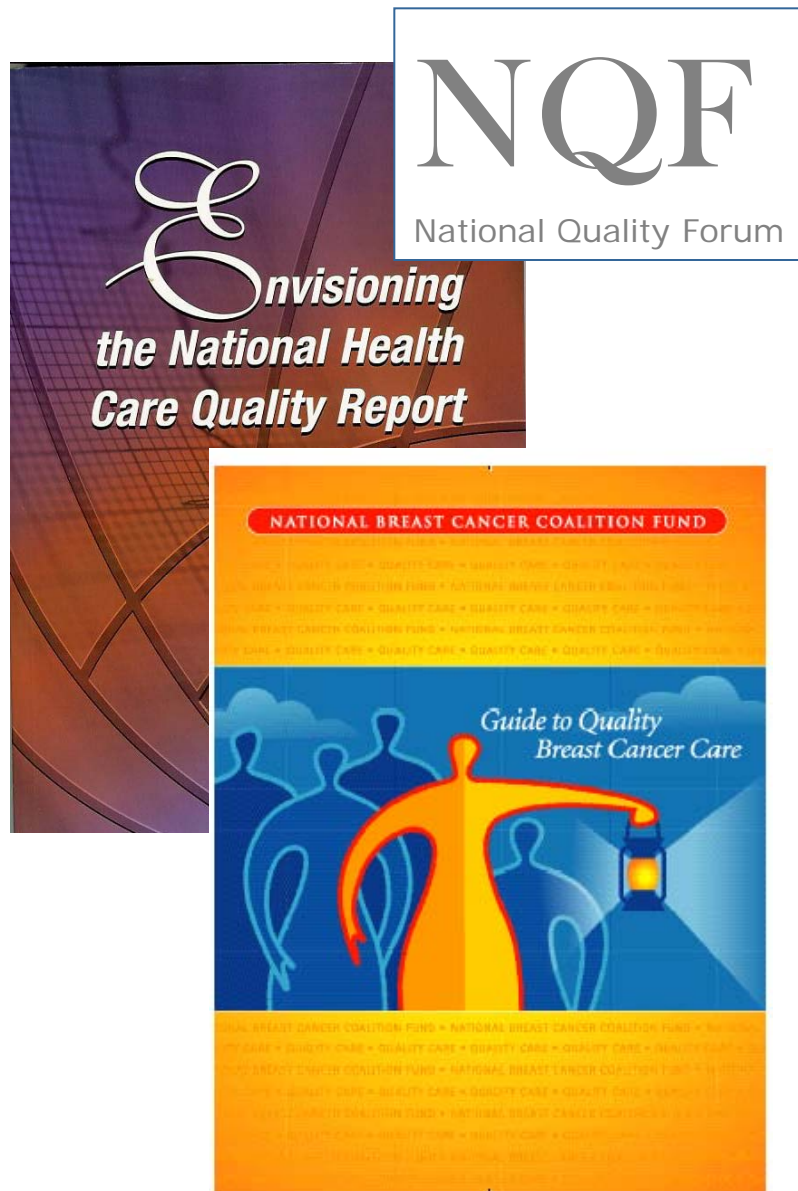I am afraid of chemotherapy. It doesn't make sense to me.

↓

I don't understand how poisoning my body can make me better.

↓

I need my immune system to fight the cancer, but chemo weakens my immune system.

High quality, patient-centered care

Core Themes:
- fully informed
- play a key role in making healthcare decisions
- treatments reflect patients' want, needs and preferences

Key questions

What is decision quality?

How are we doing?

Can we do better?

Defining decision quality:

For patients that meet clinical criteria, decision quality is defined as the extent to which patients are

- –Informed,
- –Meaningfully involved,
- –And receive treatments that reflect their goals

Sepucha et al. 2004 Health Affairs; Elwyn BMJ 2006

Key questions

What is decision quality?

How are we doing?

Can we do better?

Measuring knowledge

- Key facts relevant to decision
  - Disease, options, outcomes, likelihood

- Perceptions not enough
  - Patients don't know what they don't know

- Facts ≠ knowledge (but hard to be informed without knowing some facts)

# Are breast cancer patients well-informed?

- Survey of 1,800 women from Detroit and LA
  - ~50% knew survival was same with mastectomy and lumpectomy (Fagerlin et al. 2006)

  - 11% answered three basic questions about reconstruction correctly (Morrow et al. 2005)

- Vastly over-estimated benefit of chemotherapy (Ravdin et al. 1998)

- Vastly over-estimated risk of dying from DCIS (Rakovitch et al. 2003)

Measuring Involvement

Four key things need to happen:
1. Given options

2. Discuss PROS of options
   (A lot/Some/A little/Not at all)

3. Discuss CONS of options
   (A lot/Some/A little/Not at all)

4. Discuss patients' goals/preferences
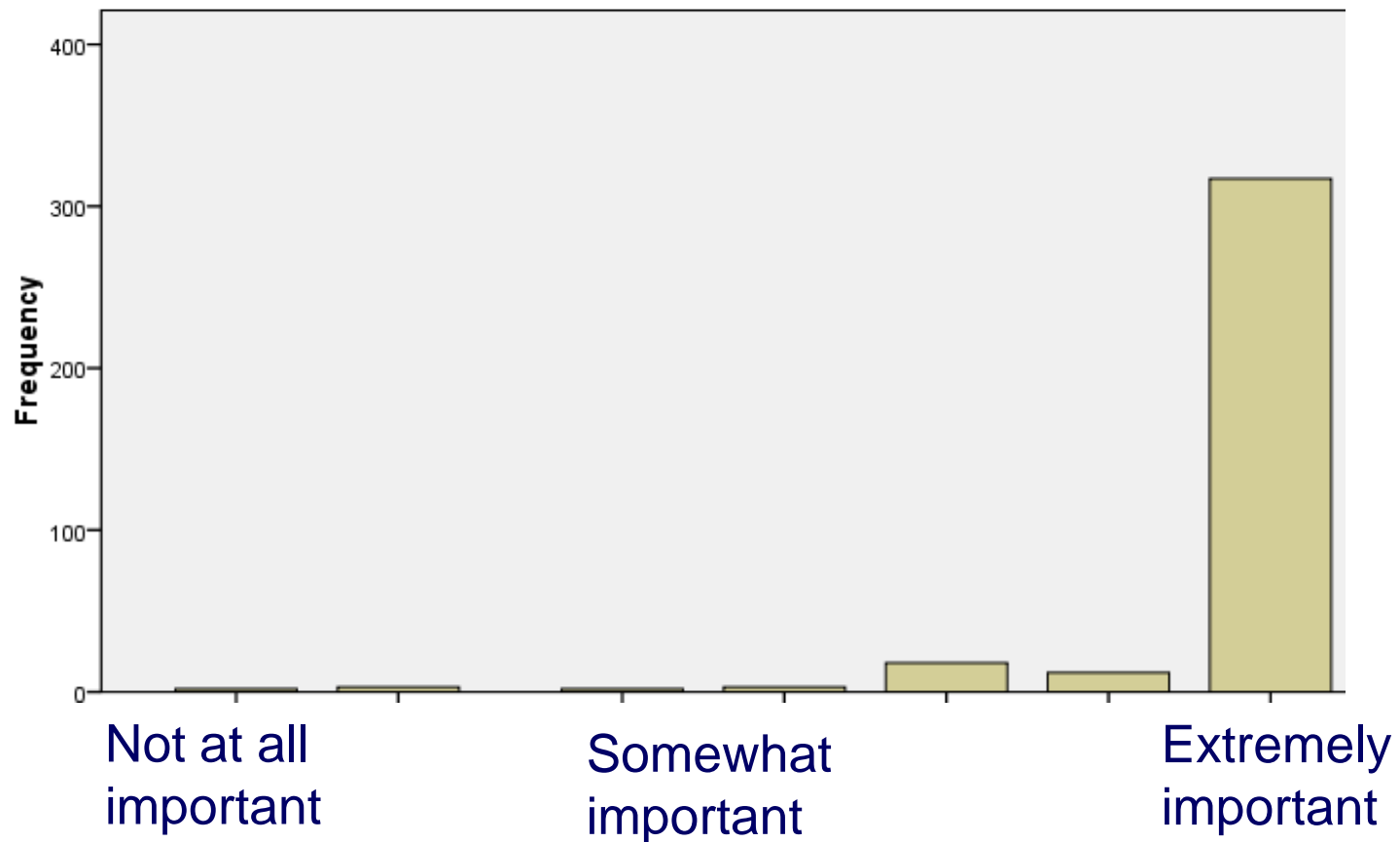
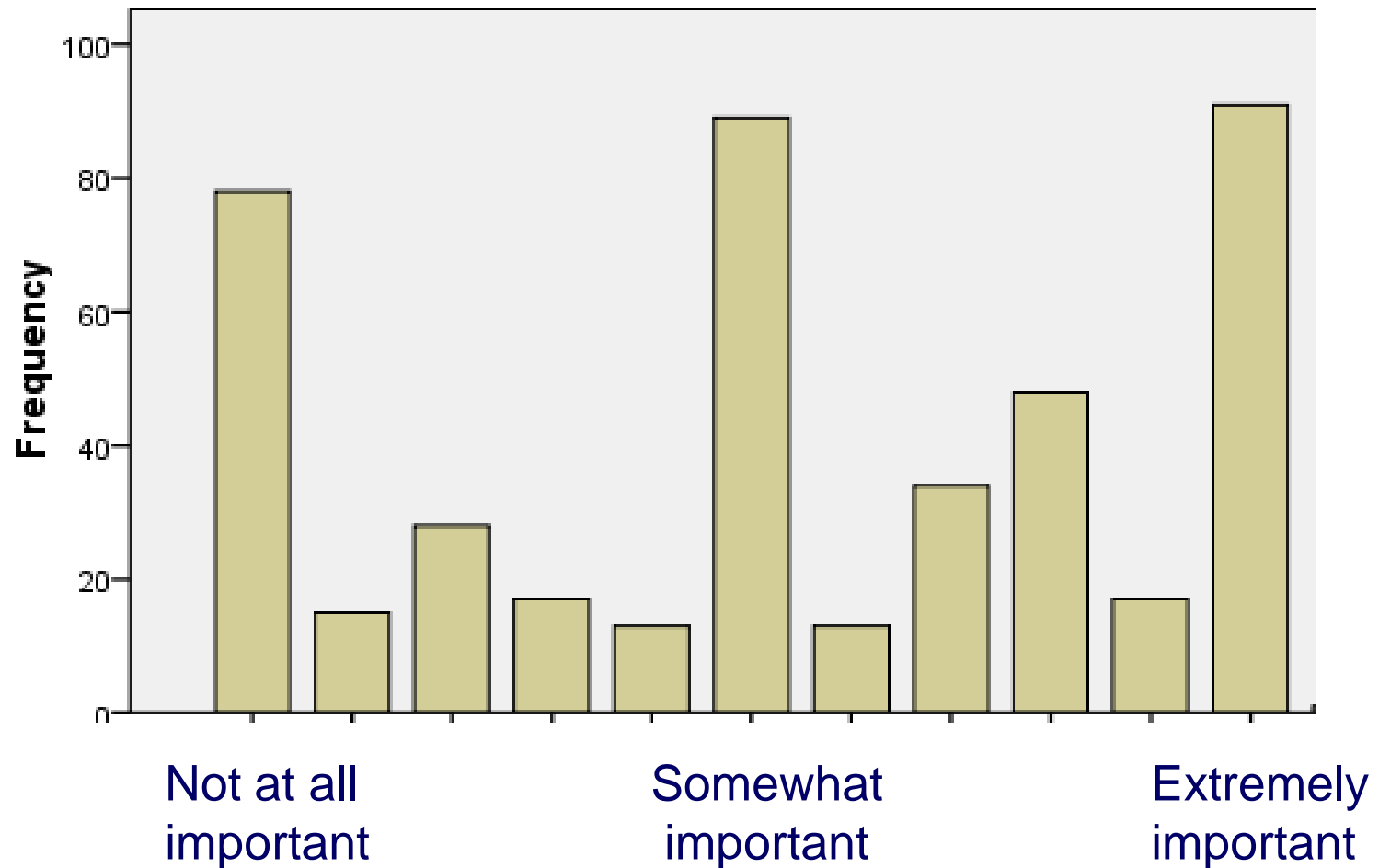# Are breast cancer patients involved?
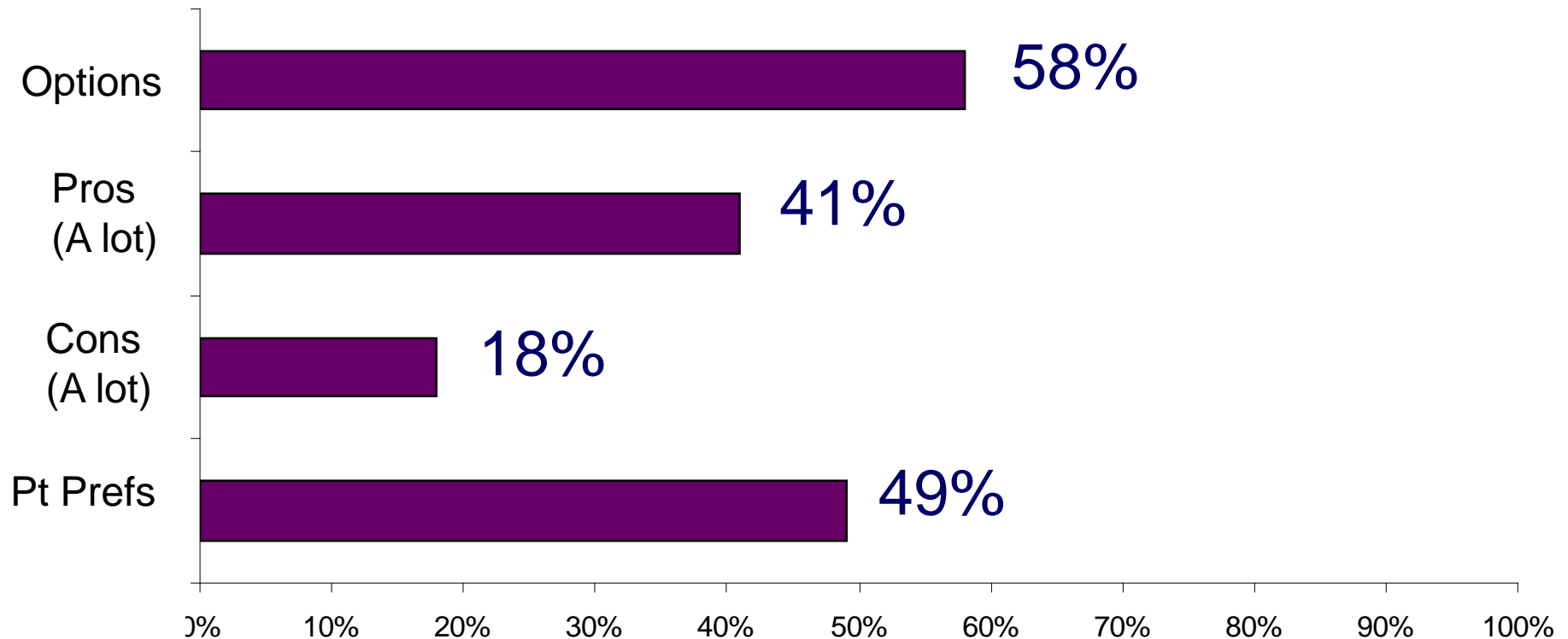
N=440, Lee et al. 2009

Measuring goals

- Salient issues upon which the decision rests

- Challenge: goals change with experience, knowledge, and over time

How important is it to reduce the chance of having cancer come back in the breast?

How important is it to keep your breast?

Concordance

We are matching right treatment with right patient, most of the time but…

- 18% preferred mastectomy but had lumpectomy

- 20% preferred reconstruction but didn't have it

- 16% preferred chemo but didn't have it

Lee et al, 2009; Lee et al 2010

Key questions

What is decision quality?

How are we doing?

Can we do better?
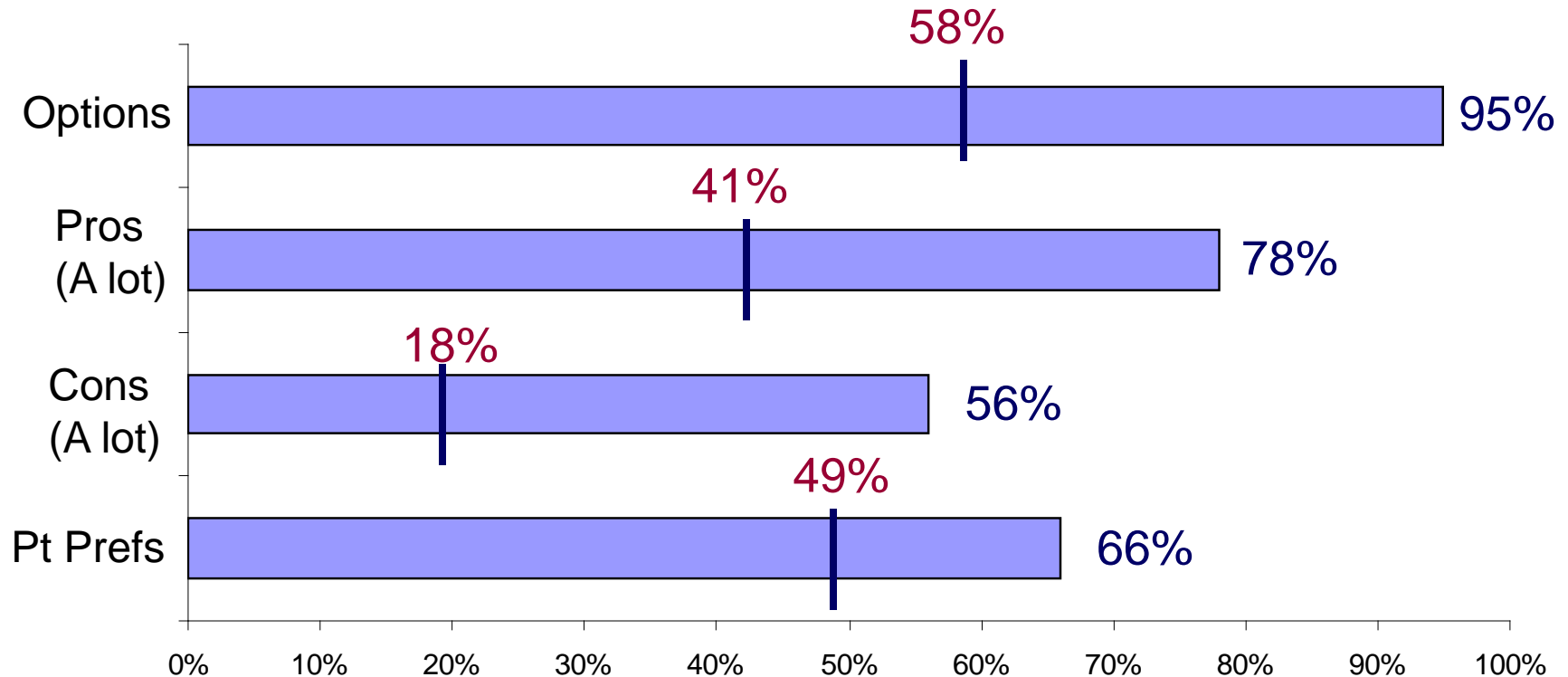
Case 1: UCSF Decision Services

- Decision aids
- Question listing
- Note taking

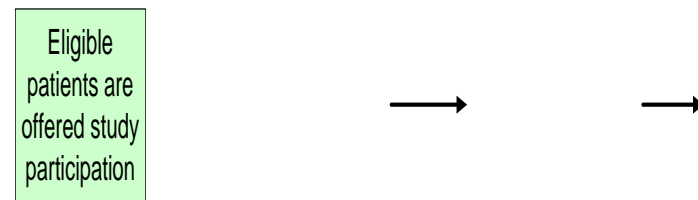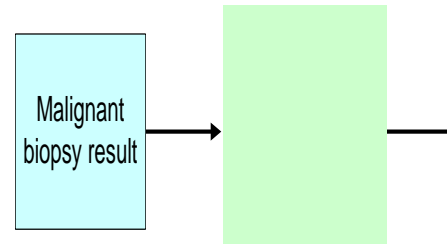| Monday	Tuesday	Wednesday	Thursday	Friday
Eugene Fan	Jimmy Barnes	Andrea Spillmann	Clark Fisher	Julia Pederson

What's possible after decision support?

N=131, Belkora et al. 2011

Case 2: Dartmouth Breast Center

1. Workflow redesign

2. Decision aids

3. Clinical decision support

INTEGRATING DECISION SUPPORT
IN BREAST CANCER CARE

Malignant biopsy result

Eligible patients are offered study participation

S

Values : <u>Decision Making</u>
Leaning toward : Mastectomy
Sure about choice : No
Knowledge :
 Understands :
  ☑ survival rates
  ☑ recurrence rates

Value	Rating
Keep breast	8
Minimize chance of recurrence	8
Avoid radiation	10
Did everything possible	7
Minimize length of tx	6
Avoid breast reconstruction	5
Do what doctor thinks best	3
Remove breast (peace of mind)	4

0 1 2 3 4 5 6 7 8 9 10

Less important   Very important

D
n
A
r

What's possible: Knowledge scores

Correct response (%) (n = 115)	Post consult
1. Survival rate	96%
2. Recurrence rates	63%
3. Recurrence likehood	94%
4. Urgency of decision	99%
TOTAL (average)	92%

Collins et al 2009

Summary

- Quality of cancer treatment decisions is variable, often poor

- Shared decision making, supported by decision aids and other tools, works and it is happening (just not enough)

- Accountability and quality improvement through measurement of decision quality is important

Thank you!

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