Informed Medical
Decisions Program

Shared Decision Making: Why and How?

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Babson Executive Conference Center, Wellesley
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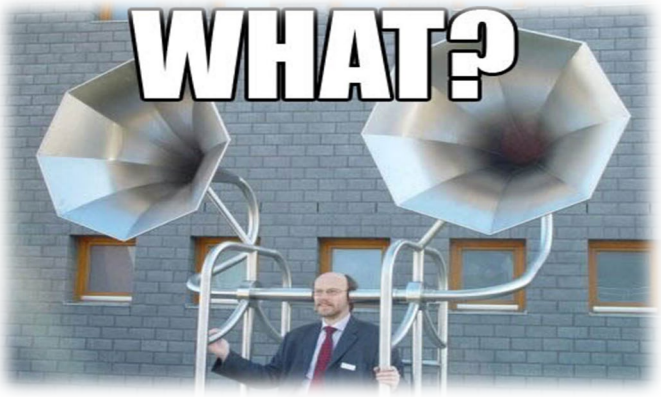
Informed Medical Decisions Program Vision

To inform and amplify the patient's voice in healthcare decisions.



Disclosure: I am a primary care physician at Massachusetts General Hospital (MGH) and Professor of Medicine at Harvard Medical School, both nonprofits.
I receive salary support from Amgen through MGH for a supplement to an NIH-funded clinical trial on gout management

The NEW ENGLAND JOURNAL of MEDICINE

Clinicians, in turn, need to relinquish their role as the single, paternalistic authority and train to become more effective coaches or partners — learning, in other words, how to ask, **"What matters to you?"** as well as **"What is the matter?"**

Barry and Susan Edgman-Levitan, P.A.

Shared Decision Making — The Pinnacle of Patient-Centered Care

Michael J. Barry, M.D., and Susan Edgman-Levitan, P.A.

Nothing about me without me.

— Valerie Billingham, *Through the Patient's Eyes*, Salzburg Seminar Session 356, 1998

Caring and compassion were once often the only "treatment" available to clinicians. Over time, advances in medical science have provided new options that, although often improving outcomes, have inadvertently distanced physicians from their patients. The result is a health care environment in which patients and their families are often excluded from important discussions and left feeling in the dark about how their problems are being managed and how to navigate the overwhelming array of diagnostic and treatment options available to them.

An audio interview with Dr. Barry is available at NEJM.org

In 1988, the Picker/Commonwealth Program for Patient-Centered Care (now the Picker Institute) coined the term "patient-centered care" to call attention to the need for clinicians, staff, and health care systems to shift their focus away from diseases and back to the patient and family.[1] The term was meant to stress the importance of better understanding the experience of illness and of addressing patients' needs within an increasingly complex and fragmented health care delivery system.

The Picker Institute, in partnership with patients and families, conducted a multiyear research project and ultimately identified eight characteristics of care as the most important indicators of quality and safety, from the perspective of patients: respect for the patient's values, preferences, and expressed needs; coordinated and integrated care; clear, high-quality information and education for the patient and family; physical comfort, including pain management; emotional support and alleviation of fear and anxiety; involvement of family members and friends, as appropriate; continuity, including through care-site transitions; and access to care.[1] Successfully addressing these dimensions requires enlisting patients and families as allies in designing, implementing, and evaluating care systems.

This concept was introduced in the landmark Institute of Medicine (IOM) report *Crossing the Quality Chasm*[2] as one of the fundamental approaches to improving the quality of U.S. health care. The IOM defined patient-centered care as "care that is respectful of and responsive to individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions." This definition highlights the importance of clinicians and patients working together to produce the best outcomes possible.

As the definition implies, the most important attribute of patient-centered care is the active engagement of patients when fateful health care decisions must be made — when an individual patient arrives at a crossroads of medical options, where the diverging paths have different and important consequences with lasting implications. Examples include decisions about major surgery, medications that must be taken for the rest of one's life, and screening and diagnostic tests that can trigger cascades of serious and stressful interventions.

For some decisions, there is one clearly superior path, and patient preferences play little or no role — a fractured hip needs repair, acute appendicitis necessitates surgery, and bacterial meningitis requires antibiotics. For most medical decisions, however, more than one reasonable path forward exists (including the option of doing nothing, when appropriate), and different paths entail different combinations of possible therapeutic effects and side effects. Decisions about therapy for early-stage breast cancer or prostate cancer, lipid-lowering medication for the primary prevention of coronary heart disease, and genetic and cancer screening tests are good examples. In such cases, patient involvement in decision making adds substantial value.

In an influential article on clinical practice guidelines, David Eddy argued that an intervention should be considered a "standard" only if there is "virtual unanimity among patients about the overall desirability . . . of the outcomes."[3] For the vast majority of decisions in which there is no intervention that meets this high bar, patients need to be involved in determining the management strategy most consistent with their preferences and values.

The process by which the optimal decision may be reached for a patient at a fateful health crossroads is called shared decision making and involves, at minimum, a clinician and the patient, although other members of the

50 Countries
2,000+ Teams

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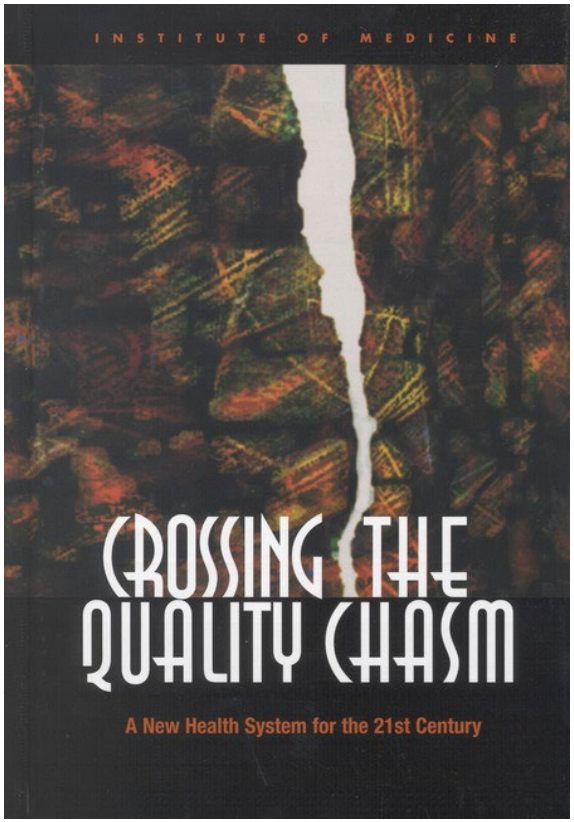
WMTY Day at MGH

IOM/NAM Crossing the Quality Chasm Report (2001)



Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001. PMID: 25057539.

Six Dimensions of Health Care Quality

1.	**Safe:** Avoiding injuries to patients from the care that is intended to help them
2.	**Timely:** Reducing waits and sometimes harmful delays for patients and providers
3.	**Effective:** Providing the appropriate level of services based on scientific knowledge
4.	**Efficient:** Avoiding waste, including waste of equipment, supplies, ideas, and energy
5.	**Equitable:** Providing care that does not vary in quality because of personal characteristics
6.	**Patient-Centered:** Providing care that is respectful of and responsive to individual patients

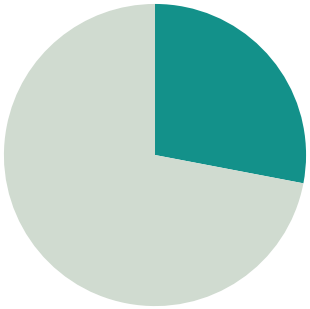
Patient-Centered Care

Providing care that is respectful of and responsive to individual patient preferences, needs, and values and that patient values guide all clinical decisions.

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.

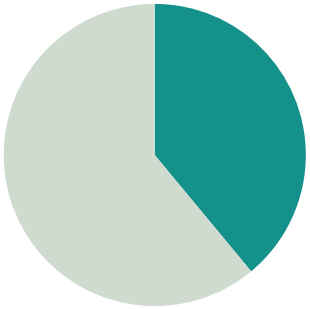
Are patients informed? Not very!

Percentage of patients undergoing hip or knee arthroplasty who answered each knowledge question correctly:



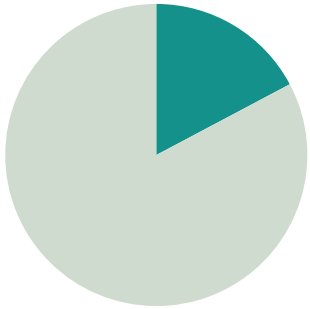
28%

How many people **get pain relief from surgery**



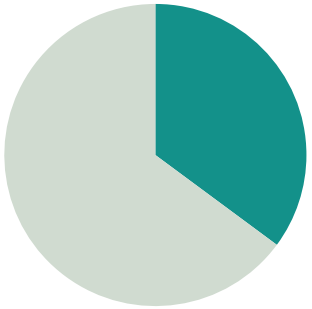
46%

How many people **experience surgical complication (e.g., wound infection)**



15%

How many people will have **replacement at least 20 years**

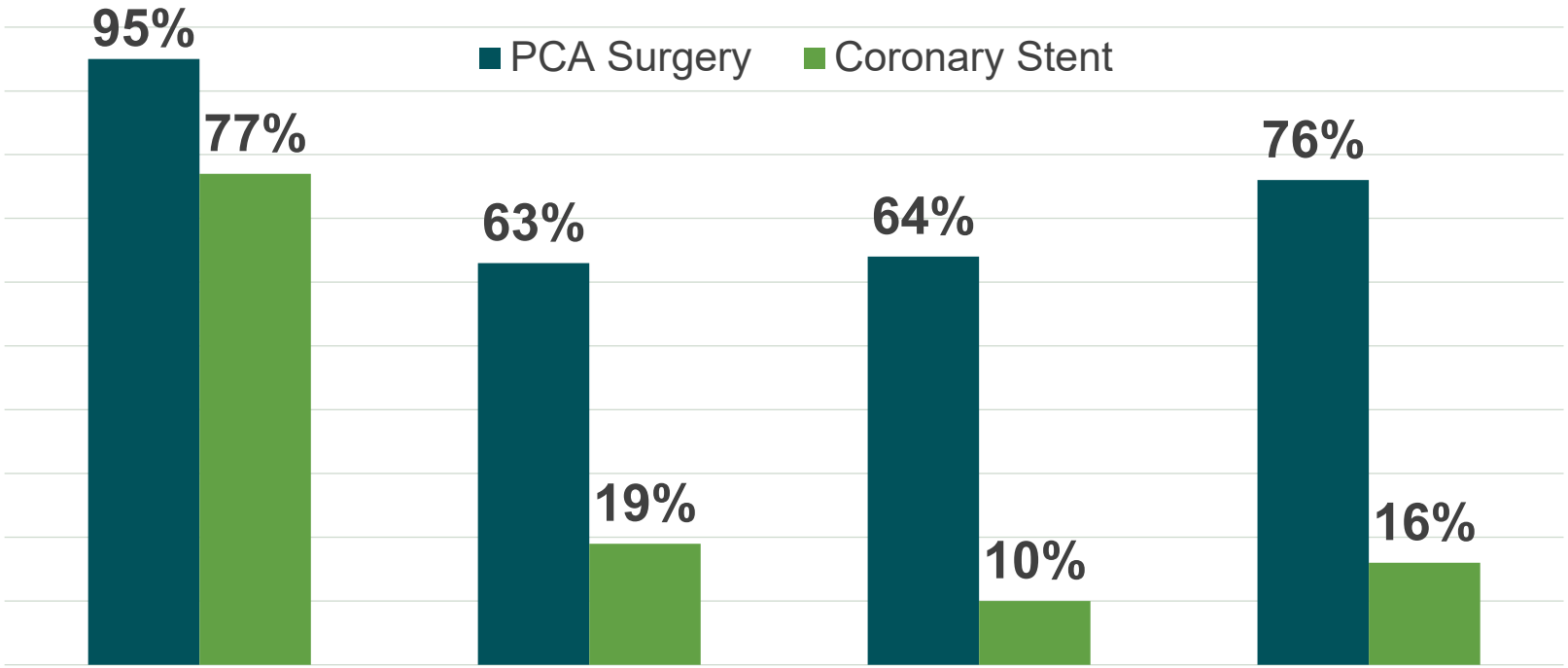


39%

How many people **return to normal activity**

Fagerlin A, et al. (2010). *Med Decis Making.* 30(5 Suppl): 35S-52S.

Are patients involved? It depends!



Fowler FJ, et al. (2012). *JGIM.* 27(8): 911-16.

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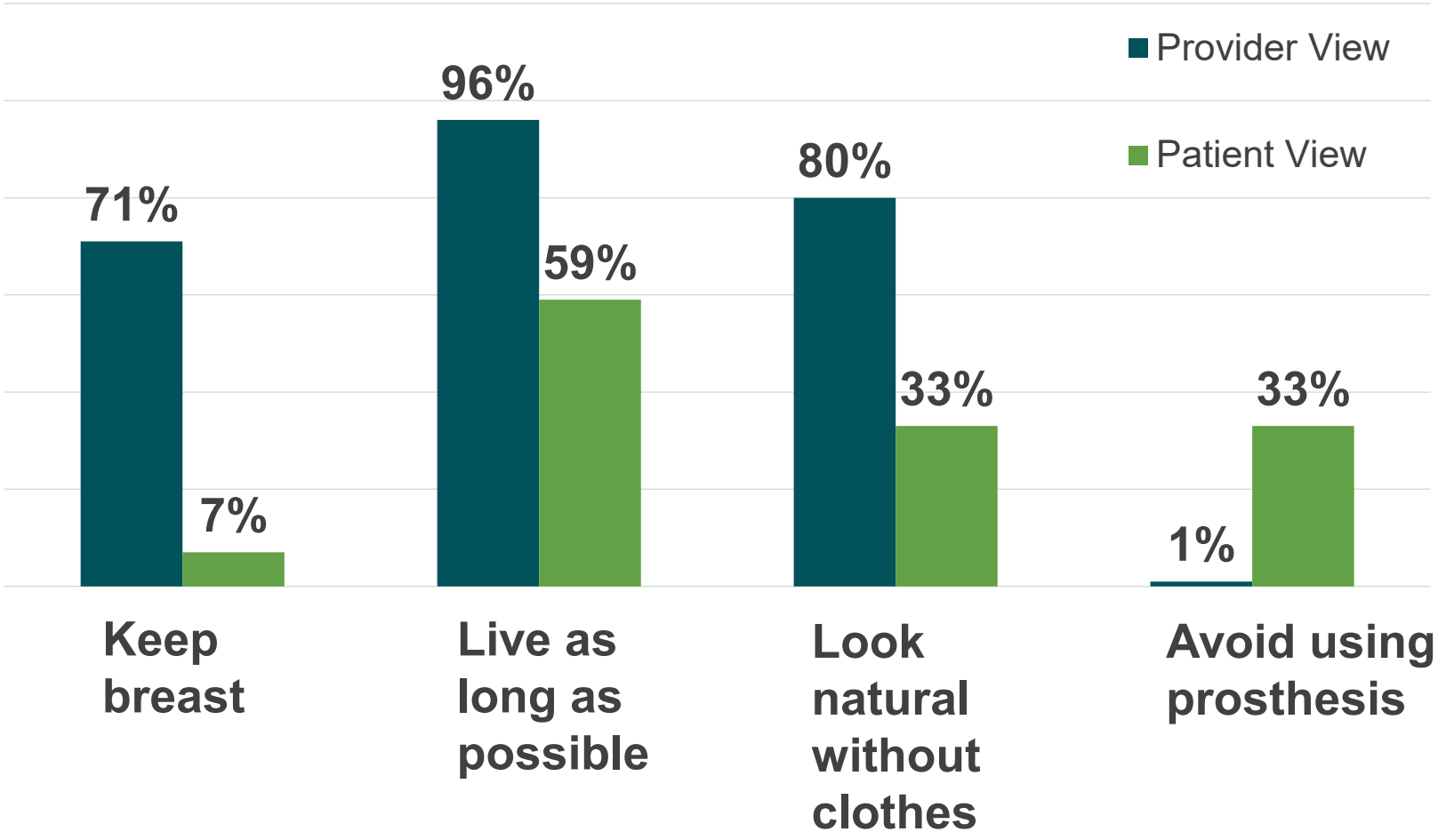
Top four goals and concerns for breast cancer decisions



Sepucha K, et al. (2008). *Patient Educ Couns.* 73: 504-10.

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The silent misdiagnosis

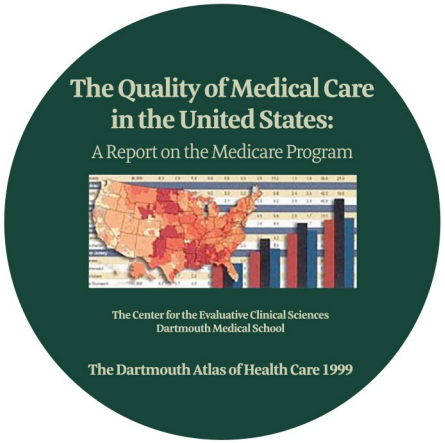
“Many doctors aspire to excellence in diagnosing disease. Far fewer, unfortunately, aspire to the same standards of excellence in diagnosing what patients want.”

Al Mulley, Chris Trimble, Glyn Elwyn

Mulley A, et al. (2012). Patients’ preferences matter: Stop the silent misdiagnosis. London: The King’s Fund.

Forces sustaining unwanted practice variation

Patients:
Making decisions in the face of avoidable ignorance



Clinicians:
Less than optimal "diagnosis" of patients' preferences

Poor Decision Quality
Unwanted Practice Variation

A word on taxonomy

Effective Care

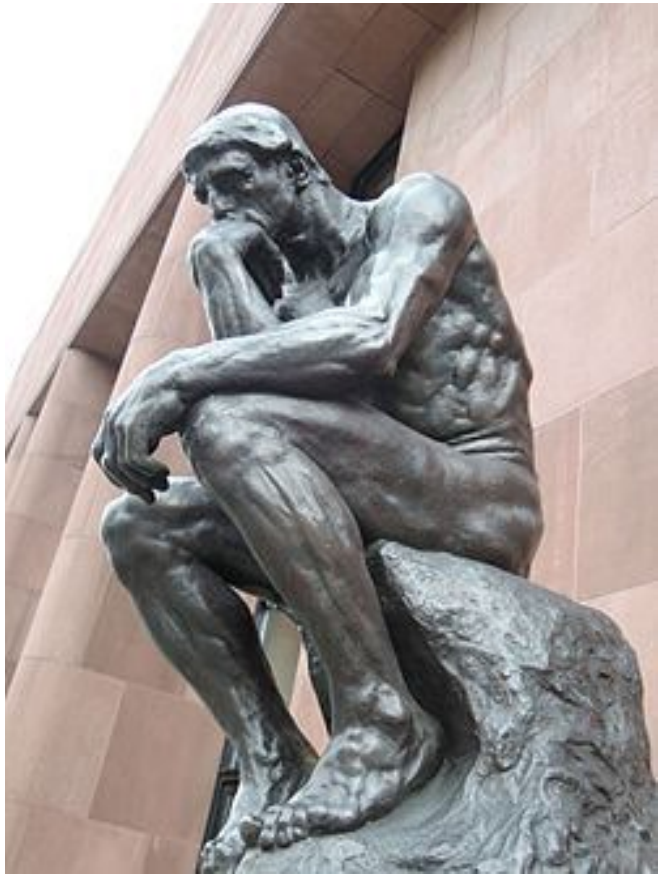
- Strong evidence base supports care
- Benefit-to-harm ratio high
- All with need should receive

A word on taxonomy

Preference-Sensitive Care

- Evidence supports different approaches
- Treatment/testing options involve trade-offs
- Personal values, preferences should drive decisions

How much of health care is “effective” versus “preference sensitive?



Previous Examples of Effective Care

- Appendicitis requires appendectomy
- Inguinal hernias require surgical repair
- Vaccinations!?
- Antibiotics for bacterial meningitis

Shared decision making model

Key characteristics:

- At least two participants (clinician & patient) are involved
- Both parties share information
- Both parties take steps to build a consensus about the preferred treatment
- An agreement is reached on the treatment to implement

Charles C, et al. (1997). *Soc Sci Med*. 44(5): 681-92.

NQF Definition of Shared Decision Making

NATIONAL QUALITY FORUM

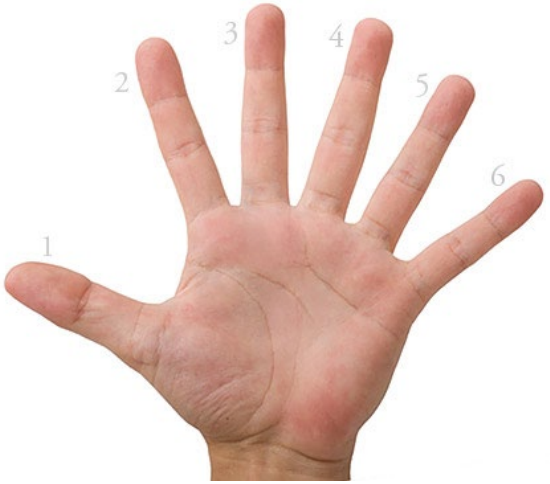
Shared decision making (SDM) is a process of communication in which clinicians and patients work together to make optimal healthcare decisions that align with what matters most to patients. SDM requires three components:

- clear, accurate, and unbiased medical evidence about reasonable alternatives—including no intervention—and the risks and benefits of each;
- clinician expertise in communicating and tailoring that evidence for individual patients; and
- patient values, goals, informed preferences, and concerns, which may include treatment burdens.

http://www.qualityforum.org/Publications/2017/10/NQP_Shared_Decision_Making_Action_Brief.aspx

Six Steps of Shared Decision Making

- Invite patient to participate
- Present options
- Provide information on benefits and harms
- Assist patient in evaluating options based on their goals and concerns
- Facilitate deliberation and decision making
- Assist with implementation



http://www.slideshare.net/fimdm/six-steps-of-shared-decision-making

Patient safety

Patient decision aids can help

- Tools designed to help people participate in decision-making
- Provide information on the options
- Help patients clarify and communicate the values they associate with different features of the options

The Ottawa Hospital A to Z Inventory of Decision Aids

- Inventory of publicly available decision aids
- Decision aids are rated according to the IPDAS criteria
- Lists of developers
- Implementation toolkits

The Ottawa Hospital | L'Hôpital d'Ottawa

Inspired by research. Driven by compassion. Inspiré par la recherche. Guidé par la compassion.

https://decisionaid.ohri.ca/azinvent.php

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The evidence about decision aids

Cochrane Review “Decision aids for people facing health treatment or screening decisions” first published in 2003

- Just updated in 2024!
- 209 trials of pDA versus usual care/other interventions (104 added since 2017 update)
- 107,698 participants

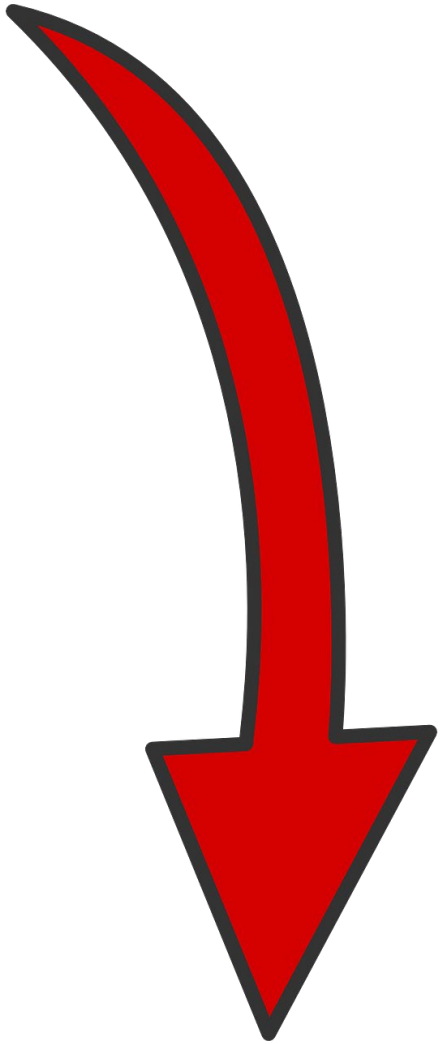
StaceyD, et al. Decision aids for people facing health treatment or screening decisions . Cochrane Database of Systematic Reviews 2024, Issue 1 . Art. No.: CD001431 . DOI: 10.1002/14651858.CD001431.pub6.

Decision aids increase:

- Patient knowledge
- Patient involvement in decision making
- Accuracy of risk perceptions
- Congruence between informed values and care choices

Decision aids decrease:

- Decisional conflict related to feeling uninformed
- Indecision about personal values
- Proportion of patients who remain undecided
- Surgery vs conservative option - HR 0.89 (0.83, 0.96)



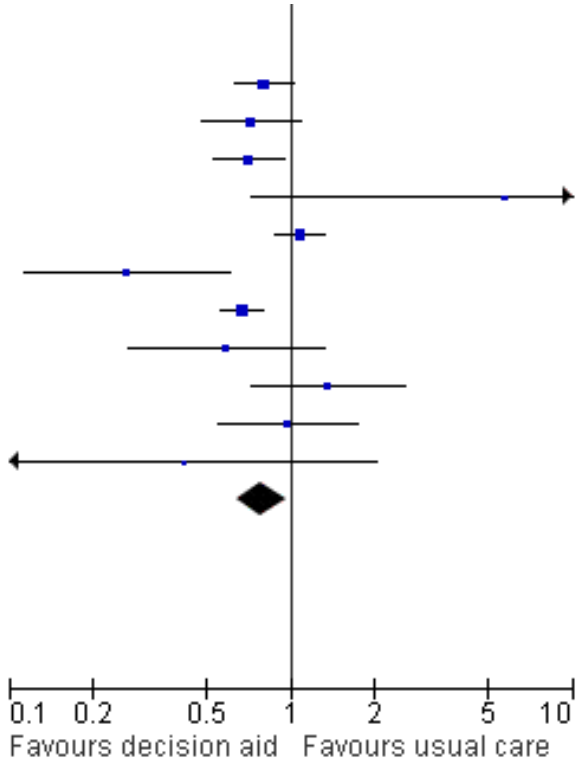
Choice of elective surgery

1.7.2 Intention to treat analysis

Kennedy 2002	82	300	101	298	15.2%	0.81 [0.63, 1.03]
Bernstein 1998	25	65	28	53	11.2%	0.73 [0.49, 1.09]
Morgan 2000	45	120	63	120	14.0%	0.71 [0.54, 0.95]
Murray 2001a	6	57	1	55	0.9%	5.79 [0.72, 46.54]
Vuorma 2003	98	184	88	179	16.2%	1.08 [0.89, 1.32]
Whelan 2004	6	94	26	107	4.6%	0.26 [0.11, 0.61]
Auvinen 2004	60	104	91	106	16.7%	0.67 [0.56, 0.81]
Barry 1997	8	104	16	123	4.9%	0.59 [0.26, 1.33]
Schwartz 2009	18	100	15	114	6.9%	1.37 [0.73, 2.57]
Tiller 2006	18	68	17	63	7.9%	0.98 [0.56, 1.73]
Vodermaier 2009	2	39	5	41	1.6%	0.42 [0.09, 2.04]
Subtotal (95% CI)		**1235**		**1259**	**100.0%**	**0.79 [0.64, 0.97]**
Total events	368		451			

Heterogeneity: $Tau^2 = 0.06$; $Chi^2 = 27.70$, $df = 10$ ($P = 0.002$); $I^2 = 64\%$

Test for overall effect: $Z = 2.20$ ($P = 0.03$)



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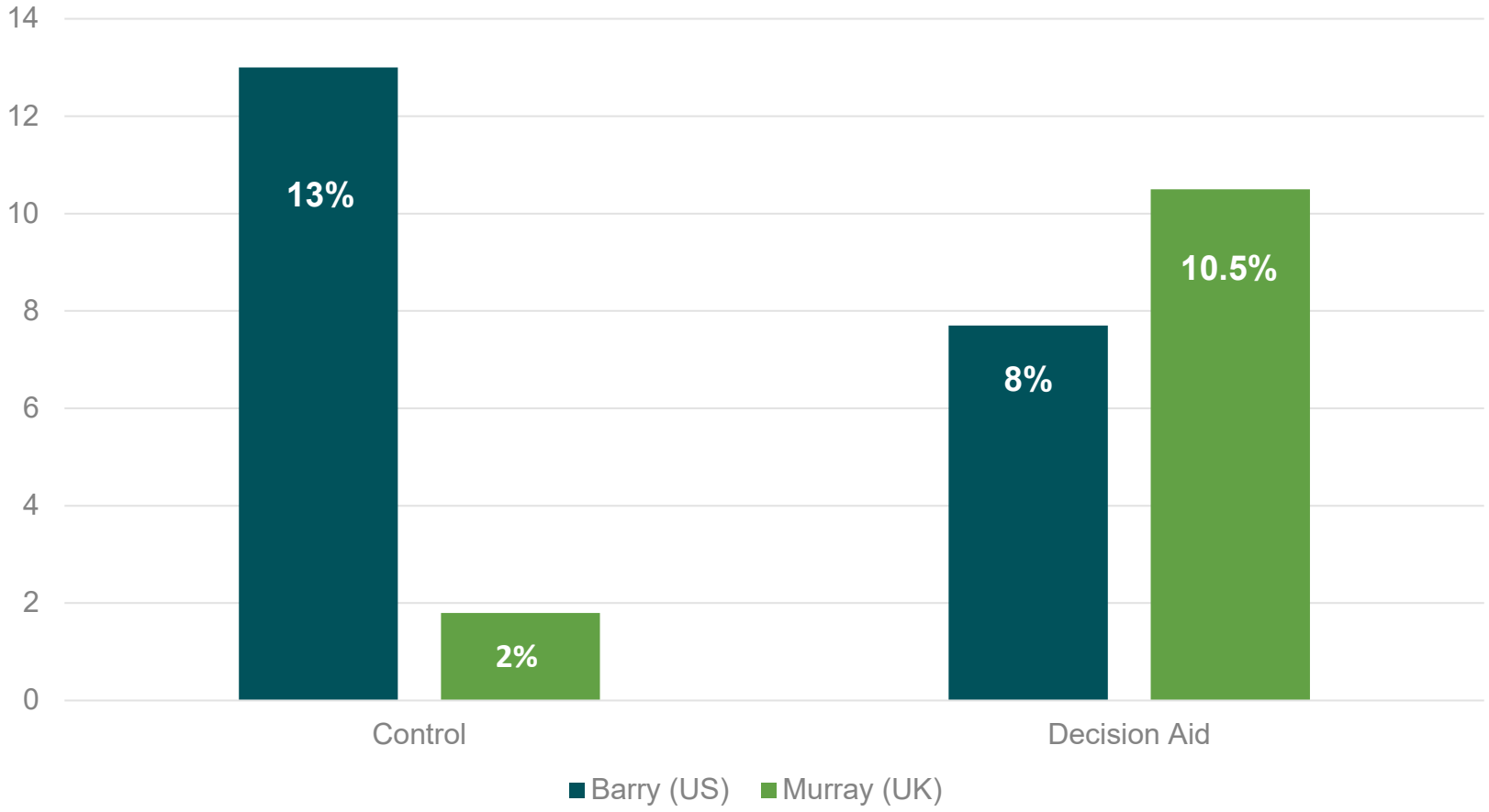
Effect of the same decision aid on BPH Surgery



Barry MJ, et al. (1997). *Dis Management Clin Outcomes*. 1: 5-14.

Murray E, et al. (2001). *BMJ*. 323(7311): 490-3.

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Hip and knee decision aids at Group Health

- Introduced DAs for hip/knee arthroplasty candidates in 2009
- Over 6 months:
  - 38% fewer knee replacements
  - 26% fewer hip replacements
  - 12-21% lower costs

Arterburn D, et al. (2012). *Health Aff (Millwood).* 31(9): 2094-104.

Hip and knee DAs among African Americans

- RCT of THR/TKR DAs among African Americans with severe OA at 3 VA clinics
- Over 3 months:
  - Increased willingness to undergo joint replacement
- Over 12 months:
  - More referrals to orthopedics; higher attendance
  - undergo joint replacement
- And finally:
  - Higher receipt of total knee replacements

Ibrahim SA, et al. (2013) *Arthritis Rheum.* 65(5): 1253-61.

Ibrahim SA, et al. (2017) *JAMA Surg* 152(1):e164225

Aligning incentives and removing barriers to SDM

Approaches:

- Clinician and patient training
- Integration into the EMR workflow
- Incentivize clinicians/health systems
  - CMS payment for lung CA screening
  - Value-based reimbursement
  - Decision quality measurement
  - Meaningful Use incentives/penalties
- Incentivize patients
  - Value-based insurance design

The goal is to change the clinical paradigm from "what's the matter" to "what matters to you."

– Susan Edgman-Levitan,
Executive Director, John D. Stoeckle Center
for Primary Care Innovation, MGH

Shared decisions in managing patients with obesity/overweight

- Is this a health problem worth addressing?
  - Consider comorbidities
- Approach to diet and nutrition
  - Diabetes Prevention Program results
  - Adjunctive treatment with medications
- Approach to exercise
- Role of medications
  - To prevent complications (eg, metformin)
  - GLP-1 agonists

Washington State is prioritizing SDM

- Shared decision making is recognized as a key component of patient-centered care

- It is recognized in many Washington policy initiatives, and afforded special status in Washington law.

- Health Care Authority has developed pDA certification criteria and has certified a number of decision aids for use in the state

For a full list of criteria go to:
http://www.hca.wa.gov/hw/Pages/shared_decision_making.aspx

Potential to lower malpractice risk

Reactions of Potential Jurors to a Hypothetical Malpractice Suit Alleging Failure to Perform a Prostate-Specific Antigen Test

Michael J. Barry, Pamela H. Wescott, Ellen J. Reifler, Yuchaio Chang, and Benjamin W. Moulton

Introduction
Screening for prostate cancer with the prostate-specific antigen (PSA) blood test is controversial, as

Information should be provided to all men about what is known and what is uncertain about the benefits, limitations, and harms of prostate can-
med decision

decision aids to about PSA test-
lt in fewer men

fear being sued does not receive
s prostate can-

A Decision Aid May Offer Liability Protection for a Bad Obstetrical Outcome: Results of Mock Trials

Suzanne Brodney, Pamela H. Wescott, Benjamin W. Moulton, Katherine Hartmann, Yuchiao Chang, and Michael J. Barry

Introduction
Increases in repeat cesareans underscore the need to examine how women make the decision about birth options after a prior cesarean.[1] Guidelines from the Royal College of Obstetricians and Gynaecologists and the American College of Obstetrics and Gynecology state that pregnant women with a prior cesarean birth should be counseled about a trial of labor after cesarean, if it is a medically reasonable choice.[2] However, despite being clinically eligible, many women are not being offered, or are not selecting a trial of labor

and treatments. This process, which is called shared decision making (SDM), accomplishes an "ethical imperative" to inform patients about their options and elicit their preferences so that the test or treatment option selected aligns with their values.[6] When patients use PDAs, they are more knowledgeable, informed, and clear about their values,[7] which allows for greater patient involvement in their own health decisions.

In 2006 the Informed Medical Decisions Foundation reported results of a study assessing the reactions of potential jurors to a hypothetical malpractice suit

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Potential to increase trust

JB&JS

OPEN ACCESS

Patients Who Reviewed a Decision Aid Prior to Major Orthopaedic Surgery Reported Higher Trust in Their Surgeon

Suzanne Brodney, PhD, Karen Sepucha, PhD, Yuchiao Chang, PhD, Ben Moulton, JD, MPH, and Michael J. Barry, MD

Investigation performed at the Informed Medical Decisions Program, Division of General Internal Medicine, Massachusetts General Hospital, Boston, Massachusetts

Background: Decision aids (DAs) are utilized to ensure that patients are informed and involved in the decision-making process. Although DAs improve decision quality, other aspects of the decision-making process, such as trust and regret, are seldom measured. The objective of the present study was to determine whether patients given a DA prior to orthopaedic surgery had greater trust and lower regret at 6 months postoperatively.

Methods: Consecutive patients were identified who underwent a hip or knee replacement or spine surgery from October 2018

Colorectal Cancer Screening (2021)

The USPSTF recommends screening for colorectal cancer in all adults aged 50 to 75 years. (A Grade)

The USPSTF recommends screening for colorectal cancer in adults aged 45 to 49 years. (B Grade)

The USPSTF recommends that clinicians selectively offer screening for colorectal cancer in adults aged 76 to 85 years. Evidence indicates that the net benefit of screening all persons in this age group is small. In determining whether this service is appropriate in individual cases, patients and clinicians should consider the patient's overall health, prior screening history, and preferences. (C Grade)

Role of SDM in Cancer Screening

Clinical Review & Education

JAMA | US Preventive Services Task Force

Collaboration and Shared Decision-Making Between Patients and Clinicians in Preventive Health Care Decisions and US Preventive Services Task Force Recommendations

US Preventive Services Task Force

The US Preventive Services Task Force (USPSTF) works to improve the health of people nationwide by making evidence-based recommendations for preventive services. Patient-centered care is a core value in US health care. Shared decision-making (SDM), in which patients and clinicians make health decisions together, ensures patients' rights to be informed and involved in preventive care decisions and that these decisions are patient-centered. SDM has a role across the spectrum of USPSTF recommendations. For A or B recommendations (judged by the USPSTF to have high or moderate certainty of a moderate or substantial net benefit at the population level), SDM allows individual patients to decide whether to accept such services based on their personal values and preferences. For C recommendations (indicating at least moderate certainty of a small net benefit at the population level), SDM is critical for individual patients to decide whether the net benefit for them is worthwhile. For D recommendations (reflecting at least moderate certainty of a zero or negative net benefit) or I statements (low certainty of net benefit), clinicians should be prepared to discuss these services if patients ask. More evidence is needed to determine if, in addition to promoting patient-centeredness, SDM reduces inequities in preventive care, as well as to define new strategies to find time for discussion of preventive services in primary care.

JAMA. 2022;327(12):1171-1176. doi:10.1001/jama.2022.3267

U.S. Preventive Services TASK FORCE 40 YEARS OF IMPROVING HEALTH

Group Information: A complete list of the members of the US Preventive Services Task Force appears at the end of this article.

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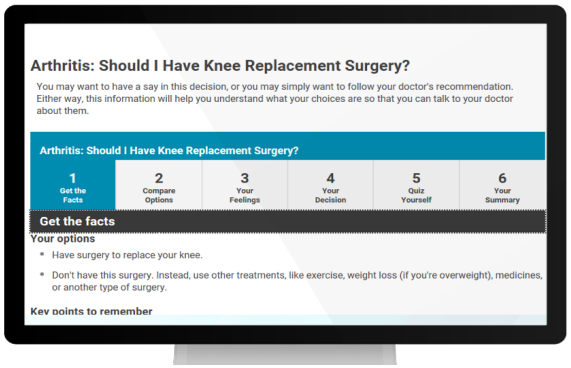
Decision Aids at MGB



- 40-50 decision aids available
- "Ordered" via electronic medical record
- Delivered via patient portal (can also be printed out)
- Summary report comes back to clinician
- Clinical decision support: alerts and prompts to order (e.g. at time of referral)

ENGAGING PATIENTS IN CLINICAL CARE

By Karen R. Sepucha, Leigh H. Simmons, Michael J. Barry, Susan Edgman-Levitan, Adam M. Licurse, and Sreekanth K. Chaguturu

Ten Years, Forty Decision Aids, And Thousands Of Patient Uses: Shared Decision Making At Massachusetts General Hospital

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Decision Aids Across our Hospital System

2,000+ clinicians ordered

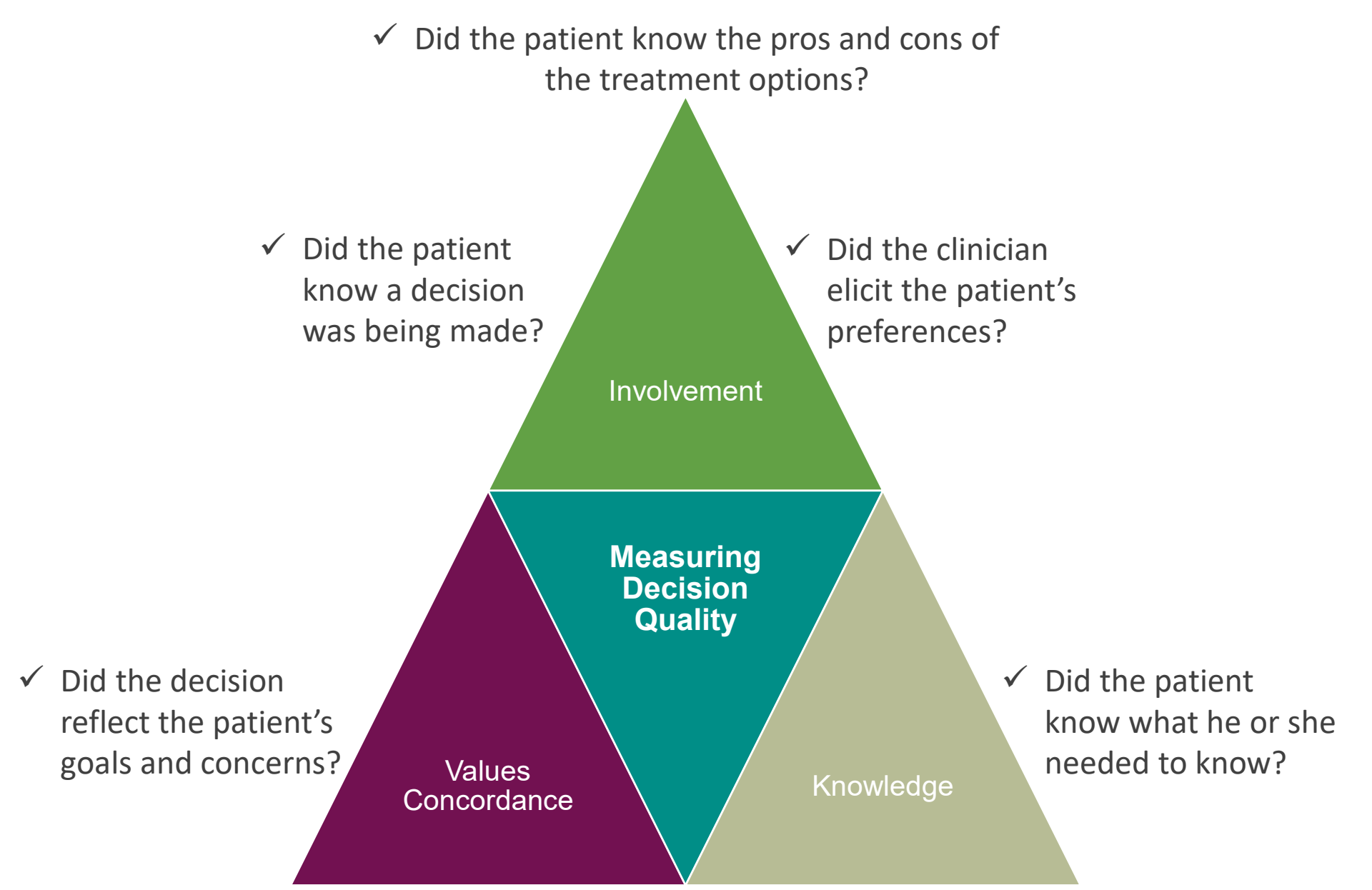
102k

decision aids for patients

Top 5 topics in 2025:

1. Quitting smoking
2. Knee osteoarthritis
3. Hip osteoarthritis
4. Prostate cancer screening
5. Lung cancer screening

Sepucha et al 2016 Health Affairs



Sepucha KR, et al. (2004). *Health Aff (Millwood).* Suppl Variation: VAR54-62.

Decision Process Measure (Early-Stage Breast Cancer Surgery)

Section 3: Talking With Health Care Providers

Please answer these questions about what happened when you talked with health care providers including doctors, nurses and other health care professionals about surgery for breast cancer. The two main options for surgery are mastectomy and lumpectomy and radiation (also called breast conserving surgery).

3.1. Did any of your health care providers talk about mastectomy as an option for you?

- ☐ Yes
- ☐ No

3.2. How much did you and your health care providers talk about the reasons to have a mastectomy?

- ☐ A lot
- ☐ Some
- ☐ A little
- ☐ Not at all

3.3. How much did you and your health care providers talk about the reasons **not** to have a mastectomy?

- ☐ A lot
- ☐ Some
- ☐ A little
- ☐ Not at all

3.4. Did any of your health care providers talk about lumpectomy and radiation as an option for you?

- ☐ Yes
- ☐ No

https://mghdecisionsciences.org/tools-training/sdm-process-survey/

Science AAAS

REPORT

Shared decision-making drives collective movement in wild baboons

Ariana Strandburg-Peshkin[1,*,†], **Damien R. Farine**[2,3,4,*,†], **Iain D. Couzin**[1,5,6], **Margaret C. Crofoot**[2,3,*]

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† These authors contributed equally to this work.

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Informed Medical
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Thank you

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