Comparative Effectiveness Research and Shared Decision Making

The Third National Comparative Effectiveness Summit
October 14, 2011
Michael J. Barry, MD
Foundation President
Foundation Mission

- **Mission**
  - The mission of the Foundation is to inform and amplify the patient’s voice in health care decisions
Foundation Principles

• Guiding Principles

We believe patients have the right to be:
  – Supported and encouraged to participate in their health care decisions
  – Fully informed with accurate, unbiased and understandable information
  – Respected by having their goals and concerns honored
The Foundation and Health Dialog

• The Foundation has a licensing agreement with Health Dialog
  – Provides royalties and contract funding to develop and maintain decision support materials

• Strict conflict-of-interest policy
  – Staff and Medical Editors are prohibited from financial support from the drug and device industries
Is Informed Consent “Real”?

- In a survey of consecutive patients scheduled for an elective coronary revascularization procedure at Yale New Haven Hospital in 1997-1998
  - 75% believed PCI would help prevent an MI
  - 71% believed PCI would help them live longer

(Holmboe ES. JGIM 2000; 15:632)
Is Informed Consent “Real”?  

• While even through the latest meta-analysis in 2009 (61 trials, 25,388 patients):
  
  – “Sequential innovations in catheter-based treatment for non-acute coronary artery disease showed no evidence of an effect on death or myocardial infarction when compared to medical therapy.”

  (Trikalinos TA. Lancet 2009; 373:911)
Is Informed Consent “Real”? 

• In a survey of consecutive patients consented for an elective coronary angiogram and possible percutaneous coronary intervention at Baystate Medical Center in 2007-2008 
  – 88% believed PCI would help prevent an MI 
  – 76% believed PCI would help them live longer 

(Rothberg MB. Annals Intern Med 2010; 153:307)
DECISIONS Survey

- Conducted by University of Michigan
- Nationwide random-digit dial telephone survey
- Probability sample of 2575 English speaking Americans age 40+
- Reported a discussion of 1 of 9 medical decisions with a health care provider within the past 2 years
- Response rate 51%

(The Decisions Study. Medical Decision Making 2010; 30 supplement 1)
DECISIONS Survey: Decisions Addressed

• Surgery
  – Back surgery,
  – Knee/hip replacement
  – Cataract extraction
• Cancer screening
  – Prostate,
  – Colorectal
  – Breast
• Medications
  – Hypertension,
  – Hyperlipidemia,
  – Depression
Epidemiology of Medical Decisions

• In the past 2 years:
  – 56% discussed starting or stopping meds for hypertension, hyperlipidemia or depression
  – 72% discussed a screening test for cancer
  – 16% discussed one of the 4 operations
Were Patients Asked for their Opinions?

• For surgery:
  – 80% the time for the orthopedic surgeries
  – 65% of the time for cataracts

• For screening:
  – 20-35% of the time

• For medications:
  – 50% of the time for cholesterol/blood pressure
  – 75% of the time for depression medication
How Much did Patients Know?

• Clinical experts identified 4-5 facts a person should know, for example, common side effects of medications or surgery

• Respondents were asked the knowledge questions related to their decision

• For 8 out of 10 decisions, fewer than half of respondents could get more than one knowledge question right.
"Diagnosis" of Patient Preferences

Patients: Making Decisions in the Face of Avoidable Ignorance

Clinicians: Poorly “Diagnosing” Patients’ Preferences

Poor Decision Quality
Unwanted Practice Variation
U.S. Coronary Bypass Rates

Ratio of Rates of Coronary Artery Bypass Grafting Procedures to the U.S. Average

- 1.50 to 1.87 (31)
- 1.80 to 1.50 (69)
- 0.90 to 1.00 (240)
- 0.75 to 0.90 (71)
- 0.50 to 0.75 (19)
- Not Populated

CABG Procedures per 1,000 Medicare Enrollees

San Francisco
Chicago
New York
Washington-Baltimore
Detroit
What is Good Medical Care?

• It is not just about doing things right
• It is also about doing the right thing
• Proven effective care: For some medical problems, there is one best way to proceed
• Preference-sensitive care: For many and perhaps most medical problems, there is more than one reasonable option
Shared Decision-Making Model

• Key characteristics:
  – At least two participants – [clinician] and 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

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 International Patient Decision Aid Standards Collaboration)
CER and Shared Decision Making

• A key part of the SDM process is a sharing of information on the options for testing or treatment and their outcomes
• CER has the potential to supply that information in a systematic, unbiased way
• So SDM supported by pDAs can be seen as a promising way of disseminating CER to improve decision making in day-to-day health care
CER and Shared Decision Making

- Interactive pDAs allow tailoring of presentation to the individual to the extent depth of CER data allows
- Linkage to clinical data in EMRs will facilitate this tailoring
- Process of developing pDAs may be an excellent way of helping prioritize data needs from CER
Cochrane Review of Decision Aids

• In 86 trials in 6 countries of 34 different decisions, use led to:
  – Greater knowledge
  – More accurate risk perceptions
  – Lower decision conflict
  – Greater participation in decision-making
  – Fewer people remaining undecided
  – Fewer patients choosing major surgery, PSA tests

(O’Connor et al. Cochrane Database of Systematic Reviews 2009, Issue 3. Art. No.: CD001431)
(Stacey et al. Updated Cochrane Review of Patient Decision Aids
Involvement

Did the patient know a decision was being made?
Did the patient know the pros and cons of the treatment options?
Did the provider elicit the patient’s preferences?

Decision Quality

Values Concordance
Did the decision reflect the patient's goals and concerns?

Knowledge
Did the patient know what he or she needed to know?

SDM: Implementation Needs

- Patients interested in being informed and activated
- Practical protocols for routine use of decision support tools
- Health care systems with incentives for good “decision quality” rather than simply “more is better”
- Clinicians and hospitals receptive to patient participation
## CER Dissemination Network

<table>
<thead>
<tr>
<th>Demonstration Sites</th>
<th>Primary Care</th>
<th>Specialty Care</th>
</tr>
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<tbody>
<tr>
<td>Massachusetts General Hospital*</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>University of North Carolina</td>
<td>X</td>
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<tr>
<td>Maine Health</td>
<td>X</td>
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<tr>
<td>Mercy Clinics Inc.</td>
<td>X</td>
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<tr>
<td>Stillwater Medical Group*</td>
<td>X</td>
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<tr>
<td>Oregon Rural Practice Based Research Network*</td>
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<tr>
<td>Palo Alto Medical Research Foundation*</td>
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<tr>
<td>Peace Health*</td>
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<td>PA FQHCs*</td>
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<td>Group Health Cooperative*</td>
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<tr>
<td>University of Washington</td>
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<td>X</td>
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<tr>
<td>Allegheny General Hospital - Breast Center</td>
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<td></td>
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<tr>
<td>University of California San Francisco - Breast Center</td>
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</tbody>
</table>

* Medical Home
## Patient Questionnaires Returned to Demonstration Sites
**July 2009 to May 2011**

<table>
<thead>
<tr>
<th>Preference-Sensitive</th>
<th>n=841</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Acute Low Back Pain</td>
<td></td>
</tr>
<tr>
<td>✓ Adjuvant Breast Cancer Therapy</td>
<td></td>
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<tr>
<td>✓ Breast Reconstruction</td>
<td></td>
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<tr>
<td>✓ Breast Cancer Surgery</td>
<td></td>
</tr>
<tr>
<td>✓ Benign Prostatic Hyperplasia</td>
<td></td>
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<tr>
<td>✓ Abnormal Uterine Bleeding</td>
<td></td>
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<tr>
<td>✓ Uterine Fibroids</td>
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<tr>
<td>✓ Coronary Artery Disease</td>
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<td>✓ Ductal Carcinoma in Situ</td>
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<tr>
<td>✓ Depression</td>
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<tr>
<td>✓ Herniated Disc</td>
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<tr>
<td>✓ Hip Osteoarthritis</td>
<td></td>
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<tr>
<td>✓ Knee Osteoarthritis</td>
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<tr>
<td>✓ Menopause</td>
<td></td>
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<tr>
<td>✓ Prostate Cancer</td>
<td></td>
</tr>
<tr>
<td>✓ Spinal Stenosis</td>
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<tr>
<td>✓ Weight Loss Surgery</td>
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</table>

<table>
<thead>
<tr>
<th>Screening</th>
<th>n=922</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Colorectal Cancer Screening</td>
<td></td>
</tr>
<tr>
<td>✓ PSA Testing</td>
<td></td>
</tr>
</tbody>
</table>
Patient Responses After Viewing DA:
Overall how would you rate the program?

Preference-Sensitive
- Poor or Fair: 30%
- Good: 64%
- Very Good or Excellent: 64%
- n=767

Screening
- Poor or Fair: 25%
- Good: 69%
- Very Good or Excellent: 69%
- n=770

Unweighted data submitted to Illume data warehouse as of 11-May-2011
Patient Responses After Viewing DA:

How important for clinicians to give DAs to patients?

- **Preference-Sensitive**:
  - Not at all: 0%
  - Somewhat: 52%
  - Very: 35%
  - Extremely: 13%
  - Total: n=767

- **Screening**:
  - Not at all: 0%
  - Somewhat: 56%
  - Very: 28%
  - Extremely: 16%
  - Total: n=770

Unweighted data submitted to Illume data warehouse as of 11-May-2011
Patient Responses After Receiving DA:

*Exposure to either video or booklet*

- **Preference-Sensitive**
  - None: 9%
  - Some: 8%
  - Most: 86%
  - All: 8%
  - n=784

- **Screening**
  - None: 8%
  - Some: 8%
  - Most: 85%
  - All: 8%
  - n=792

Unweighted data submitted to Illume data warehouse as of 11-May-2011
Percentage of Correctly Answered Knowledge Questions By Amount of DA Exposure

Unweighted data submitted to Illume data warehouse as of 11-May-2011
Patient Responses Before & After Viewing DA:
What are you leaning toward doing?

<table>
<thead>
<tr>
<th>Decision</th>
<th>Before DA</th>
<th>After DA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>16%</td>
<td>15%</td>
</tr>
<tr>
<td>Not Sure</td>
<td>89%</td>
<td>29%</td>
</tr>
<tr>
<td>No Surgery</td>
<td>45%</td>
<td>56%</td>
</tr>
</tbody>
</table>

Unweighted data submitted to Illume data warehouse as of 11-May-2011
Patient Responses Before & After Viewing DA:
What are you leaning toward doing?

CRC Screening
n=253

Unweighted data submitted to Illume data warehouse as of 11-May-2011
Patient Responses Before & After Viewing DA:
What are you leaning toward doing?

PSA Screening
n=531

Unweighted data submitted to Illume data warehouse as of 11-May-2011
Thank You!

mbarry@fimdm.org

www.informedmedicaldecisions.org