SHARED DECISION MAKING
WHAT? WHY? HOW?
Disclosures

I am employed by the nonprofit Foundation for Informed Medical Decision Making which is funded by royalties and project revenue from Health Dialog. Health Dialog co-produces patient decision aids with the Foundation and distributes them to health plans, employers and provider groups.

I’ve learned what I know about implementation from the provider organizations with whom I’ve had the opportunity to work.
Learning Objectives

After this session you will be able to:

• Identify the key components of shared decision making (SDM) and patient decision aids (DAs)
• Discuss SDM in the context of current health system reform efforts
• Describe the benefits of SDM from the patient, provider, and provider organization perspectives
• Identify the objectives and strategies needed for successful implementation of SDM and the use of DAs in provider settings
Shared Decision Making (SDM)

“the process of interacting with patients who wish to be involved in arriving at an informed, values-based choice among two or more medically reasonable alternatives”¹

Informed
- There is a choice
- The options
- The benefits and harms of the options

Values-Based
- What’s important to the patient

¹A.M. O'Connor et al, “Modifying Unwarranted Variations In Health Care: Shared Decision Making Using Patient Decision Aids” Health Affairs, 7 October, 2004
A Word on Taxonomy

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

Preference-Sensitive Care
• Evidence supports more than one approach
• Treatment/testing options involve significant trade offs
• Personal values, preferences, and life circumstances should drive decisions

SDM Sweet Spot
Preference-Sensitive Care

Interventions have **similar benefits** but **different risks**
- e.g. management of ruptured Achilles tendon

Interventions have **different benefits** and **different risks**
- e.g. surgery vs. medical management for knee osteoarthritis

Intervention has **uncertain benefits** but **certain risks**
- e.g. PSA testing for prostate cancer screening
A Word on “Engaged”

• What do we mean?
  – Involved in activity*
  – Patients involved in their health and healthcare-related activities

• What does it take (necessary but not sufficient)?
  – Welcoming providers and provider systems

• Where can we start?
  – Involving patients in medical decisions

*Merriam-Webster On-line Dictionary
SDM as Patient Engagement

Shared decision making offers a process and tools to routinely engage patients in decisions about their own health.
A Schematic of Shared Decision Making

Options

A

Benefits
Risks

B

Benefits
Risks

C

Benefits
Risks

Patient Lens

Goals and Concerns

Deliberate

Decision

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Patient Decision Aids: Tools to Facilitate SDM

- Describe a specific condition
- Present information organized around specific decisions
- Strive to keep information accessible (charts, graphs) and balanced
- Encourage patients to interpret information in the context of their own goals and concerns
- Engage viewers with real patient stories
- Advise patients to make decisions with their physician
Decision to Make

**A**
- Benefits
- Risks

**B**
- Benefits
- Risks

**C**
- Benefits
- Risks

**Patient Lens**
- **Goals and Concerns**
- **Unique Life Circumstances**
- **Benefits**
- **Risks**

**Supported by**
Patient Decision Aids

**Options**

**Deliberate**

**Decision**

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Ottawa Hospital Research Institute

Patient Decision Aids

A to Z Inventory of Decision Aids

Search all decision aids:

knee osteoarthritis

OR

Browse an alphabetical listing of decision aids by health topic.

The A to Z Inventory of Decision Aids is designed to help you find a decision aid to meet your needs. It contains up-to-date and available decision aids meet a minimal set of criteria.

More information about decision aid developers.
Patient Decision Aids

Some DAs in public domain, others are commercial products

IPDAS = International Patient Decision Aid Standards
Edited Version of DA
“Treatment Choices for Knee Osteoarthritis”
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A Chorus of Voices Calling for SDM
President’s Commission 1982

• First time shared decision making mentioned

• Informed consent is an ethical obligation that involves SDM and is rooted in mutual respect

• Patient entitled to accept or reject medical interventions based on personal values
Affordable Care Act

CMS Innovation Center shall design, implement, and evaluate 18 different models to control costs and enhance quality

- 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
CMS Innovation Center Award

Collaborative receives $26M Innovation Grant from Center for Medicare and Medicaid Innovation

“... to engage patients and implement shared decision making”
Pioneer ACOs Promote SDM

“A critical foundation of the proposed rule is its unwavering focus on patients. We envision that successful ACOs will honor individual preferences and engage patients in shared decision making about diagnostic and therapeutic options.”

Pioneer ACO Selection Criteria: Patient Centeredness – “demonstrate the ability to engage patients in shared decision making taking into account patient preferences”
SECTION 2: PATIENT/CAREGIVER EXPERIENCE

2013 ACO Narrative Measure Specifications
Patient/Caregiver Experience Domain

CMS has finalized the use the Clinician and Group Consumer Assessment of Health Care Providers and Systems (CG CAHPS) to assess patient and caregiver experience of care. CMS plans to use the adult 12 month base survey and certain of the supplemental modules for the adult survey:

- ACO 1 (NQF #0005): Getting Timely Care, Appointments, and Information
- ACO 2 (NQF #0005): How Well Your Providers Communicate
- ACO 3 (NQF #0005): Patient Rating of Provider
- ACO 4 (NQF #0005): Access to Specialist
- ACO 5 (NQF #0005): Health Promotion and Education
- ACO 6 (NQF #0005): Shared Decision Making
- ACO 7 (NQF #0006): Health Status/Functional Status
Comprehensive Primary Care Initiative

- 500 primary care practices in 5 states
- “Practices will engage patients and families in shared decision making”
Meaningful Use

• Stage 2
  – “smart information prescribing”

• Stage 3
  – Incorporating patent-generated health information

Stage 3 Recommendations

**MENU:** Provide 10% of patients with the ability to submit patient-generated health information to improve performance on high priority health conditions, and/or to improve patient engagement in care (e.g. patient experience, pre-visit information, patient created health goals, shared decision making, advance directives, etc.). This could be accomplished through semi-structured questionnaires, and EPs and EHs would choose information that is most relevant for their patients and/or related to high priority health conditions they elect to focus on.
States are Coming on Board

States with SDM Initiatives

- Washington
- Oregon
- Oklahoma
- Minnesota
- Maine
- Vermont
- Massachusetts
- Connecticut
RESOLVED, That our American Medical Association educate and communicate to physicians about the importance of shared decision-making tools through its publications and assist the medical community in moving towards patient-centered care. (Directive to Take Action)
Driving Patient Demand for Shared Decisions, Better Value, and Care Improvement

An Institute of Medicine Workshop
Sponsored by the Gordon and Betty Moore Foundation and Blue Shield of California Foundation

A Learning Health System Activity
IOM Roundtable on Value & Science-Driven Health Care

February 25-26, 2013
The National Academy of Sciences
2101 Constitution Avenue, NW
Washington, DC
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The Evidence About Decision Aids

Review of 86 randomized trials evaluating patient decision aids

• Increase patient knowledge
• Increase patient involvement in decision making
• Increase the proportion of patients with accurate risk perceptions (patients have more realistic expectations)
The Evidence About Decision Aids

• Increase the consistency between patient decisions and patient values
• Reduce decisional conflict related to feeling uninformed or unclear about personal values
• Reduce the proportion of patients who remain undecided
• Reduce the choice of major elective surgery in favor of more conservative options
The Evidence About Decision Aids

Review of 86 randomized trials evaluating patient decision aids

• Increase patient knowledge
• Increase patient involvement in decision making
• Reduce the choice of major elective surgery in favor of more conservative options
## Are Patients Informed?

<table>
<thead>
<tr>
<th>Question</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>How many people</td>
<td></td>
</tr>
<tr>
<td>... get pain relief from surgery</td>
<td>28</td>
</tr>
<tr>
<td>... experience a surgical complication (e.g. wound infection)</td>
<td>46</td>
</tr>
<tr>
<td>... will have replacement last at least 20 years</td>
<td>15</td>
</tr>
<tr>
<td>How long most people require to return to normal activity</td>
<td>39</td>
</tr>
</tbody>
</table>

The Decisions Study. Medical Decision Making 2010; 30 supplement 1
Demonstration Site Program

Objective: to demonstrate that shared decision making and the use of patient decision aids can effectively and efficiently become part of day-to-day care
Data Slides Removed
The Primary Care Physician’s Perspective of SDM

A National Survey of 402 Primary care physicians
Lake Research Partners
Importance of Being Informed

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:

<table>
<thead>
<tr>
<th>Situation</th>
<th>% Very important for patients to be well informed</th>
<th>% Patients very well informed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing chronic conditions</td>
<td>15%</td>
<td>89%</td>
</tr>
<tr>
<td>Changing lifestyle behaviors</td>
<td>19%</td>
<td>87%</td>
</tr>
<tr>
<td>Taking new prescription medications</td>
<td>16%</td>
<td>82%</td>
</tr>
<tr>
<td>Having surgery</td>
<td>18%</td>
<td>80%</td>
</tr>
<tr>
<td>Undergoing cancer screenings</td>
<td>20%</td>
<td>77%</td>
</tr>
</tbody>
</table>
## Are Patients Involved?

<table>
<thead>
<tr>
<th>Patient Recollection of Decision Making Process</th>
<th>PCa Survey n=685 (%)</th>
<th>CA Stent n=472 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor discussed reasons for surgery</td>
<td>625 (95)</td>
<td>341 (77)</td>
</tr>
<tr>
<td>Doctor discussed reasons might not want surgery</td>
<td>416 (63)</td>
<td>85 (19)</td>
</tr>
<tr>
<td>Doctor discussed any alternative as serious option</td>
<td>408 (64)</td>
<td>43 (10)</td>
</tr>
<tr>
<td>Doctor asked about patient preference for Rx</td>
<td>497 (76)</td>
<td>69 (16)</td>
</tr>
</tbody>
</table>

*Fowler et al, JGIM 2/28/12*
Data Slide Removed
# Top Three Goals and Concerns for Breast Cancer Decisions

<table>
<thead>
<tr>
<th>Condition: Goal</th>
<th>Pat</th>
<th>Prov</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your breast?</td>
<td></td>
<td>71%</td>
<td></td>
</tr>
<tr>
<td>Live as long as possible?</td>
<td></td>
<td>96%</td>
<td></td>
</tr>
<tr>
<td>Look natural without clothes</td>
<td></td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td></td>
<td>0%</td>
<td></td>
</tr>
</tbody>
</table>

KR Sepucha et al/Pt Education and Counseling 73(2008)504-10
## Top Three Goals and Concerns for Breast Cancer Decisions

<table>
<thead>
<tr>
<th>Condition: Goal</th>
<th>Pat</th>
<th>Prov</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your breast?</td>
<td>7%</td>
<td>71%</td>
<td>P&lt;0.01</td>
</tr>
<tr>
<td>Live as long as possible?</td>
<td>59%</td>
<td>96%</td>
<td>P=0.01</td>
</tr>
<tr>
<td>Look natural without clothes</td>
<td>33%</td>
<td>80%</td>
<td>P=0.05</td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td>33%</td>
<td>0%</td>
<td>P&lt;0.01</td>
</tr>
</tbody>
</table>

KR Sepucha et al/Pt Education and Counseling 73(2008)504-10
Group Health Cooperative

6 months follow up

- 38% drop knee replacement surgery
- 26% drop hip replacement surgery
- 12-21% lower costs

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

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 Washington State. Consistent with prior randomized trials, our 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.
Health Dialog Experience

- DAs plus telephonic decision support
- One year follow up
- Results
  - 5.3% reduction overall medical costs
  - 9.9% fewer preference-sensitive surgeries
  - 12.5% fewer hospital admissions
Data Slides Removed
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SDM: Making It Happen

Where the Rubber Meets the Road
The Primary Care Physician’s Perspective of SDM

A National Survey of 402 Primary care physicians
Lake Research Partners
Support for Principle of SDM

In your view, does "shared decision-making" sound like a positive or negative process?

- Very positive: 52%
- Somewhat positive: 41%
- Neutral: 5%
- Somewhat negative: 2%
- Negative: 0%
Biggest Barrier to SDM

For you personally, what is the number one barrier to engaging patients in a shared-decision making process?

- Not enough time for detailed discussions: 45%
- Patients have difficulty understanding: 38%
- No trusted source of information for patients: 6%
- Prefer patients rely on my recommendations: 4%
Compared to Visits with Patients Who Didn’t View DA:

Length & Quality of Visit

- **Length of Visit**
  - 61% Longer/Worse
  - 11% Shorter/Better
  - 28% About the Same
  - 0% Longer/Worse

- **Quality of Visit**
  - 72% Shorter/Better
  - 3% Longer/Worse
  - 25% About the Same
  - 0% Longer/Worse

N≈75
Anticipated Impact of SDM

Do you think a shared decision-making process would result in patients being more likely to:

<table>
<thead>
<tr>
<th>Activity</th>
<th>% Much more likely</th>
<th>% Somewhat more likely</th>
<th>% More likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better manage their chronic condition(s)</td>
<td>40%</td>
<td>51%</td>
<td>91%</td>
</tr>
<tr>
<td>Adhere to their prescription medications</td>
<td>35%</td>
<td>55%</td>
<td>90%</td>
</tr>
<tr>
<td>Avoid medications of little or no proven...</td>
<td>26%</td>
<td>50%</td>
<td>76%</td>
</tr>
<tr>
<td>Opt for surgical procedure</td>
<td>12%</td>
<td>41%</td>
<td>53%</td>
</tr>
<tr>
<td>Request imaging tests</td>
<td>14%</td>
<td>38%</td>
<td>52%</td>
</tr>
<tr>
<td>Request unnecessary screenings or tests</td>
<td>15%</td>
<td>28%</td>
<td>43%</td>
</tr>
</tbody>
</table>
Key Objectives For Successful Implementation of SDM with DAs

1. Engage & Train Providers & Staff
2. Target Individuals or Populations
3. Identify & Engage Patients
4. Distribute DAs
5. Encourage Viewing
6. Provide Decision Support
7. Measure Impact
8. Provide feedback
Key Objectives For Successful Implementation of SDM with DAs

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Motivation = Importance + Confidence
Six Steps of SDM

• Invite patient to participate
• Present options
• Provide information on benefits and risks
• Assist patient in evaluating options based on their goals and concerns
• Facilitate deliberation and decision making
• Assist with implementation
Work together to make the best treatment decision for you.
Key Objectives For Successful Implementation of SDM with DAs

- Engage & Train Providers & Staff
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- Distribute DAs
- Encourage Viewing
- Provide Feedback

- Target patients that can be identified
- Target patients in a “decision window”
- Leverage non-physician staff
- Leverage technology
  - Primary care: registries (screening) and referral systems
  - Sub-specialty care: appointment systems
- Engage patients by explaining the SDM process and its importance
Key Objectives For Successful Implementation of SDM with DAs

- Engage & Train Providers & Staff
- Target Individuals or Populations
- Identify & Engage Patients
- Distribute DAs
- Encourage Viewing
- Provide Decision Support
- Measure Impact
- Encourage Viewing
- DAs come as print, video and web products
  - Use multiple formats and access channels to increase access
  - Pre-visit distribution “decompresses” the visit and allows for personalized discussions
  - Post-visit distribution requires a “close the loop” strategy
Key Objectives For Successful Implementation of SDM with DAs

- Engage & Train Providers & Staff
- Target Individuals or Populations
- Identify & Engage Patients
- Distribute DAs
- Encourage Viewing
  - Provide Decision Support
  - Measure Impact
  - Provide feedback
- Enthusiastic endorsement helps
- Clinical context matters
- Viewing deadlines motivate
- Reminders can help, too
Many patients will need some help:
- Understanding the information
- Clarifying what’s personally important
- Preparing for physician visits
- Implementing decisions
Support may be provided:
- By physicians or non-physicians
- In person, by phone, and in groups
Key Objectives For Successful Implementation of SDM with DAs

- Engage & Train Providers & Staff
- Target Individuals or Populations
- Identify & Engage Patients
- Distribute DAs
- Encourage Viewing
- Provide Decision Support
- Measure Impact
  - Decision Quality
    - Knowledge
    - Process
    - Value concordance
  - Screening rates
  - Referral rates
  - Utilization and cost
  - Provide feedback
Key Objectives For Successful Implementation of SDM with DAs

- Engage & Train Providers & Staff
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- Distribute DAs
- Provide Decision Support
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- Measure Impact

Decision Quality Measurement Instruments

- [http://www.massgeneral.org/decisionsciences/research/DQ_Instrument_List.aspx](http://www.massgeneral.org/decisionsciences/research/DQ_Instrument_List.aspx)
- [https://cahps.ahrq.gov/clinician_group/cgsurvey/adult12mopcmheng2.pdf](https://cahps.ahrq.gov/clinician_group/cgsurvey/adult12mopcmheng2.pdf)
- [http://www.facs.org/ahp/cahps/about-scs.html](http://www.facs.org/ahp/cahps/about-scs.html)
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Engage & Train Providers & Staff
Target Individuals or Populations
Identify & Engage Patients
Distribute DAs
Encourage Viewing
Provide Decision Support
Measure Impact
Provide feedback

Patient-specific reports facilitate SDM conversations
Project-level reports allow for quality improvement
THANK YOU
RICHARD WEXLER, MD
RWEXLER@IMDFOUNDATION.ORG

Shared Decision Making
A Journey Worth Taking