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# Shared Decision Making for Financial Advocates

ACCC Financial Advocacy Network Summit  
August 16, 2018  
Downtown Washington DC

# Shared Decision Making

**For Financial Advisors**

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Washington, D.C.

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# Shared Decision Making: Bridging Knowledge Gaps

- **33%** of patients with advanced incurable non small cell lung cancer believe their cancer is curable
- **50%** of patients do not know the stage of their cancer
- **70%** of patients hold opinions about their prognosis that differs from their oncologist
- **95%** of patients with advanced incurable cancer do not adequately understand their prognosis

# Shared Decision Making: Benefits of Patient Decision Aids

- Disclosure of treatment options: risks, benefits of each
- Assists patients with identifying their preferences and values
- Facilitates decision making between patient and provider in establishing what is best for the patient
- SDM is a significant patient safety link
- Shared decision making and quality PtDAs are “perfected informed consent”

# Shared Decision Making: Defining What It Is


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 medical intervention—and the risks and benefits of each
- clinician expertise in communicating and tailoring that evidence for individual patients
- patient values, goals, informed preferences, and concerns, which may include treatment burdens.

# Shared Decision Making: What is a Patient Decision Aid

Patient decision aids are tools designed to help people better participate in healthcare decision making. These resources provide information on the risks, benefits, and alternatives as well as burdens of options and help patients clarify and communicate their personal values on different features of the options. Patient decision aids do not advise people to choose one option over another, nor do they replace clinician consultation. Instead, patient decision aids prepare patients to make informed decisions, together with their clinicians, that align with their values, goals, and preferences.

# Decision Aid Example

Decision Aids ▾ Using Our Aids About Contact Us US English ▾

Decision Aid Generator

**Prostate Cancer**

*Treatment Options for Low-risk Prostate Cancer*

*This decision aid is for men with cancer cells only in the prostate and who are at low risk for spread. It is not for men who are at higher risk for cancer spread.*

Last Update Jul 9, 2018 | Last Review Jul 28, 2018

**Generate Aid** | **References**

**STEP 1:** Select options to compare (maximum 3)

- Watchful waiting
- Active surveillance
- External beam radiation therapy
- Brachytherapy
- Open prostatectomy
- Robotic prostatectomy

**NEXT >**

Submit questions or comments about this decision aid.

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**Competing Interests**

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# Decision Aid Example

## Prostate Cancer: Treatment Options for Low-risk Prostate Cancer

The prostate is a gland below the bladder in men. Cancer is when cells in the body grow in abnormal ways.

*This decision aid is for men with cancer cells only in the prostate and who are at low risk for spread. It is not for men who are at higher risk for cancer spread.*

Patient Questions	Watchful waiting	Brachytherapy	Open prostatectomy
<b>What does the treatment involve?</b>	As long as you have no new symptoms, you will not have tests or treatments.	Grain-size pieces of metal that give off radiation are put into your prostate. They are left in place, but only give off radiation for a short time. You typically go home the same day. Discuss costs.	You will have surgery to remove your prostate. You may be in the hospital up to 3 days. You may have a tube (catheter) in your penis to drain pee for up to 2 weeks. Discuss costs.
<b>What is my chance of dying from prostate cancer?</b>	Out of 100 men: <ul style="list-style-type: none"> <li>fewer than 1 (less than 1%) die from prostate cancer by 10 years</li> <li>2 (2%) or more die from prostate cancer by 15 years</li> </ul>	Out of 100 men: <ul style="list-style-type: none"> <li>fewer than 1 (less than 1%) die from prostate cancer by 10 years</li> <li>there is not enough research to know your risk of dying by 15 years</li> </ul>	Out of 100 men: <ul style="list-style-type: none"> <li>fewer than 1 (less than 1%) die from prostate cancer by 10 years</li> <li>1 (1%) die from prostate cancer by 15 years</li> </ul>
<b>Will my cancer spread?</b>	Cancer may spread to other parts of the body in about 6 out of 100 men (6%) by 10 years.	Cancer may spread to other parts of the body in up to 5 out of 100 men (5%) by 10 years.	Cancer may spread to other parts of the body in about 2 out of 100 men (2%) by 10 years.
<b>When will I recover?</b>	Does not apply	Most men are back to usual activities in about 5 days. You may need to avoid sex or use condoms for a month to avoid passing radioactive seeds to your partner.	Some men return to work or usual activities 3 weeks after surgery. It can take up to 4 months to recover.
<b>What are the risks and side effects?</b>	Out of 100 men not treated for prostate cancer: <ul style="list-style-type: none"> <li>up to 47 (47%) have problems with erections</li> <li>about 10 (10%) leak pee</li> </ul>	Out of 100 men about: <ul style="list-style-type: none"> <li>61 (61%) have problems with erections</li> <li>6 to 20 (6% to 20%) pee often</li> <li>19 (19%) leak pee</li> <li>5 (5%) have diarrhea</li> <li>2 (2%) have problems peeing</li> </ul>	Soon after surgery, out of 100 men about: <ul style="list-style-type: none"> <li>9 to 21 (9% to 21%) need a blood transfusion</li> <li>2 (2%) get an infection</li> <li>2 (2%) get a blood clot or have a stroke</li> </ul> In the long term, out of 100 men about: <ul style="list-style-type: none"> <li>67 (67%) have problems with erections</li> <li>23 (23%) leak pee</li> <li>7 (7%) have problems peeing</li> </ul>



# Shared Decision Making: Making the Connections

- SDM is at the heart of patient engagement
- Transparency and therapeutic alliance strengthened by SDM – pinnacle of patient-centered care
- Failure to inform is a significant liability issue
- SDM is a significant patient safety link
- Shared decision making and quality PtDAs are “perfected informed consent”

# Making Health Care Decisions

Volume One: Report

The Ethical and  
Legal Implications of  
Informed Consent in the  
Patient-Practitioner  
Relationship



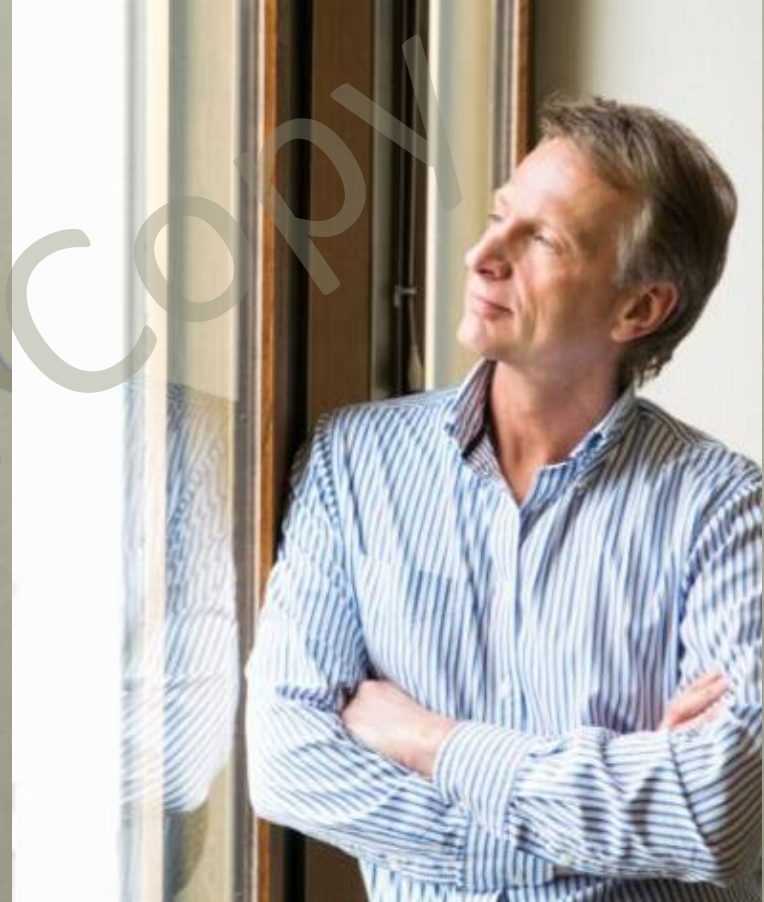
President's Commission for the Study of  
Ethical Problems in Medicine and  
Biomedical and Behavioral Research

# President's Commission

- First time shared decision making mentioned
- Informed consent is ethical obligation that involves SDM and is rooted upon mutual respect
- Foundation is based on open, honest, transparent communication
- **NOT** a ritualistic signature on a written form
- Patient entitled to accept or reject medical interventions based on **personal values**

# Patients Don't Know What They Don't Know

- Patients make a surprisingly large number of medical decisions each year:
  - **82%** of adults over the age of 40 have made a **medical decision** in the past two years
  - **54%** of these adults have faced **two or more** of these types of decisions



# Patients Don't Know What They Don't Know



- When asked about 9 major medical decisions
  - Patients on average **knew less than ½** of the critical information
- Why does this matter?
  - **1/3** of medical decisions have **two or more treatment options**
  - There is no **'right'** course of action
  - The patient must be **fully informed** and decide **with** their physician

# Example: Early Stage Breast Cancer

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

# But There Is More To Consider

## Mastectomy

Same

Lose Breast

Low  
(1-5%)

Not Common

Rare

Survival

Cosmetics

Recurrence

Radiation

Additional Surgery

## Lumpectomy

Same

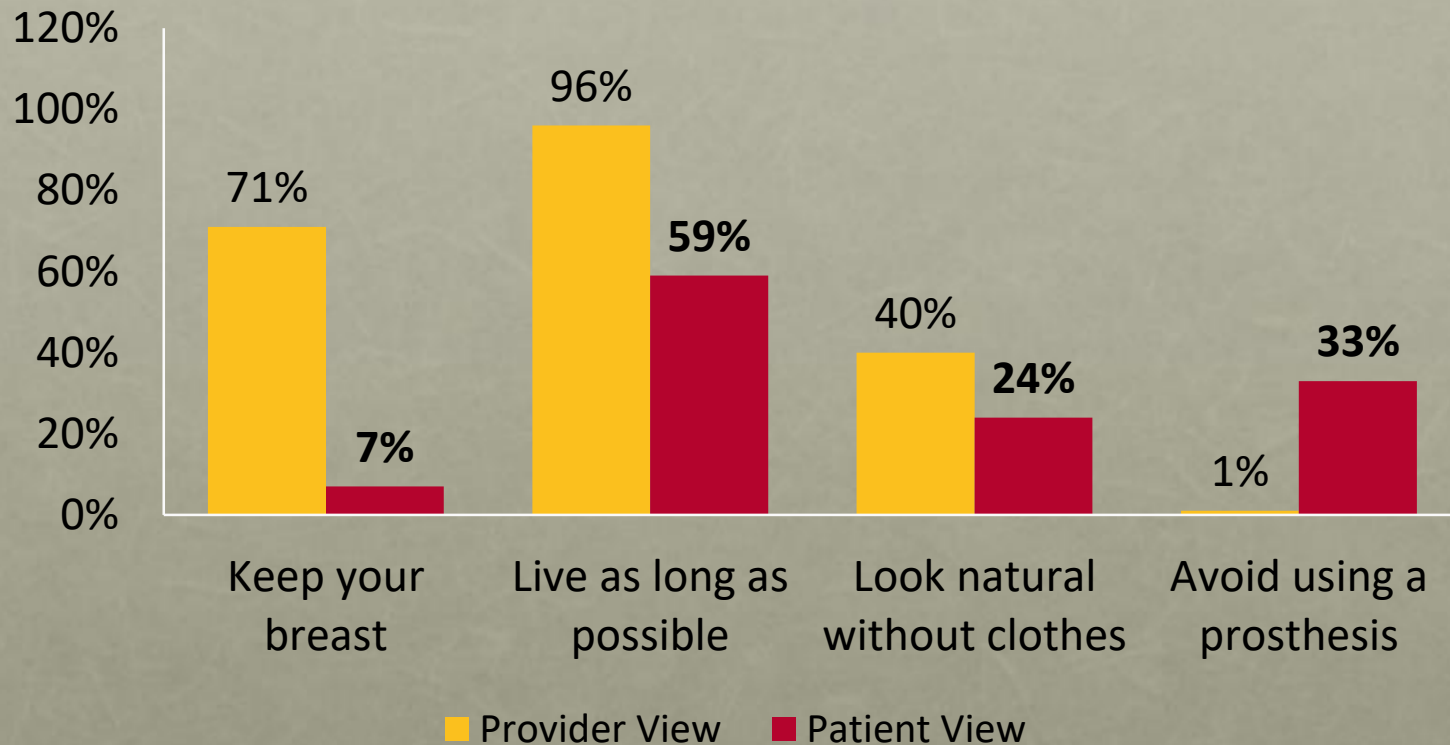
Keep Breast

Slightly Higher  
(5-15%)

6+ Weeks

Not Common  
(20-50%)

# Top Three Goals and Concerns for Breast Cancer Decisions





# Wrong Site Surgery: Rhode Island Hospital

- The Rhode Island Department of Health is investigating Rhode Island Hospital in Providence after the hospital admitted to operating on the wrong body part for another patient, marking at least the **5<sup>th</sup> wrong-site surgery** at the hospital since 2007.



# Patient Safety

How do we describe operating on a patient who would say **NO** to surgery if alternatives, risks and benefits were well understood?



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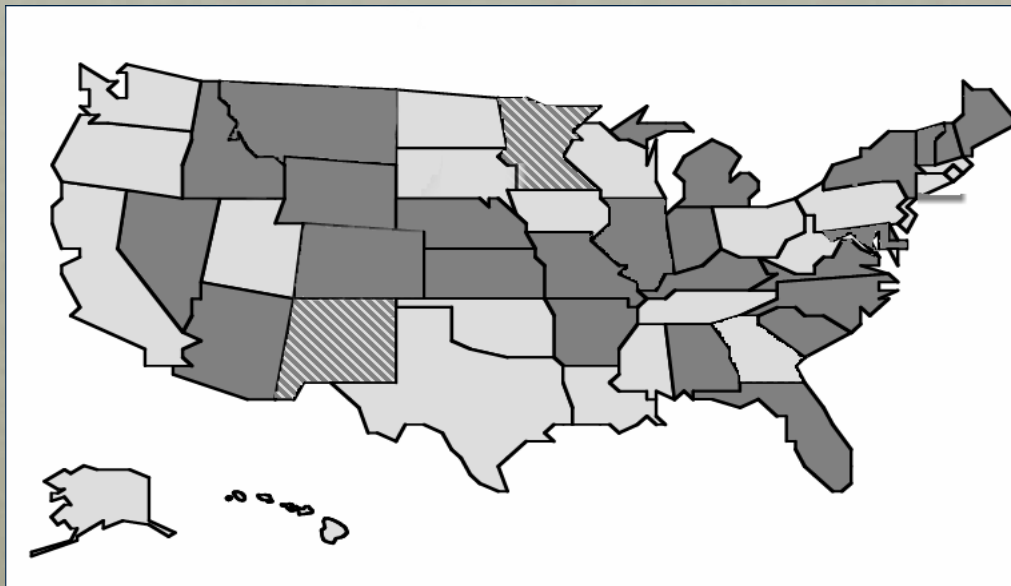
## ARTICLES

- 429** **Rethinking Informed  
Consent: The Case for Shared  
Medical Decision-Making**  
*Jamie Staples King*  
*Benjamin W. Moulton*
- 503** **The Mental Health Paradigm  
and the MacArthur Study:  
Emerging Issues Challenging  
the Competence of Juveniles  
in Delinquency Systems**  
*David R. Katner*

## NOTES AND COMMENTS

- 585** **My Computer, My Doctor:  
A Constitutional Call for  
Federal Regulation of  
Cybermedicine**  
*Carmen E. Lewis*

# Informed Consent Standards



**23 Patient States vs. 25 Physician States**  
**2 Hybrid States**

# 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



# Patient Satisfaction and Claims Frequency Initiative

- “Patient satisfaction scores continue to show a correlation to medical malpractice claim frequency while more clinical measures of quality do not seem to be statistically linked to malpractice claims. **We have observed that systems having better patient satisfaction scoring have fewer malpractice claims.”**

# Risk Management and Liability Reduction

- SDM should be seen as a patient safety initiative and a risk mitigation program for health care providers
- CRICO, the Harvard MPL carrier, reported for 2009-13 that nearly 30% of malpractice cases are attributed to communication failures – resulting in nearly 2,000 patient deaths and costing over \$1.7 billion  
<https://www.rmfm.harvard.edu/Malpractice-Data/Annual-Benchmark-Reports/Risks-in-Communication-Falures>
- **Shared decision making is the antidote to miscommunication and is the heart of patient engagement**

# Considerable Evidence of Impact

- In 130 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 patients choosing major surgery





# “Perfected Informed Consent”

**Traditional  
Informed  
Consent**

- Risks
- Benefits
- Alternatives
- Severity
- Probability



**Shared  
Decision  
Making**

- Values
- Preferences
- Risks
- Benefits
- Alternatives
- Subjective

By David Arterburn, Robert Wellman, Emily Westbrook, Carolyn Rutter, Tyler Ross, David McCulloch, Matthew Handley, and Charles Jung

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The People-to-People Health  
Foundation, Inc.

# Introducing Decision Aids At Group Health Was Linked To Sharply Lower Hip And Knee Surgery Rates And Costs

**ABSTRACT** Decision aids are evidence-based sources of health information that can help patients make informed treatment decisions. However, little is known about how decision aids affect health care use when they are implemented outside of randomized controlled clinical trials. We conducted an observational study to examine the associations between introducing decision aids for hip and knee osteoarthritis and rates of joint replacement surgery and costs in a large health system in

**David Arterburn** (arterburn.d@ghc.org) is a general internist and associate investigator at Group Health Research Institute and an affiliate associate professor at the University of Washington, in Seattle.

**Robert Wellman** is a

introduction of decision aids was associated with 26 percent fewer hip replacement surgeries, 38 percent fewer knee replacements, and 12–21 percent lower costs over six months. These findings support the

concept that patient decision aids for some health conditions, for which treatment decisions are highly sensitive to both patients' and physicians' preferences, may reduce rates of elective surgery and lower costs.

Group Health Research  
Institute.

**Carolyn Rutter** is a biostatistician and senior investigator at Group Health

**EXHIBIT 1****Group Health Patient Satisfaction Survey Results On Decision Aids**

<b>Please rate how well the decision aid:</b>	<b>Excellent/ very good</b>	<b>Good</b>	<b>Fair/ poor</b>	<b>Total responses per question (out of 2,223)</b>	<b>% positive ratings out of total responses<sup>a</sup></b>
Helped you understand your health condition	1,428	613	112	2,153	94.8
Helped you understand the treatment choices for your health condition	1,573	499	84	2,156	96.1
Helped you understand what is most important to you when thinking about treatment choices for your health condition	1,500	536	112	2,148	94.8
Helped you prepare to talk with your health care provider about treatment choices for your health condition	1,528	508	103	2,139	95.2

**SOURCE** Group Health Research Institute. **NOTES** Raw data from 2,223 survey participants, out of 12,263 surveys mailed with decision aids from January 2009 to April 2011. Data provided by Group Health Research Institute and on file with authors. <sup>a</sup>Positive rating means excellent, very good, or good.

# Section 3021 CMS Innovation Center

- Test innovative payment models to reduce costs and enhance quality. To design, implement and evaluate 18 different models.
  - 9) “Assisting applicable individuals in making informed health care choices by paying providers for using patient decision support tools that improve individual understanding of medical options.”



**Authorized not Appropriated  
10 Billion FY 2011-2019**

# CMMI Attempted to Test Two Models

- **SDM model:** randomize ACOs to implement SDM visits
- **DDS model:** randomize geographic regions to have DSOs provide PDAs for SDM direct to Medicare beneficiaries
- The basic concept to test was good
- The method to recruit implementers and manage the trial was not ultimately feasible – too cumbersome, too complicated, both cancelled in last six months

COMPILATION OF PATIENT PROTECTION  
AND AFFORDABLE CARE ACT

[As Amended Through May 1, 2010]

## Section 3506 Program to Facilitate Shared Decision Making

(c) Establishment of independent standards for patient decision aids for preference sensitive care

(1) Contract with entity to establish standards and certify patient decision aids

# Why Certify?

- Hundreds of patient decision aids
- Variable quality
- Quality can affect patient knowledge and decision quality
- Rising number of aid producers/marketers
- Potential for bias from poor evidence review
- Potential for bias from conflict of interest

# What is the Medicare Lung Cancer Screening Reimbursement?

- In eligible high-risk, long-term smokers, Medicare will reimburse for:
  - A counseling/SDM visit
  - Annual low-dose CT scans (LDCT)
- Reimbursement requires:
  - **SDM conversation, supported by decision aids**
  - Discussion of key facts about pros and cons of screening
  - **Smoking cessation counseling**

CANCER CENTER OF EXCELLENCE

Are you a long-term smoker?  
A lung screening could save your life.

MOUNT SINAI MEDICAL CENTER IS PROUD TO OFFER DISCOUNTED LOW-DOSE CT SCREENINGS DURING THE MONTH OF NOVEMBER, LUNG CANCER AWARENESS MONTH.

**LUNG CANCER SCREENINGS FOR \$100**

Smokers are up to 30 times more likely than non-smokers to develop lung cancer - the deadliest of all cancers - but more than 90 percent of patients can be cured of lung cancer if they are diagnosed early. If you smoked for 25 years or longer, even if you've quit, you are equally at a high risk of lung cancer screening to help assess your risk of developing the disease. So what are you waiting for? Schedule your screening today by calling 305.535.3434.

Mount Sinai  
MEDICAL CENTER  
Comprehensive Cancer Center

305.535.3434 • [msmc.com](http://msmc.com)



# Markets for Shared Decision Making: OHRP

Office of Human Research Protection is amending the common rule which governs human subject research to require meaningful informed consent, specifically:



- Informed consent must begin with a concise and focused presentation of the **key information** that is most likely to assist a prospective subject or legally authorized representative in understanding the reasons why one might not want to participate in the research. This part of the informed consent must be organized and presented in a way that facilitates comprehension.
- Informed consent as a whole must present information in sufficient detail relating to the research, and must be organized and presented in a way that does not merely provide lists of isolated facts, but rather facilitates the prospective subject's or legally authorized representative's understanding of the reasons why one might or might not want to participate.

# WA State Passed Three Bills

- 2007: Passed legislation that explicitly recognizes SDM as an enhanced informed consent for Preference-Sensitive Conditions if provider uses a “certified aid”
  - Led to Group Health demonstration project
- 2009: Passed Bree Collaborative which promoted SDM
- 2012: Passed legislation allowing CMO of HCA to “certify aids” moving forward with criteria
- Payment of providers for SDM being considered

“Those who say it can not be done,  
should not interrupt those who are  
doing it.”

Chinese Proverb