

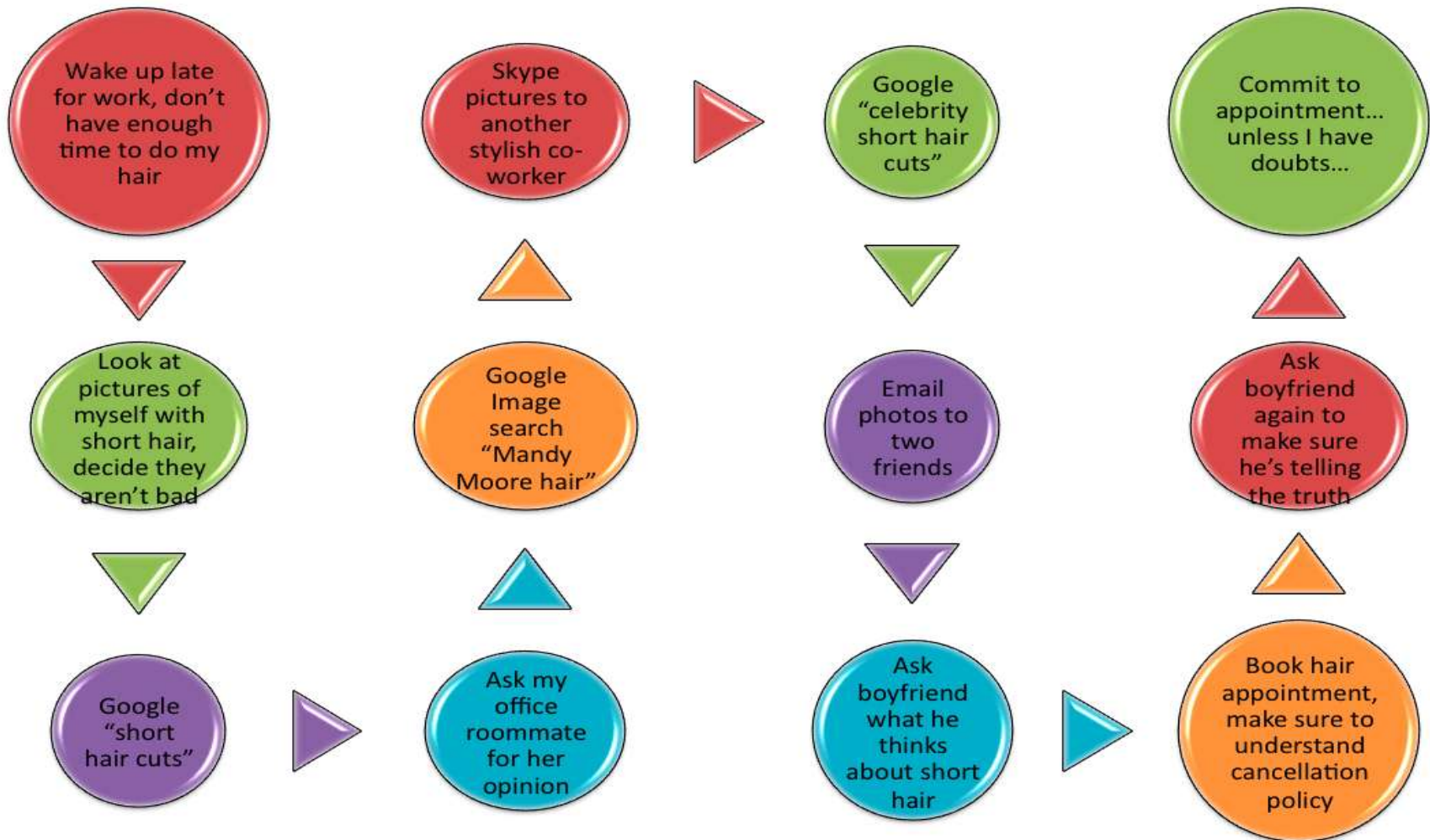


Shared Decision-Making:
Bringing Patients into their Healthcare Loop

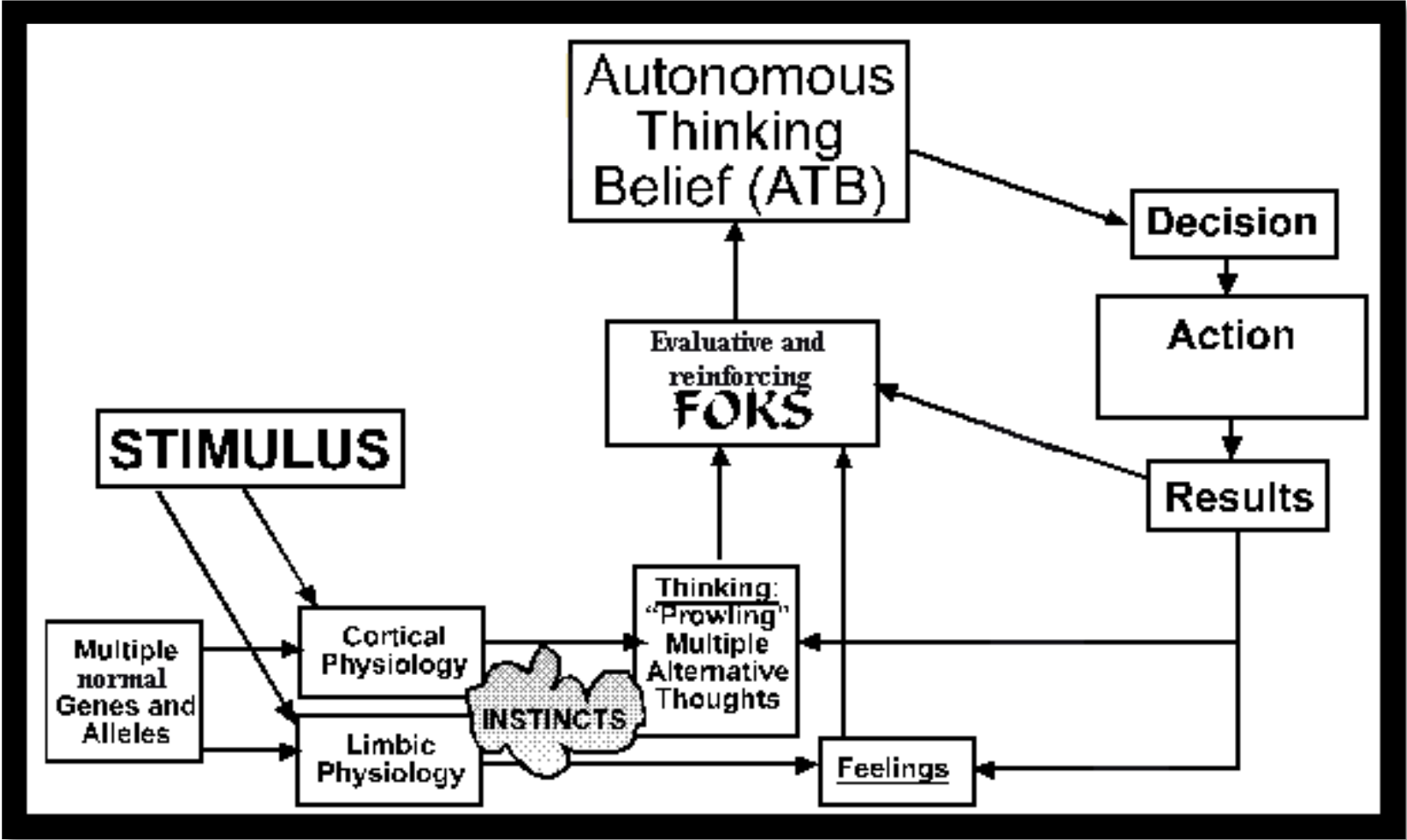
Suresh R. Mulukutla, MD FACC

Director, Interventional Cardiology &
HVI Center for Quality, Outcome, and Clinical Research

Complexity of Everyday Decisions



Normal Decision-Making Apparatus



Traditional Decision-Making Model: Paternalism at Its Peak



Variation in Medical Practice



- 10-fold variation in tonsillectomy
- 8-fold risk of death with surgery
- “... tendency for the operation to be performed for no particular reason and no particular result.”
- “...sad to reflect that many of the anesthetic deaths... were due to unnecessary operations.”



1938: J Allison Glover

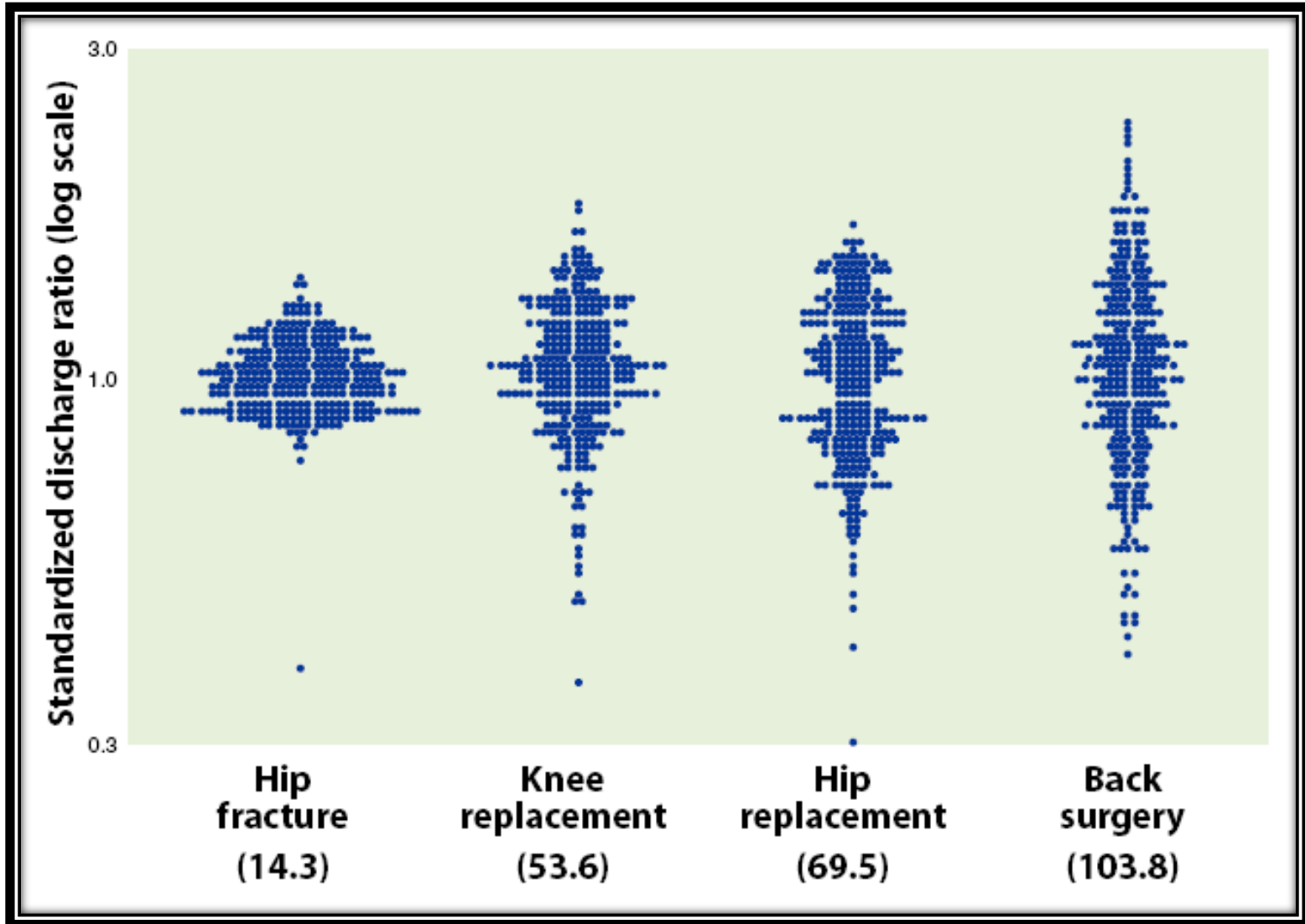
Variation in Medical Practice...It Still Exists!



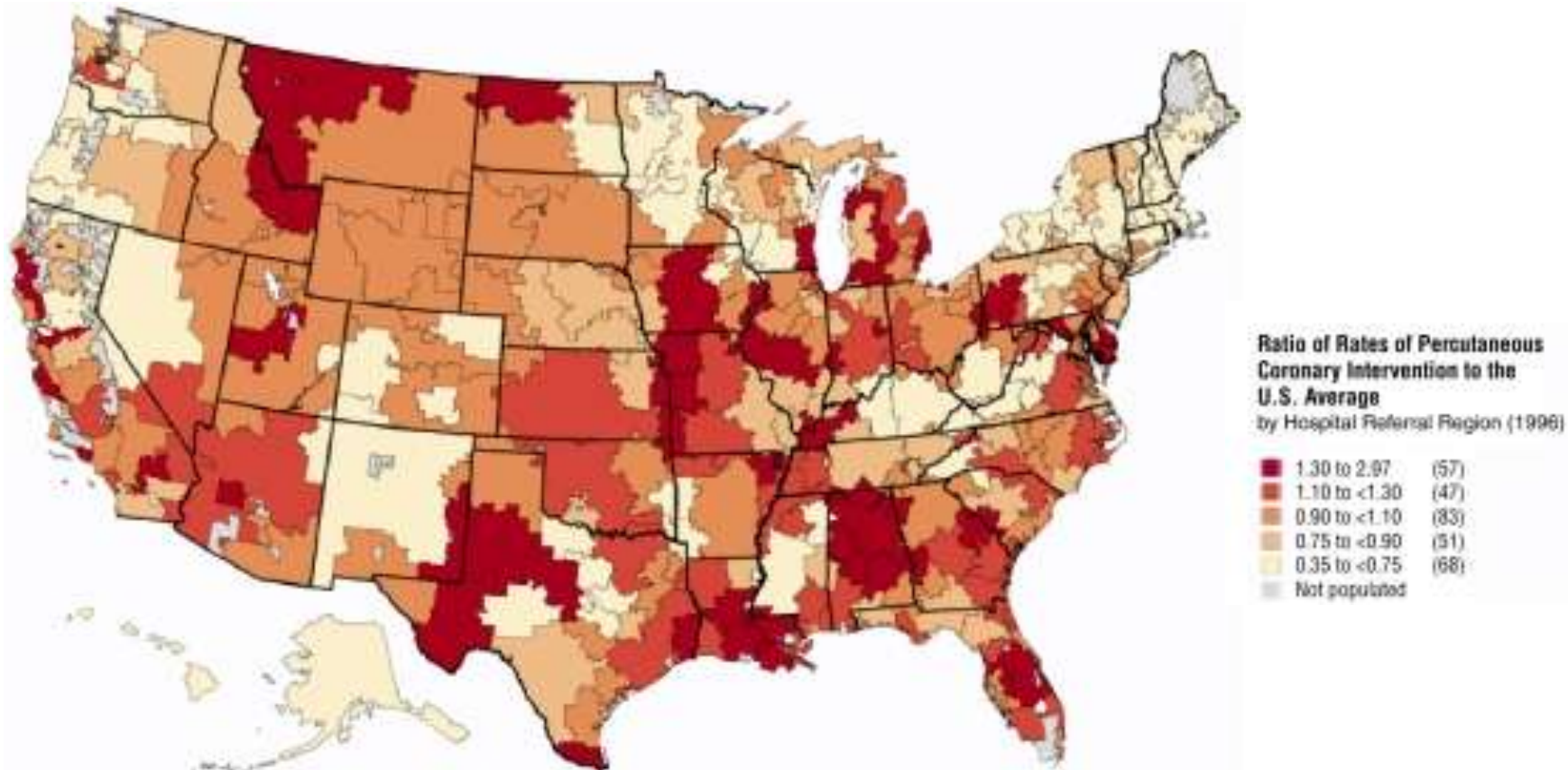
John E. Wennberg, 1973

- 17-fold variation in tonsillectomy
- 6-fold variation in hysterectomy
- 4-fold variation in prostatectomy
- “Need for assessing outcome of common medical practices”
- “Professional uncertainty and problem of supplier-induced demand”

Variation in Discharges following Orthopedic Surgery



Variability in Coronary Revascularization



Ratio of Rates of PCI (Stent Procedures) to US Average

Variability in Cardiovascular Decision Making

Table 1. ACC/AHA Indications vs Catheterization Laboratory Recommendations, New York, January 1, 2005–December 31, 2007: Indications for ACC/AHA Class I and Class IIa Regarded as Equal

ACC/AHA Indication/Cath Lab Recommendation	CABG, n (%)	PCI, n (%)	Medical Treatment, n (%)	None, n (%)	Total, n (%)
CABG	712 (53)	455 (34)	156 (12)	14 (1)	1337 (100)
PCI	124 (2)	5660 (94)	255 (4)	12 (<1)	6051 (100)
CABG and PCI	84 (5)	1608 (93)	26 (2)	4 (<1)	1722 (100)
Neither CABG or PCI	70 (6)	261 (21)	873 (71)	19 (2)	1223 (100)
Total	990 (10)	7984 (77)	1310 (13)	49 (<1)	10 333 (100)

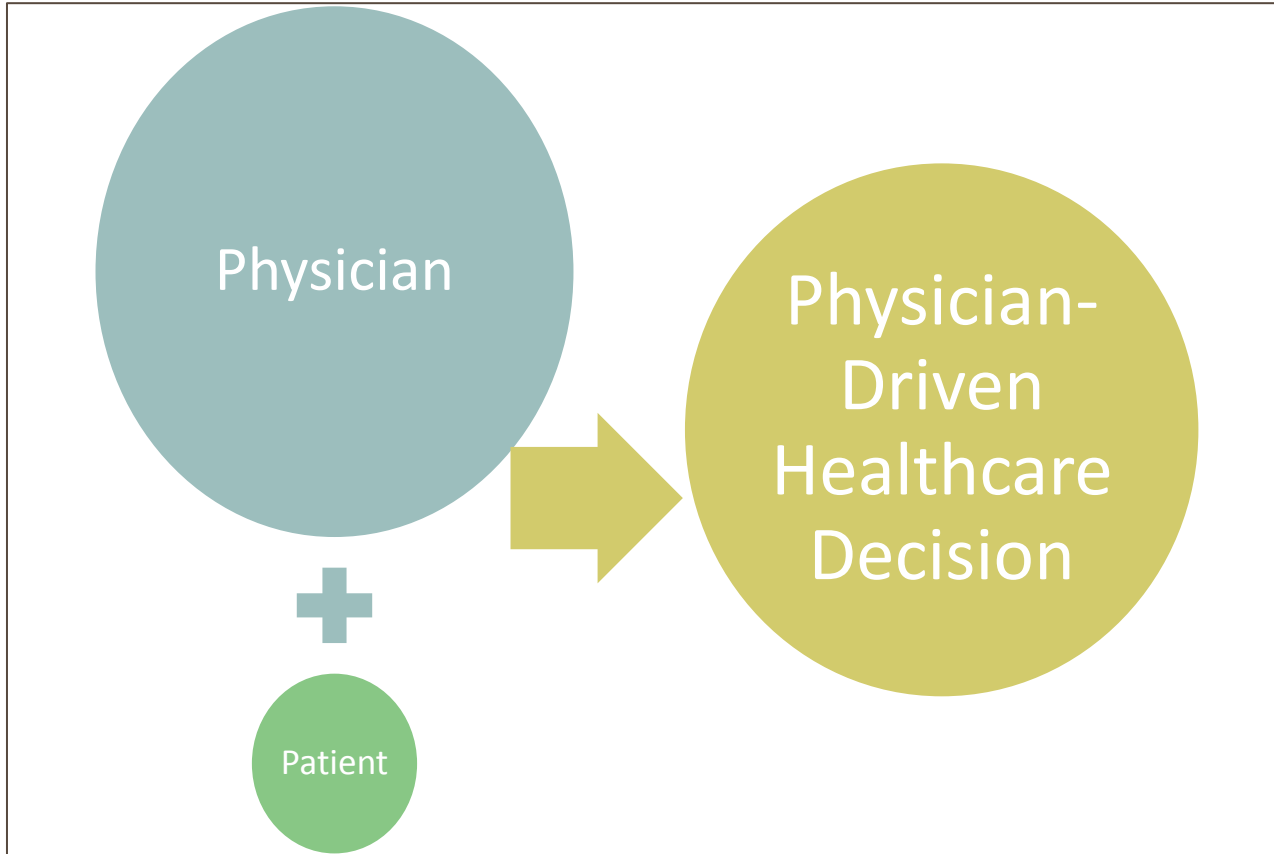
Cath Lab indicates catheterization laboratory.

Hannan EL, Racz MJ, Gold J, Cozzens K, Stamato NJ, Powell T, Hibberd M, Walford G. Adherence of catheterization laboratory cardiologists to American College of Cardiology/American Heart Association guidelines for percutaneous coronary interventions and coronary artery bypass graft surgery: what happens in actual practice? *Circulation*. 2010; 121: 267–275.

Strategies to Reducing Variation

- Shared Decision-Making: Engage patients in decision and allow for decisions to be driven based on their understanding and their own preferences
- Adjust supply of healthcare (clinicians, beds, etc)
- Change financial incentives for healthcare providers

Traditional Healthcare Decision-Making: An Unequal Partnership



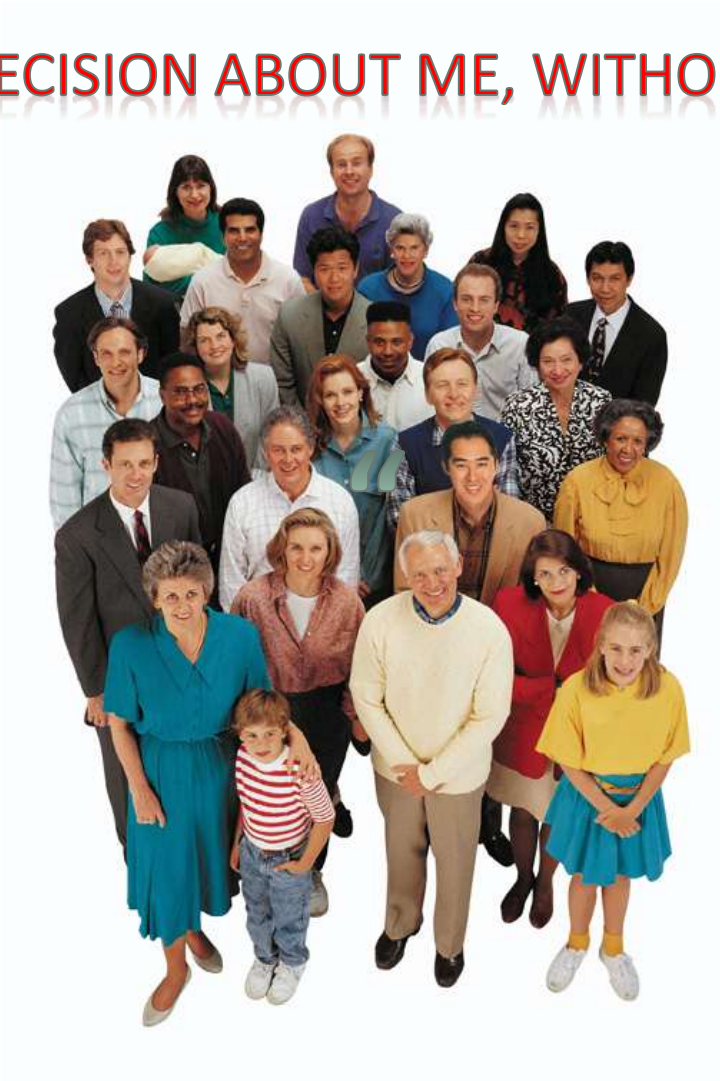
Shared-Decision Making - Definition

Shared decision making is a process in which clinicians and patients work together to clarify treatment, management or self management support goals, sharing information about options and preferred outcomes with the aim of reaching mutual agreement on the best course of action.

(Shared Decision Making. Coulter, Collins. Kings Fund, July 2011)

Shared Decision Making

“NO DECISION ABOUT ME, WITHOUT ME”



Forging a New Partnership



Activated, engaged patients

Partnership
Sharing Information
Setting Expectations



Trained Healthcare Professionals



Patient-Centered Outcomes

Creating a New Paradigm in the Redesign of Health Care

Table 2. Ten Rules to Guide the Redesign of Health Care^a

- 1. Care based upon continuous healing relationships.** Patients should receive care whenever they need it and in many forms, not just face-to-face visits. This rule implies that 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.
- 2. Customization based on patient needs and values.** The system of care should be designed to meet the most common types of needs but have the capability to respond to individual patient choices and preferences.
- 3. The patient as the source of control.** Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision making.
- 4. Shared knowledge and the free flow of information.** Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information.
- 5. Evidence-based decision making. Patients should receive care based on the best available scientific knowledge.** Care should not vary illogically from clinician to clinician or from place to place.
- 6. Safety as a system property.** Patients should be safe from injury caused by the care system. Reducing risk and ensuring safety require greater attention to systems that help prevent and mitigate errors.
- 7. The need for transparency.** The health care system should make information available to patients and their families that allows them to make informed decisions when selecting a health plan, hospital, or clinical practice or choosing among alternative treatments. This should include information describing the system's performance on safety, evidence-based practice, and patient satisfaction.
- 8. Anticipation of needs.** The health system should anticipate patient needs rather than simply reacting to events.
- 9. Continuous decrease in waste.** The health system should not waste resources or patient time.
- 10. Cooperation among clinicians.** Clinicians and institutions should actively collaborate and communicate to ensure an appropriate exchange of information and coordination of care.

^a Reprinted with permission from *Crossing the Quality Chasm* © 2001 by the National Academy of Sciences, courtesy of the National Academies Press, Washington, DC, Table 2, pp. 8–9.

Barriers to Shared Decision Making

We do it already!

My patients don't want it

I don't have the time!

Will it work?

I don't know how to do it!



What if they don't do what I think they should do?

Barriers to SDM are Not Easily Overcome

Healthcare providers

- Challenge to autonomy
- Don't want to recognize preference sensitive decisions
- Difficulty in communicating nuanced data to non-medical individuals

Practice

- Lack of time
- Lack of reimbursement
- Logistics are not conducive to practicing SDM

Patients

- Patients want to give up autonomy
- Literacy challenges

Lack of Decision Aids

What's the Barrier?

Why should I incorporate SDM?

OR

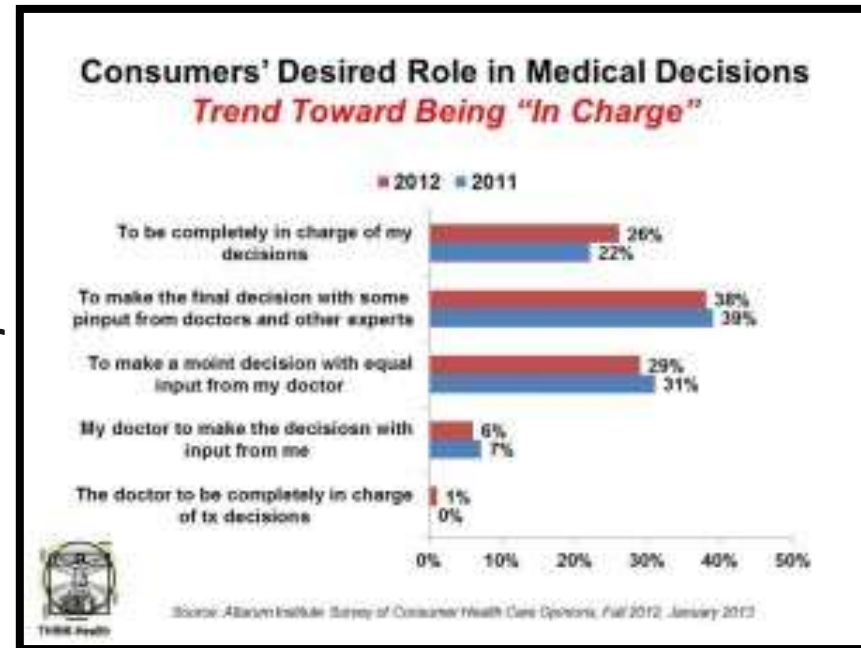
How can I incorporate SDM?

Why Should We Incorporate SDM?

- **Ethical imperative** (patients want to be involved, and clinicians think they're doing it by they are not)
- **Legal imperative** (medicolegal requirement to discuss options, risks, and consequences)
- **Evidence based care** (patients are more knowledgeable than we give them credit for)
- **Appropriate allocation of resources** (patients get 'the care they *need* and no less, the care they *want* and no more')

Misalignment of Physician-Patient Perceptions

- 85% of physicians believe that they share decisions about treatments with patients... 50% of patients believe this to be true
- Only 65% of patients feel that they had enough information for a recent decision
- Patients are more willing to use decision aids than providers perceive
- Patients willing to discuss decisions with other members of healthcare team more than physicians perceive



Activating Patients Empowers Them



Activating Patients Empowers Them

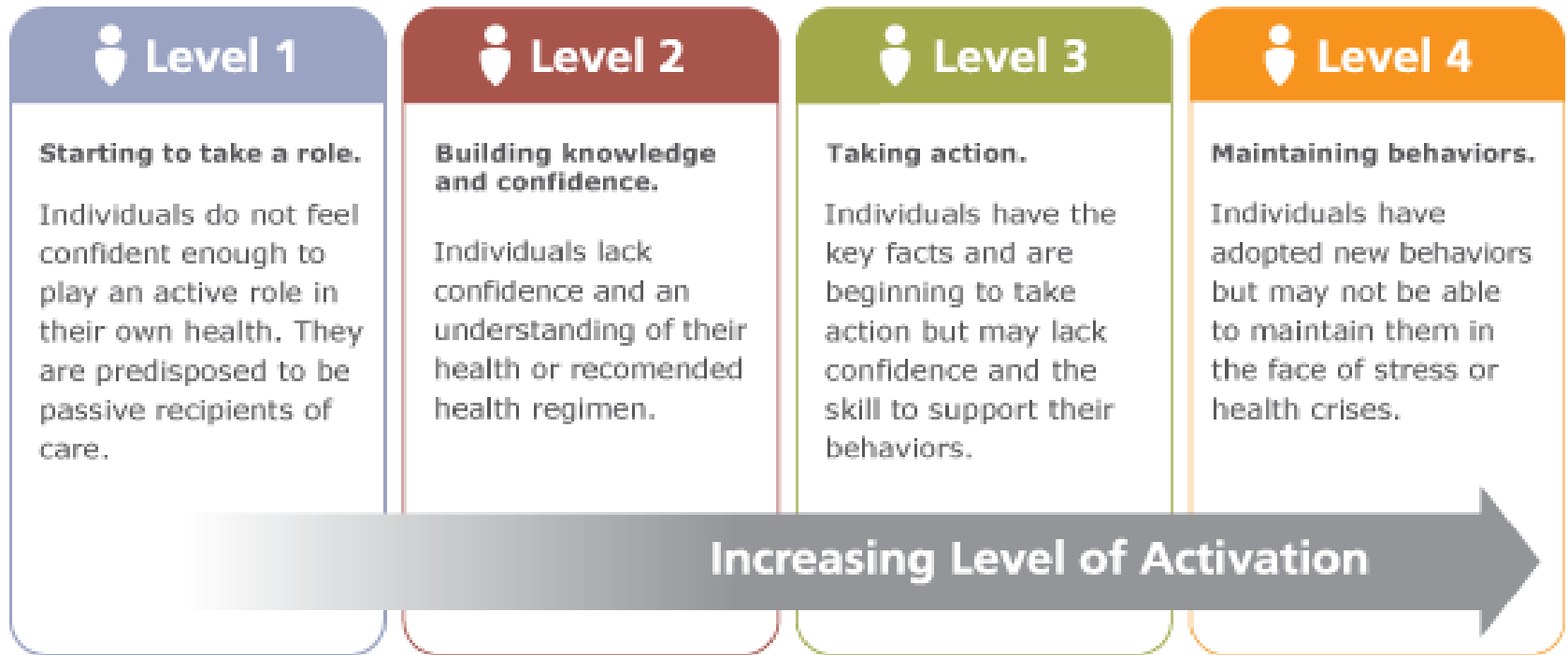


Patient Activation Measure

- **Activated** patients with the knowledge and skills to manage their own health and healthcare...
- **...Working in partnership** with prepared and trained clinical teams in scheduled appointments in a supportive system...
- **...To proactively manage health** and to anticipate and plan for times of need (care planning and anticipatory care planning)

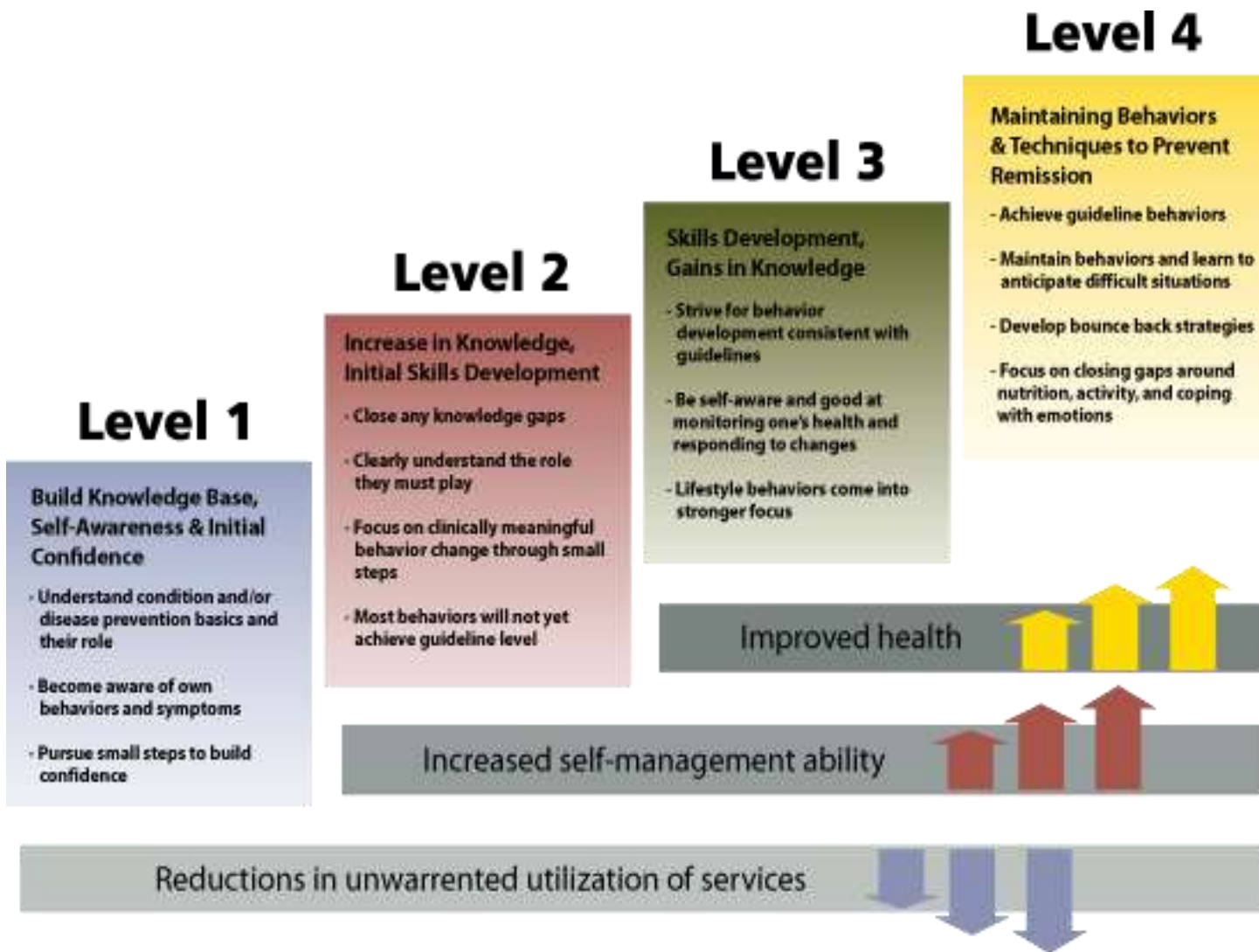
Hibbard JH et al. *Health Services Research*. 2004.

Patient Activation is a Journey



Compared with people at low levels of activation, people at high levels of activation tend to enjoy a higher quality of life, have better clinical outcomes and make more informed decisions about accessing medical services.

Levels of Activation: A Tailored Approach



Shared decision making about treatments:

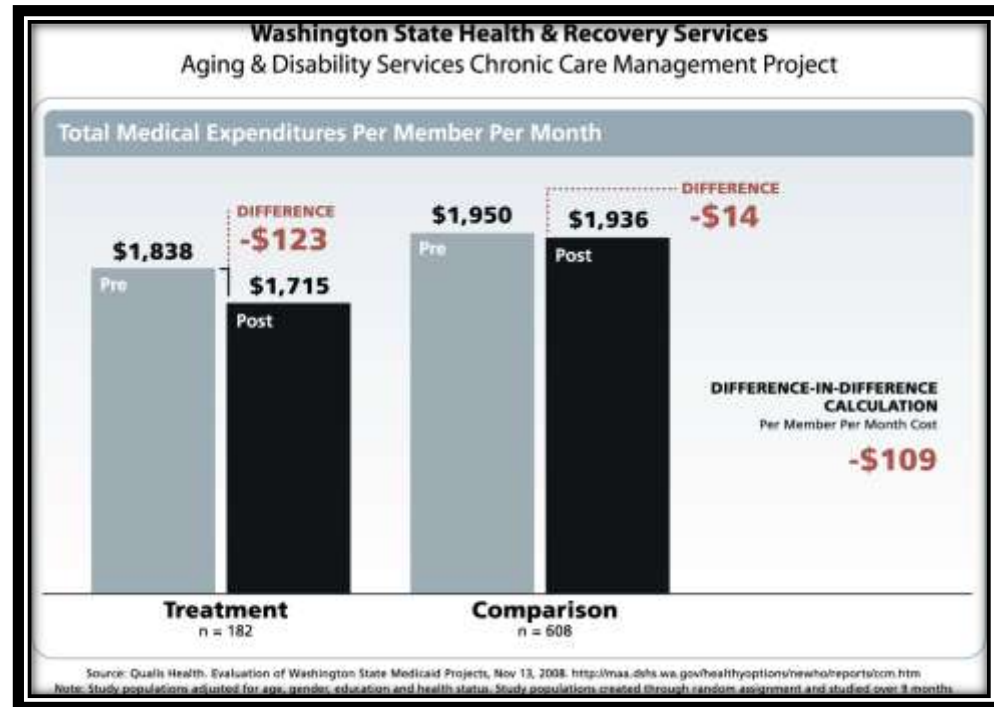
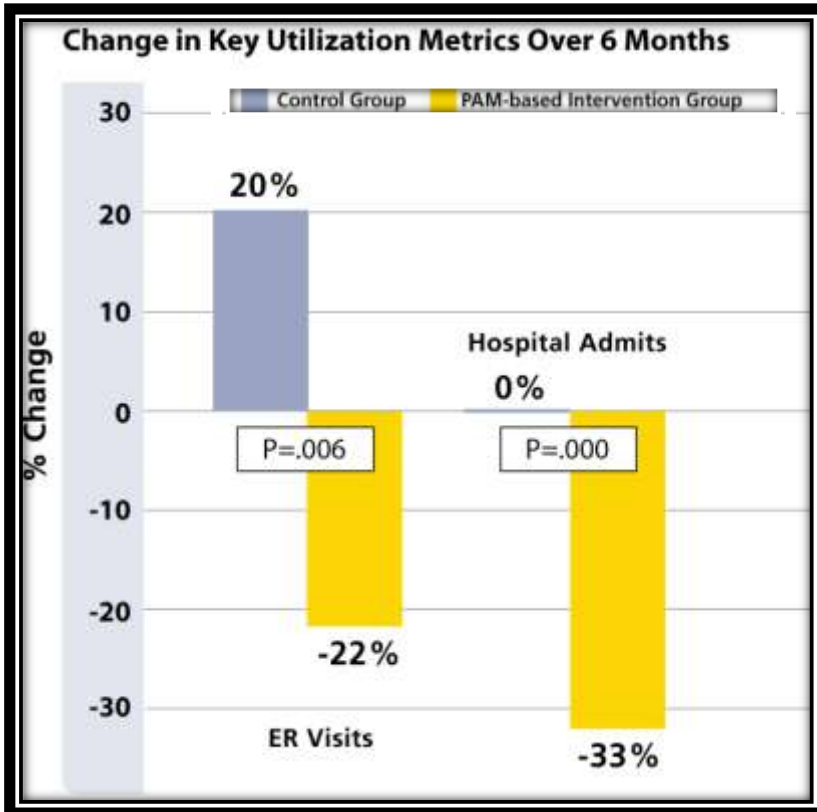
Patients who don't have decision support:

- Are 59 times more likely to change their mind
- Are 23 times more likely to delay their decision
- Are five times for likely to regret their decision
- Blame their practitioner for bad outcomes 19% more often

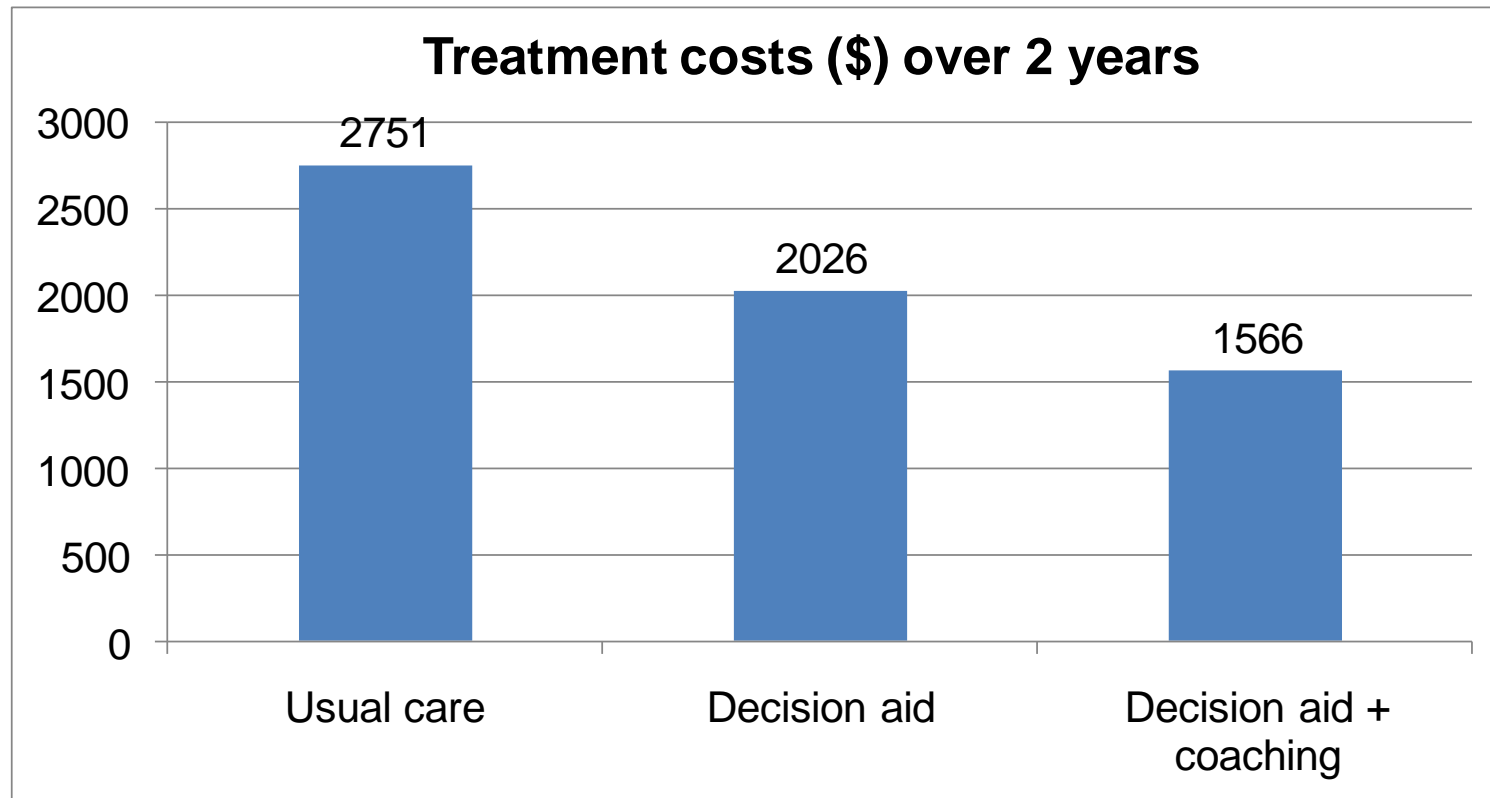
Shared decision making about treatments:

- Reduces unwarranted variation due to practitioner preferences
- Improves satisfaction
- Reduces wish to proceed to invasive treatments
- Reduces negligence claims

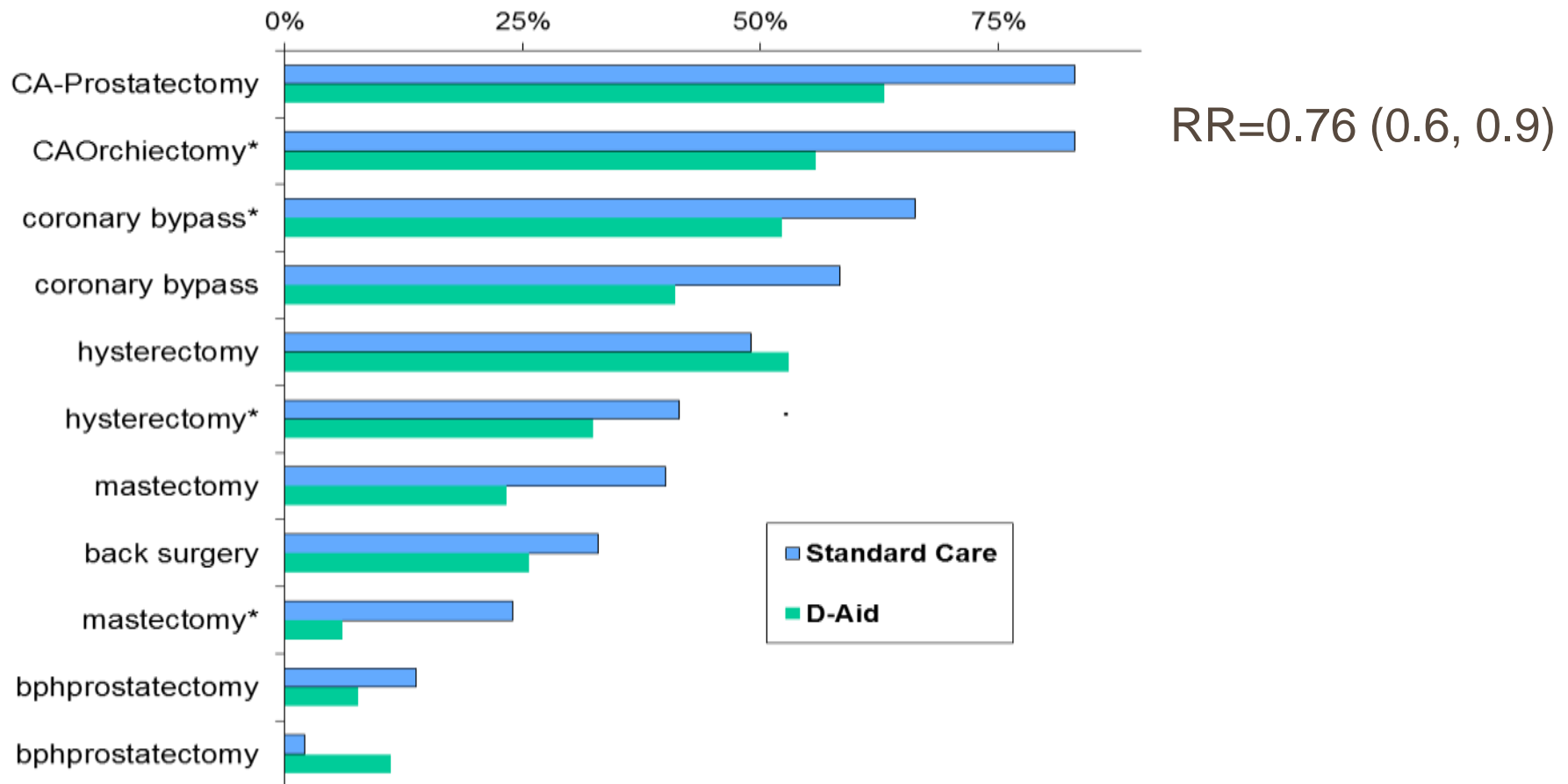
Benefits of Patient Activation



Decision aid and coaching in gynaecology



Decision Aids reduce rates of discretionary surgery



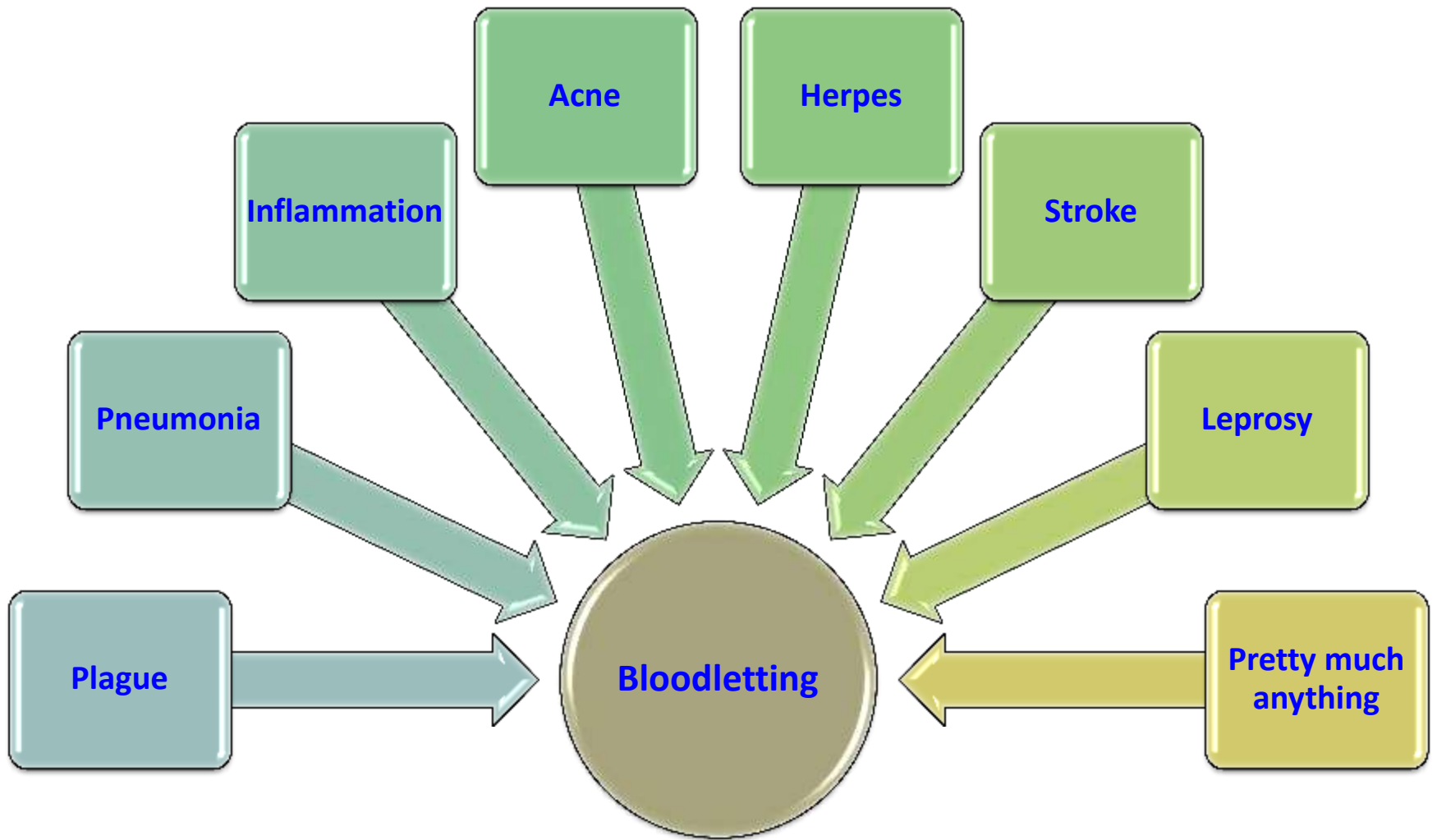
Self management of warfarin and INR.

Cochrane review Heneghan et al April 2010

1. Clinician management of warfarin and INR
2. Self monitoring of INR and clinician advice re: warfarin dose
3. Self management of INR and warfarin

Compared to groups 1 and 2, group 3 have

- same risk of bleeding
- 50% fewer thrombotic episodes
- 36% lower mortality



Patient Activation Through Decision Aids

...People are supported to make *informed* and *personally relevant* decisions about managing their own health and healthcare



Am I going to stick to that exercise regime?

Should I take that pill today?

Do I really want that heart operation?

Types of Decision Aids

Format

- Paper and pencil
- Boards
- Audio booklets
- Videos
- Computer interactive
 - CDs
 - Web-based
 - <http://www.optiongrid.org/>
 - <http://decisionaid.ohri.ca/>
 - www.hitchcock.org/dept/csdm
 - <http://decisionaid.ohri.ca>
 - www.fimdm.org

To be used

- Alone
- With family members
- With practitioner
- With health educator

TREATING YOUR High Cholesterol



THE Facts:

What is cholesterol?

- A type of fat in the blood
- Comes from the food you eat
- Normally made by the body

What can high cholesterol cause?

- **Heart Attack**
 - Blood vessels to the heart muscle get clogged
 - Part of the heart gets damaged
- **Stroke**
 - Blood vessels to the brain get clogged
 - Part of the brain gets damaged

How can you lower your risk?

- Eating right
- Exercise
- **A pill like a statin**
 - Lowers the cholesterol the body makes
 - Lowers the risk of heart attack or stroke
 - Works only if you take it every day

JOHN'S Story



- Had high cholesterol
- Is taking a statin
- Originally had headaches
- Talked to his doctor
- Changed to a different statin pill
- Lowered his cholesterol
- Is doing fine!



HOW MUCH WILL A Statin help?



- 😊 Avoided a heart attack or stroke by taking a statin
- 😄 Did not have a heart attack or stroke
- 😞 Had a heart attack or stroke

For every 100 people taking a statin

- ⦿ Six people missed having a heart attack or stroke by taking a statin every day.
- ⦿ If you already had a heart attack or stroke, then your benefits from a statin are even better!



ROSA'S Story



- ⦿ Has diabetes and high blood pressure
- ⦿ Doctor said she should take a statin
- ⦿ Didn't want to take another pill
- ⦿ She had a heart attack
- ⦿ She got better and started taking a statin
- ⦿ 15 years later, she is doing fine!

WHAT ARE THE Side Effects?

NOTES FOR MY NEXT Doctor's Visit

.....

.....

.....

.....



Skin rash



Headache



Upset stomach

- Most of these side effects go away in a week



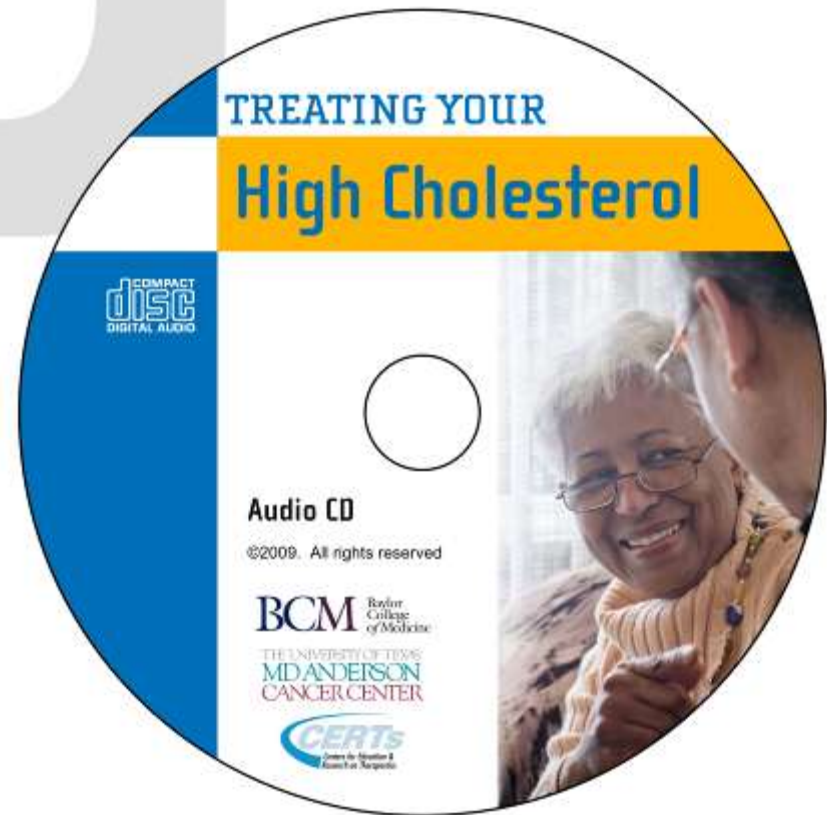
Muscle aches

- People often have aches, but it is not from the statin.
- Usually caused by something else!



What else will my doctor check?

- Your liver to make sure it is doing ok
- If you have problems, talk to your doctor



A Patchwork of Life: One Woman's Story

For Women Making Breast Cancer
Treatment Decisions

Baylor College of Medicine





A Patchwork of Life

- About Breast Cancer
- Breast Cancer Diagnosis
- Making a Surgery Decision

✓ Story/video

✓ How to Use this Section

✓ Therapies and Tests Before Surgery

✓ Lumpectomy or Breast Conserving Surgery

✓ Radiation Therapy

● Mastectomy

● Breast Reconstruction and Prosthesis

✓ Comparison of Lumpectomy and Mastectomy

✓ Consequences of Not Receiving Treatment

✓ Participation in Clinical Studies

✓ Steps for Making an Initial Decision

Making a Surgery Decision



RESTART



PAUSE

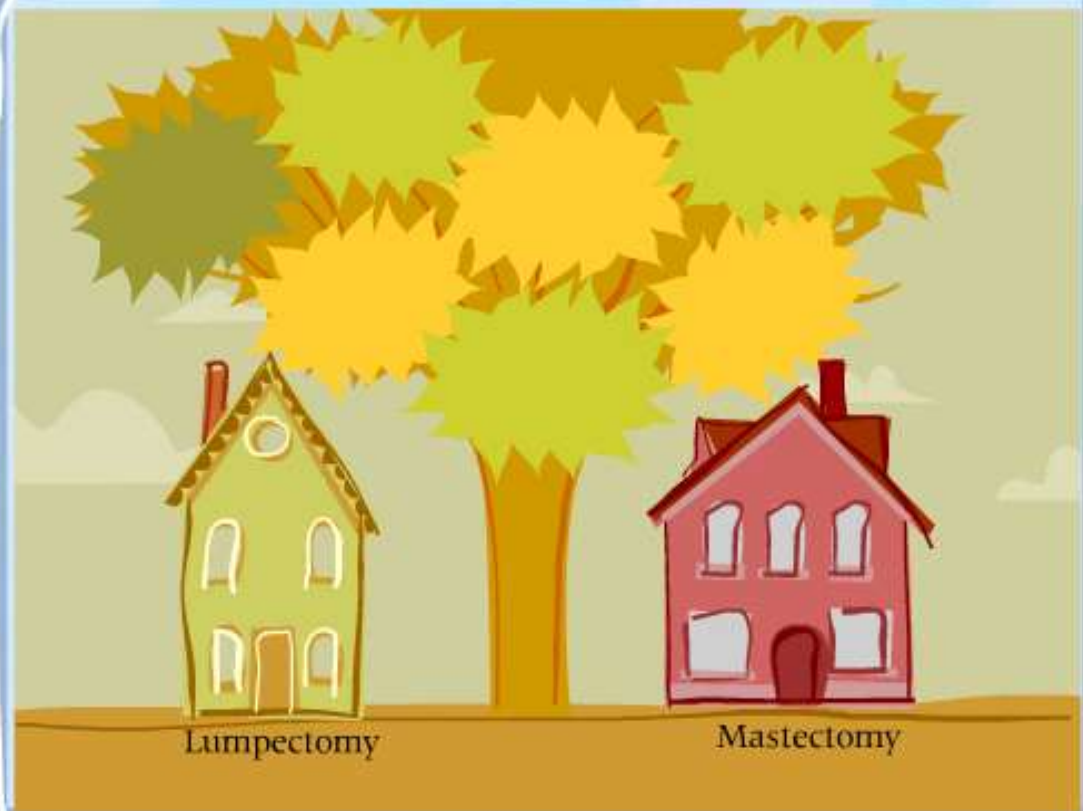


A Patchwork of Life

- About Breast Cancer
- Breast Cancer Diagnosis
- Making a Surgery Decision
 - ✓ Story/video
 - **How to Use this Section**
 - Therapies and Tests Before Surgery
 - Lumpectomy or Breast Conserving Surgery
 - Radiation Therapy
 - Mastectomy
 - Breast Reconstruction and Prosthesis
 - Comparison of Lumpectomy and Mastectomy
 - Consequences of Not Receiving Treatment
 - Participation in Clinical Studies
 - Steps for Making an Initial Decision
 - Story/video Conclusion
- Medical and Anti-Estrogen Treatments

Making a Surgery Decision

How to Use this Section



← BACK

REPEAT

NEXT →



A Patchwork of Life

- About Breast Cancer
- Breast Cancer Diagnosis
- Making a Surgery Decision
 - ✓ Story/video
 - ✓ How to Use this Section
 - ✓ Therapies and Tests Before Surgery
 - ✓ Lumpectomy or Breast Conserving Surgery
- Radiation Therapy
- Mastectomy
- Breast Reconstruction and Prosthesis
- Comparison of Lumpectomy and Mastectomy
- Consequences of Not Receiving Treatment
- Participation in Clinical Studies
- ✓ Steps for Making an Initial Decision

Making a Surgery Decision

Consequences of Not Receiving Radiation

Effective in killing microscopic cancer cells left behind



< 5%



A Patchwork of Life

- About Breast Cancer
- Breast Cancer Diagnosis
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 - ✓ Story/video
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Making a Surgery Decision

Introduction

1. Compare lumpectomy and mastectomy

2. Review items in jewelry box

3. Make an initial choice



A Patchwork of Life: One Woman's Story

For Women Making Breast Cancer Treatment Decisions

Possible surgical options to treat early stage breast cancer:

Lumpectomy, Mastectomy

My initial treatment decision: Lumpectomy

Things I want to discuss with my doctor:

- **Therapies and Tests Before Surgery**
 - ✓ More chemotherapy after surgery



A Patchwork of Life

- About Breast Cancer
- Breast Cancer Diagnosis
- Making a Surgery Decision
 - ✓ Story/video
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Making a Surgery Decision

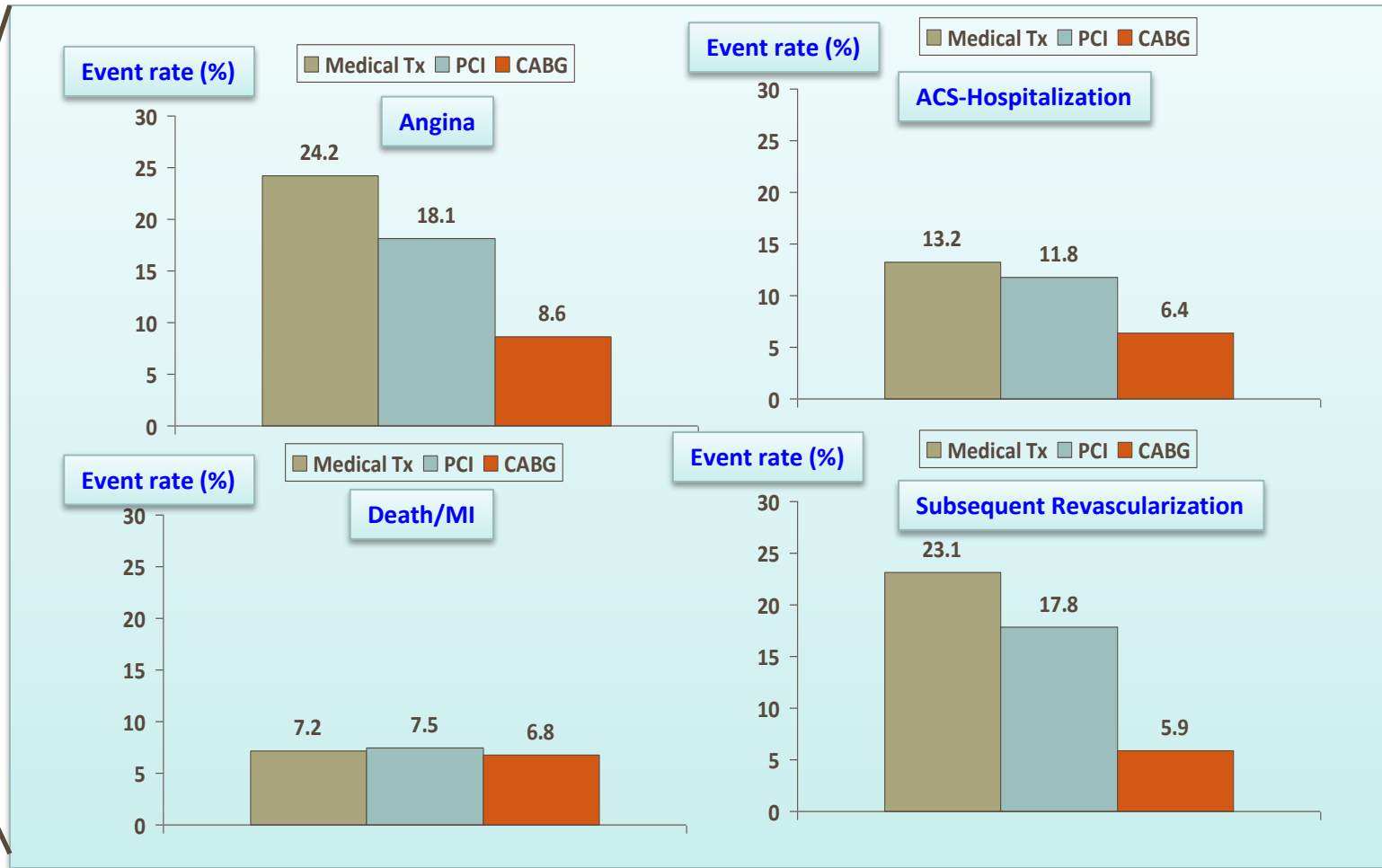
Introduction

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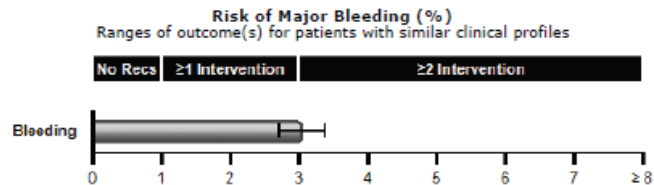
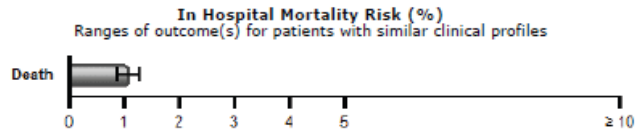
3. Make an initial choice

Coronary Revascularization Aid



Other New Decision Aids in Cardiology

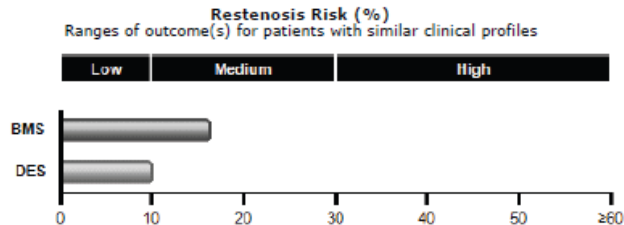
Patient-Specific Risk Assessments for PCI



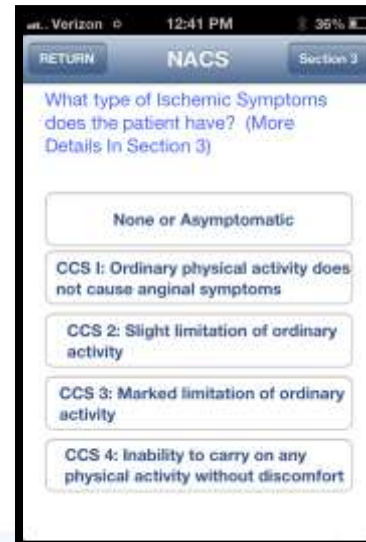
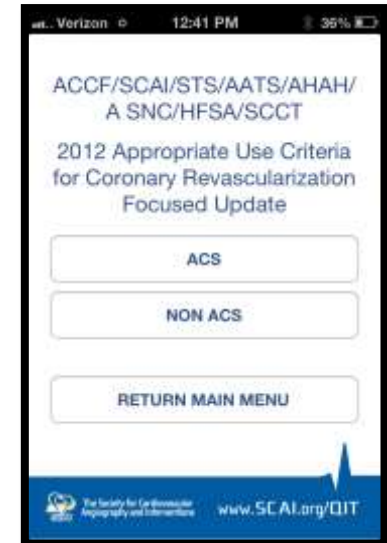
Potential interventions include:

Bleeding avoidance therapies: (1) bivalirudin, (2) closure device, and/or (3) radial case.

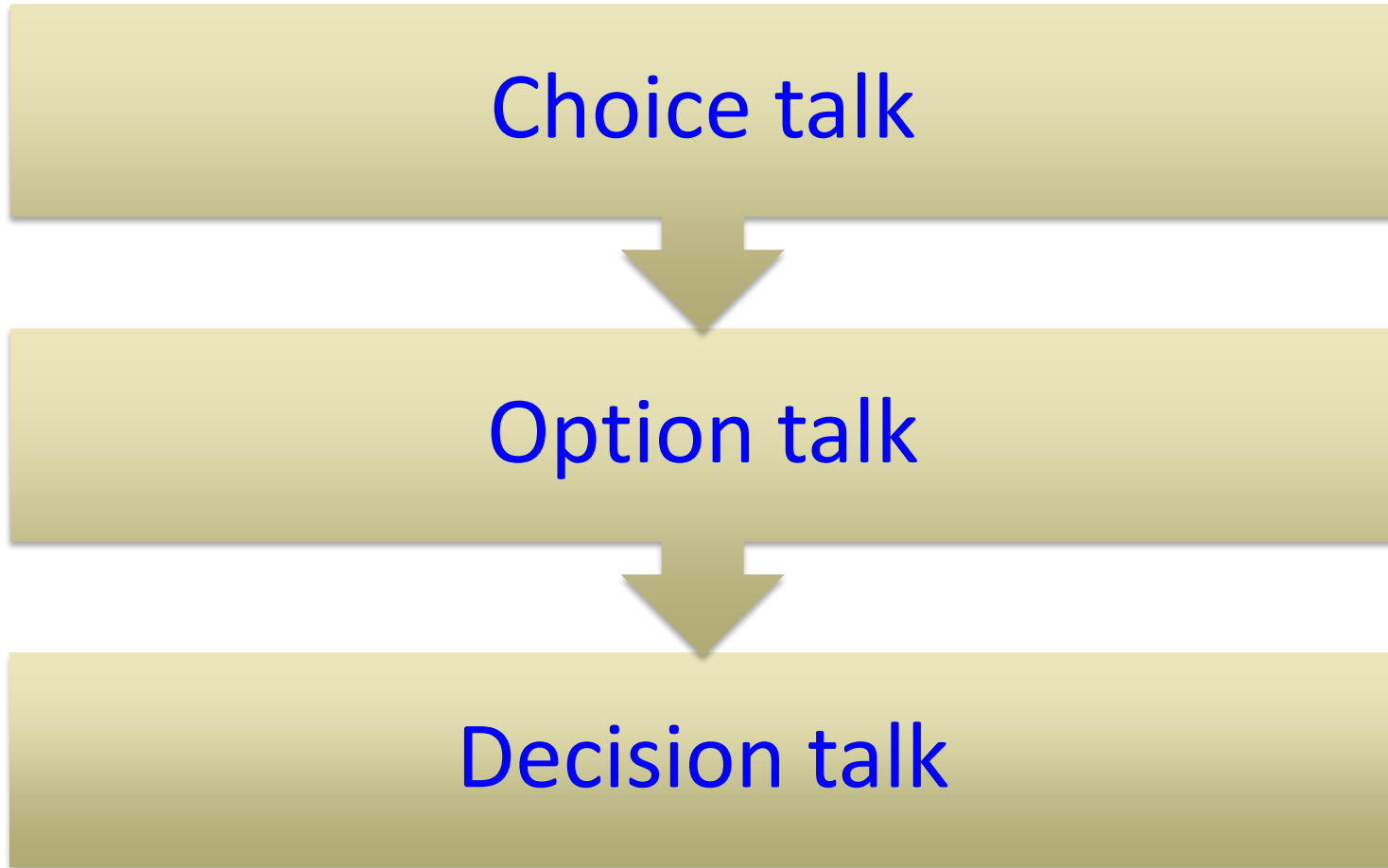
Additional actions: (1) inpatient admission, and/or (2) small sheath sizes.



Consider BMS for low risk patients, and DES for high risk patients.



3 key stages



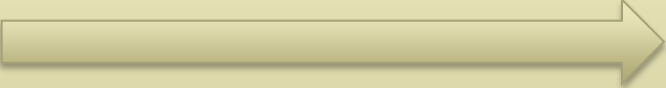
2 key enablers

Provide decision aid/option grid



Support deliberation

Deliberation

Prior preference  Informed preference

Choice talk

Option talk

Decision talk

Decision support

Choice talk

1. **Establish** diagnosis or explanation
2. **Step back.** Check there is agreement on nature of the problem.

‘we agree that there is a problem with arthritis in your knee....pause’

3. **Choice exists.** Be explicit- many patients expect to be told what to do.

‘There are a number of things we can discuss’

‘I’d like to share some information with you about your options- is that OK?’

Choice talk

4. Justify choice and clarify partnership/support

'We need to think about what's important for you'

'I am here to help you think this through'

5. Check reaction. Patient engagement may be evident- however if not:

'Before we think this through in more detail, I just want to check that you are comfortable with us thinking this through together'

6. Defer closure and emphasize partnership. Some patients want you to decide; however this will lead to a decision that is not informed by 'what matters to them'

I really want us to come to a decision that's right for you. To help us do that, why don't we look at a little more information. Is that OK?

Clinical scenario

- Mrs Jones is 68
- She is overweight and complaining of knee pain
- An Xray confirms arthritis
- You have just told her she has arthritis
- The options she faces include getting more active, losing weight, taking analgesics or seeing a surgeon with a view to an injection or possible surgery

2. Option talk. Introduce option grid

Step 1. *'Here is an option grid'*

- Tell them that this is a summary of the reasonable options

Step 2. *'Please take a look at it'*

- Check they are happy to read it for themselves

Step 3. *'Highlight the bits that matter most to you'*

- Supports them to guide the conversation

2. Option talk.

Step 4. *'Do you have any questions?'*

- Focusses conversation on what matters for them

Step 5. *'It's yours to keep'*

- Reinforces that the information is theirs
- Remind them to look for other sources of information

3. Preference talk, decision talk

Step 6. *‘In terms of what you know about your options, what’s most important for you?’*

- An open question which invites patients to express their preferences; they may be most interested in risk, predictability, outcome, recovery etc etc

Step 7. *‘To come to a decision that’s right for you, what else do you need to know?’*

- Ask if patients have knowledge gaps as a result of expressing their preferences

3. Decision talk

Step 8. *‘Are we ready to make a decision about what’s right for you’*

- An open question that invites reflection
- May be followed by *‘what else do you need to know’*
- Or: *‘it’s natural to feel uncertain. Take your time.’*

Step 9. Patient articulates decision. Affirm decision, reinforce partnership.

- *‘We agree that we’ll go ahead and.....’*

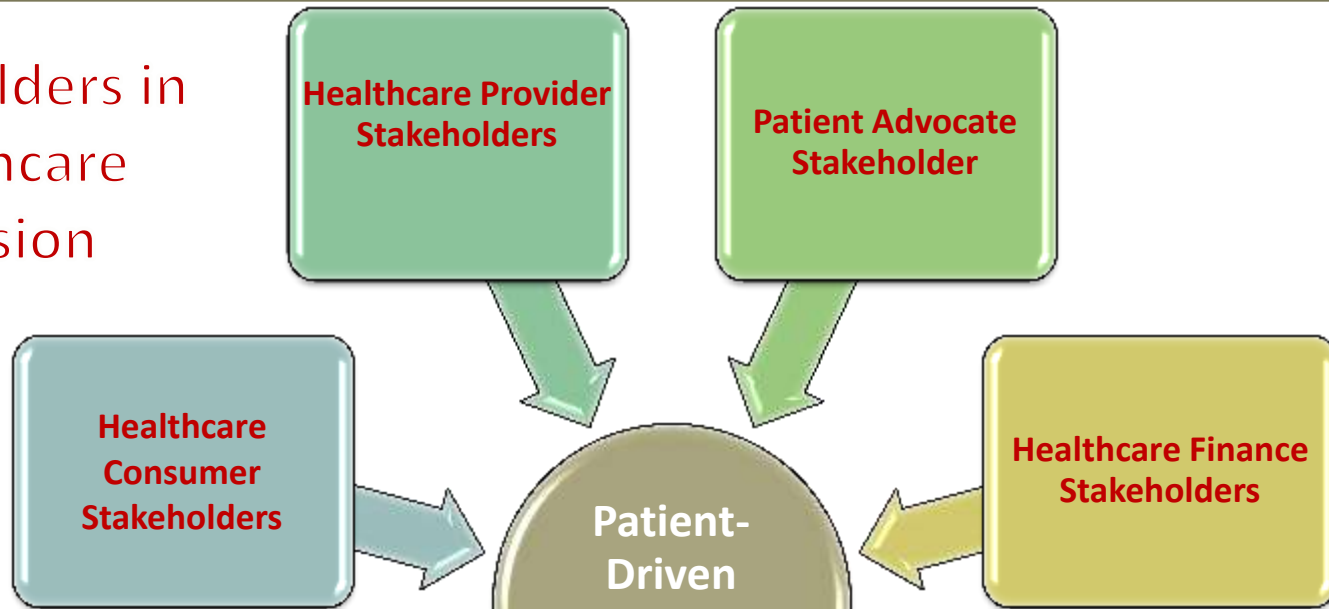
4. Confidence talk

Step 10. Check for confidence

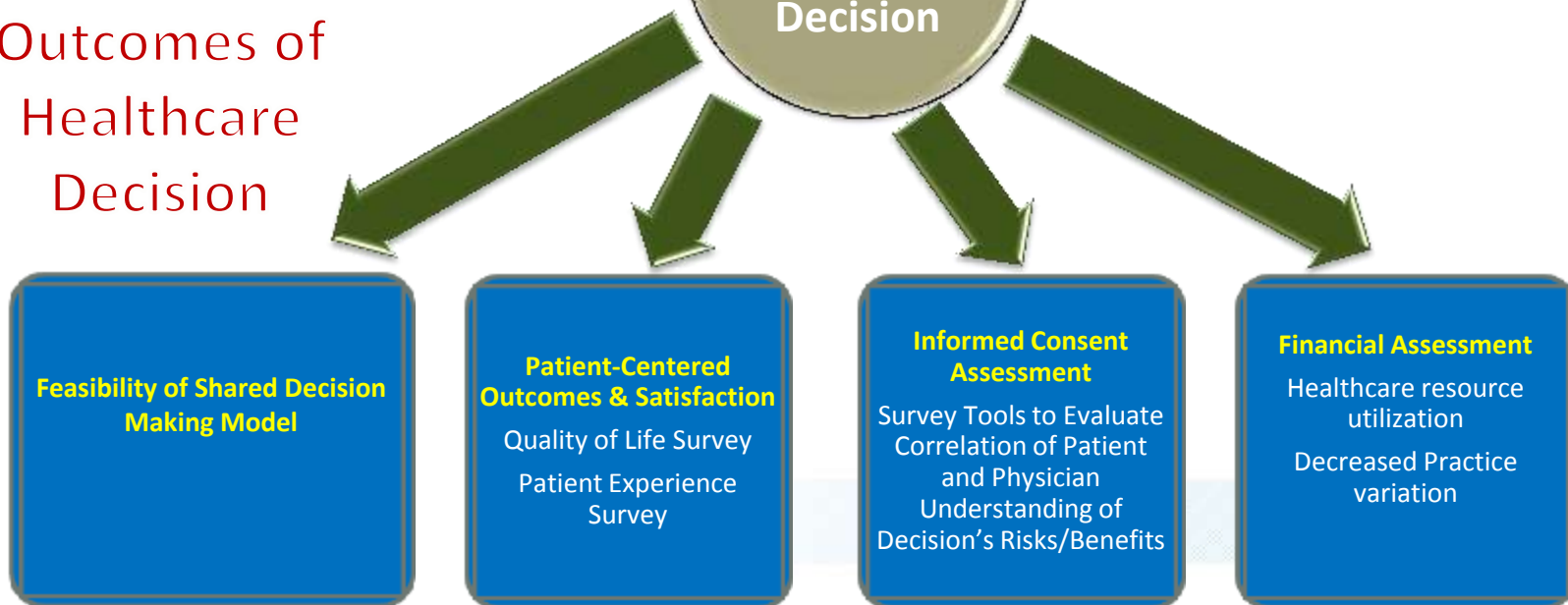
‘ On a scale of 0-10, how confident are you that this is the right decision for you?’

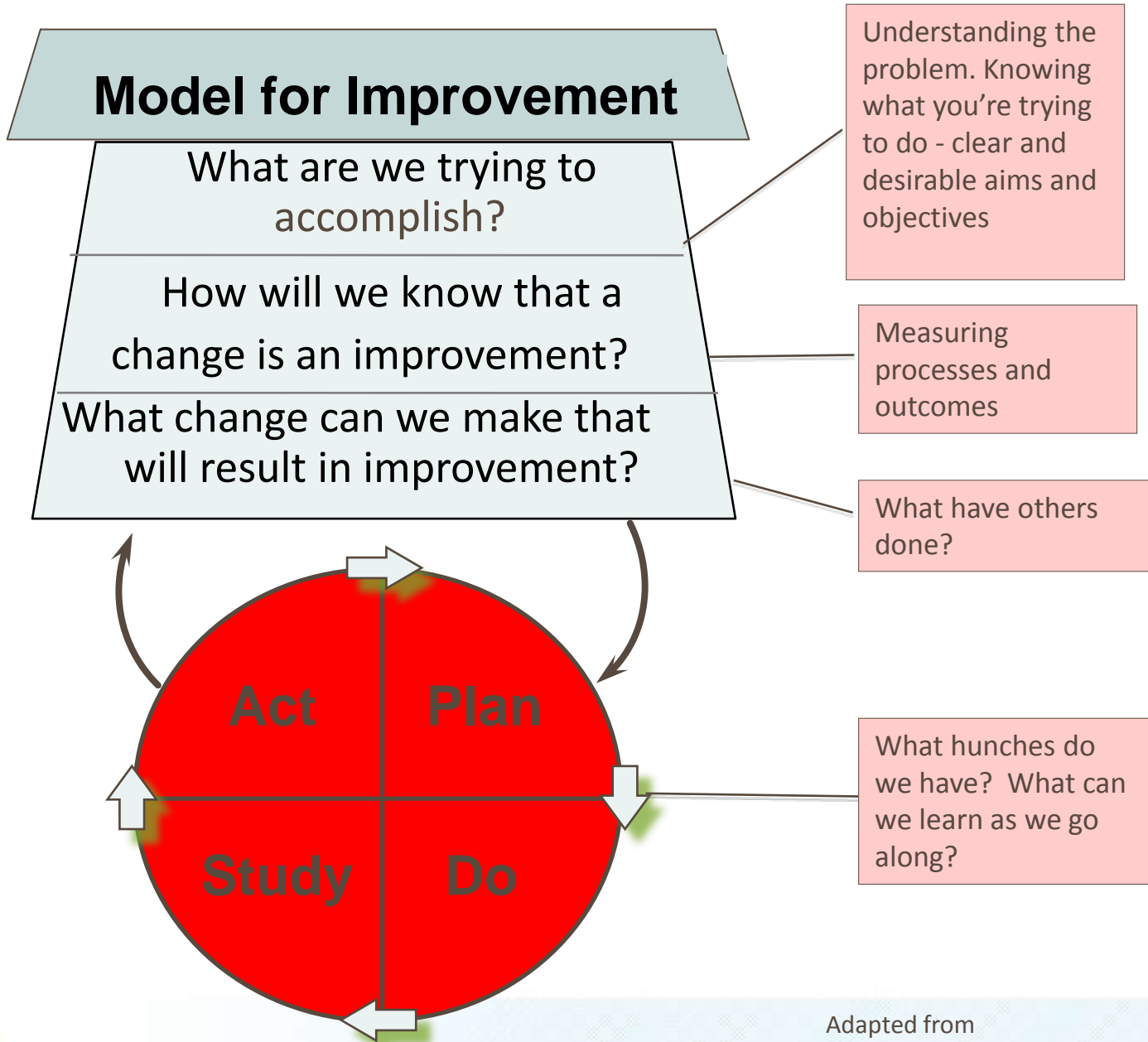
Shared Decision Making in Healthcare

Stakeholders in Healthcare Decision

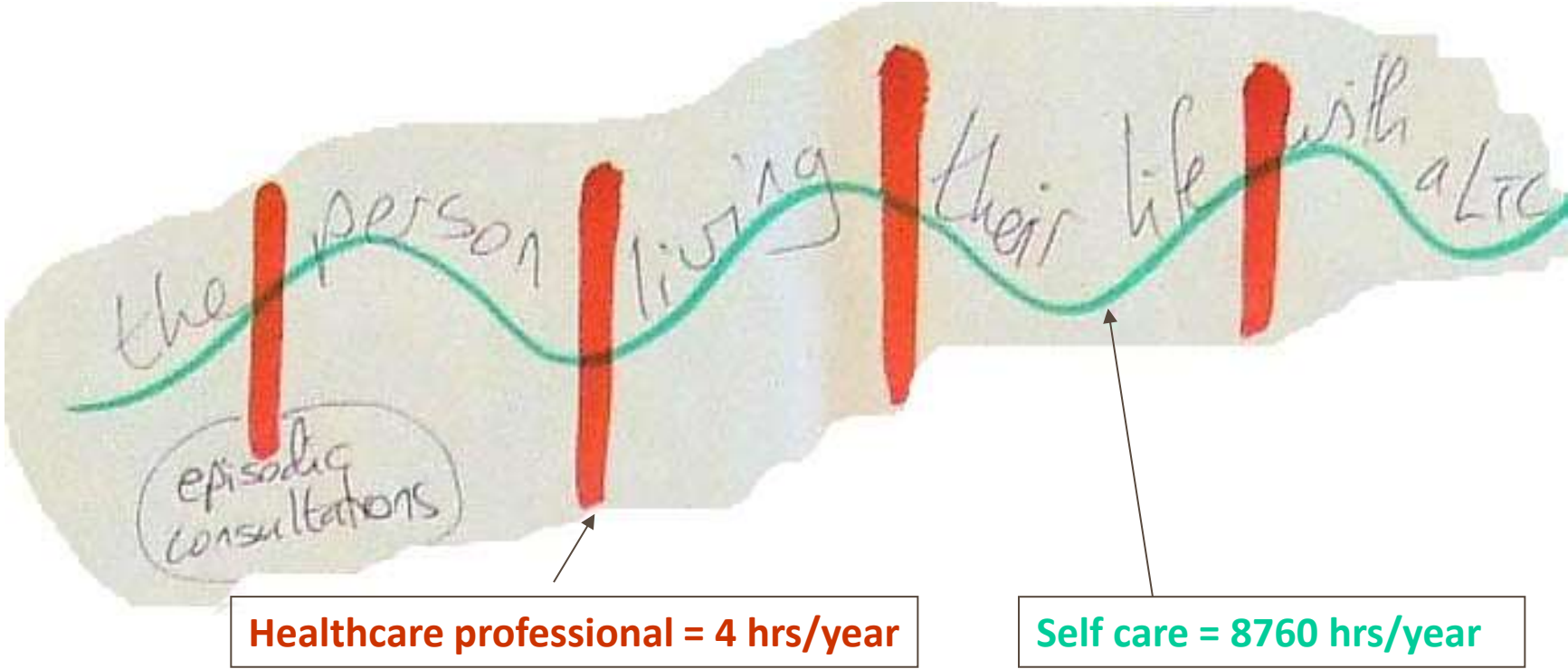


Outcomes of Healthcare Decision





Shared Decision Making: An Obligation to Patients



Beckwith Institute Grants: Making Shared Decision Making a Reality

THE
BECKWITH
INSTITUTE | FRONTLINE
INNOVATION
PROGRAM

THE
BECKWITH
INSTITUTE | CLINICAL
TRANSFORMATION
PROGRAM