Moving Toward Patient-Centered Care:
Changing Patient and Physician Behavior

Ronald E. Myers, PhD
Professor and Director, Division of Population Science,
Department of Medical Oncology and Associate Director
of Population Science, Kimmel Cancer Center,
Thomas Jefferson University
(ronald.myers@jefferson.edu

March 21, 2012
Learning Objectives

• Describe decision aids used in health care

• Discuss the decision counseling program in the context of individualized medical care

• Explain the potential impact of mediated support and obstacles to implementation in practice
Outline

- Patient-Centered Care and Decision Support Interventions
- Prostate Cancer Screening RCTs and Screening Guidelines
- Mediated Decision Support in Prostate Cancer Screening
- Research on Decision Support in Cancer Screening, Risk Assessment, and Treatment
- Patient Centered Outcomes Research

No conflicts of interest to declare concerning the presentation, “Mediated Decision Support in Prostate Cancer Screening.”
Patient-centered care is “care that is respectful of and responsive to individual patient preferences, needs, and values (and ensures) that patient values guide all clinical decisions.”

(Crossing the Quality Chasm, IOM, 2001)

“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.”

(Barry and Edgman-Levitan, NEJM, 2012)
Decision Support Interventions Defined

• “Decision support interventions help people think about choices they face; they describe where and why choice exists; (and) they provide information about options, including where reasonable, the option of taking no action.”

• Decision support interventions can be used for one-way delivery of information to patients (non-mediated) or in the context of a two-way interaction between a patient and a health care provider (mediated)

(Elwyn et al., 2010)
Types of Decision Support Interventions

- Print materials (pamphlets, brochures, booklets)
- Audiovisual or digital recordings
- Computer or Web-based software applications
- Oral, scripted presentations
- Decision counseling
International Patient Decision Aids Standards (IPDAS) Criteria

- Provides information about options in sufficient detail
- Presents probabilities in an unbiased, understandable way
- Includes methods for clarifying and expressing personal values
- Includes structured guidance in deliberation and communication
- Ensures decision making is informed and values based
- Presents information in a balanced manner
- Has a systematic development process
- Uses up-to-date scientific evidence
- Discloses conflicts of interest
- Uses plain language

(http://ipdas.ohri.ca/)
Implementing Decision Support in Practice: Are We There Yet?

- Population-based survey mailed to 878 physicians: surgeons, medical oncologists, & radiation oncologists
- 69% of respondents aware of decision aids, and 46% were aware of decision aids relevant to their practice
- Only 24% were currently using decision aids
- Main barriers to the use of decision aids in practice
  - Lack of awareness
  - Limited resources/time

(J Clin Oncol 28:2286-2292)
Prostate Cancer and Screening RCTs
New Cancer Cases and Deaths for Men, 2012

• New Cases
  – All sites: 848,170
    ❖ Prostate: 241,740 (28.5%)

• Deaths
  – All sites: 301,820
    ❖ Prostate: 26,170 (8.7%)

The NCI reported the following data on prostate cancer death rates by years:
1975 - 1987, an annual increase of 0.9%; 1987 - 1991, an annual increase of 3.0%
PSA – A Test to Screen for Early Prostate Cancer

1970s: T. Ming Chu, PhD, ScD initiated research to isolate a protein that is associated with prostate cancer (prostate specific antigen)

1979: First major paper in Journal of Urology

1984: Patent issued

1986: FDA approval as a monitor for treatment response and disease recurrence

1994: FDA approval as a screening test
Non Sequitur

LOOK, HALF THE WORK IS DONE!
ALL YOU NEED TO DO IS FILL IN THE
TOP PART SO WE CAN LEGALLY
SAY THE BOTTOM PART

CONCLUSION:
EATING CHOCOLATE
WILL MAKE YOU LOOK
YOUNGER AND THINNER

© '10 Wulum Ink, Inc. 4-ZZ
Distributed by UNIVERSAL UCLICK
WULUMINK@PARTYLINE.NET
www.comics.com/nonsequitur
Prostate, Colon, Lung, and Ovarian Cancer Trial

- NCI-funded Prostate, Lung, Colon, and Ovarian Cancer (PLCO) Trial

- 1993-2001: 76,693 men 55-74 years of age at 10 US study centers

- Random assignment either to a Control Group (N=38,343) or a Treatment Group (38,350)
  - Control Group received usual care
  - Treatment Group received annual PSA testing (4 ng/ml = abnormal PSA result) and DRE
Observations and Issues in PLCO

- 4,307 cancer cases in control group and 5,990 cancer cases in screening group (+22% increase in treatment group)

- The incidence of death per 10,000 person-years was 2.0 (50 deaths) in the screening group and 1.7 (44 deaths) in the control group (rate ratio, 1.13; 95% CI, 0.75 to 1.70)

European Randomized Study of Screening for Prostate Cancer (ERSPC)

- The Netherlands, Belgium, Sweden, Finland, Italy, Spain, Switzerland
- 1991-2003: 182,000 men 50-74 years of age
- Random assignment either to a Control Group (N=99,184) or a Treatment Group (82,816)
  - Control Group received usual care
  - Treatment Group received annual PSA testing (3 or 4 ng/ml = abnormal PSA result) and DRE at intervals of 2 or more years
Observations and Issues in ERSPC

- Rate ratio for prostate cancer death (screening/control) of 0.80 (95% CI: 0.65, 0.98, adjusted p-value=0.04)

- 20% reduction in prostate cancer death, accompanied by high risk for over diagnosis

What Do We Know Now?

- Meta-analysis of 5 five RCTs with a 341,351 participants 50-74 years of age with 7 to 15 years of follow up

- Prostate cancer diagnosis rates were higher in intervention vs control groups (RR=1.35, CI: 1.06,1.72)

- No statistically significant differences in prostate cancer-specific mortality between treatment and control groups
  - ERSCP analysis of men 55-69 years of age showed 20% reduction in prostate cancer-specific mortality

- Treating early prostate cancer may reduce mortality, but, aggressive treatment (surgery, radiation) can cause serious side-effects (e.g., incontinence, impotence, and bowel stricture)

Approximately 92% of the study participants were followed to 10 years and 57% to 13 years. At 13 years, 4250 participants had been diagnosed with prostate cancer in the intervention arm compared with 3815 in the control arm. Cumulative incidence rates for prostate cancer in the intervention and control arms were 108.4 and 97.1 per 10 000 person-years, respectively, resulting in a relative increase of 12% in the intervention arm (RR = 1.12, 95% CI = 1.07 to 1.17). After 13 years of follow-up, the cumulative mortality rates from prostate cancer in the intervention and control arms were 3.7 and 3.4 deaths per 10 000 person-years, respectively, resulting in a non-statistically significant difference between the two arms (RR = 1.09, 95% CI = 0.87 to 1.36).

“After a median follow-up of 11 years in the core age group, the relative reduction in the risk of death from prostate cancer in the screening group was 21% (rate ratio, 0.79; 95% confidence interval [CI], 0.68 to 0.91; P = 0.001), and 29% after adjustment for noncompliance. The absolute reduction in mortality in the screening group was 0.10 deaths per 1000 person-years or 1.07 deaths per 1000 men who underwent randomization. The rate ratio for death from prostate cancer during follow-up years 10 and 11 was 0.62 (95% CI, 0.45 to 0.85; P = 0.003) . . . There was no significant between group difference in all-cause mortality.”

USPSTF (2008) Guidelines

USPSTF: Men < 75 years (Grade I – Insufficient Evidence to Recommend), and > 75 years w/ life expectancy < 10 years (Grade D – Do not Screen)

- Clinicians should discuss the potential benefits and known harms of PSA screening with men . . . and inform them about the gaps in evidence. Personal preferences of these patients should guide the physician decision about whether or not to order the test.

- DRAFT 2012: The U.S. Preventive Services Task Force (USPSTF) recommends against prostate-specific antigen (PSA)-based screening for prostate cancer. This is a grade D recommendation.

http://www.uspreventiveservicestaskforce.org/uspstf12/prostate/draftrecprostate.htm
ACS: Men at average risk and ≥ 50 years, higher risk and ≥ 45 years, and appreciably higher risk and ≥ 40 years

- Asymptomatic men who have at least a 10-year life expectancy have an opportunity to make an informed decision with their health care provider about whether to be screened for prostate cancer after receiving information about uncertainties, risks, and potential benefits associated with prostate cancer screening. Screening should not occur without an informed decision-making process.

Informed, Shared Decision Making and Need for Tools
Decision Making in Practice

- Most primary care physicians recommend and/or perform prostate cancer screening with little or no discussion with patients.

- As a result, most men do not make an informed or shared decision about whether to have prostate cancer screening.

Need for New Methods

• Decision support tools (e.g., brochures and other print materials, decision boards, videotapes, CDs, and websites) to convey information
  – Increase patient knowledge, decrease decisional conflict, increase satisfaction, and decrease screening

• Need for research on impact of decision support tools that provide information, elicit value-based preference, and engage patients and providers in shared decision making in prostate cancer screening
Mediated Decision Support in Prostate Cancer Screening

Patient Education and Counseling 83 (2011) 240–246

Supported by Centers for Disease Control and Prevention (M-0554)
Mediated Decision Support: Decision Counseling

• An interaction between a provider or trained agent and patient intended to increase knowledge and facilitate preference clarification

• Decision counseling session
  – Review information related to screening
  – Identify and rank important decision factors (1-2-3)
  – Determine decision factor weights (level of influence)
  – Compute preference score
  – Interpret and validate preference

• Encourage informed/shared decision making
Study Setting and Patient Population

• Urban primary care practices
  – Site A: An internal medicine practice and a family medicine practice
  – Site B: An internal medicine practice

• Asymptomatic male patients
  – 50 to 69 years of age
  – Office visit within past year
  – Eligible for prostate cancer screening
  – Scheduled appointment for non-acute care
Study Design

<table>
<thead>
<tr>
<th>Eligibility assessment</th>
<th>Baseline Survey</th>
<th>Random Assignment</th>
<th>Intervention</th>
<th>Endpoint Survey</th>
<th>Audit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential Participants</td>
<td>Responders n = 313</td>
<td>Control n = 157</td>
<td>• Mailed booklet • In-office patient satisfaction survey • Chart prompt</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>N = 776</td>
<td></td>
<td>Treatment n = 156</td>
<td>• Mailed booklet • In-office decision counseling • Chart prompt</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

- Random Assignment
- Intervention
- Endpoint Survey
- Audit

Control n= 157

Treatment n= 156

- Mailed booklet
- In-office patient satisfaction survey
- Chart prompt
- In-office decision counseling
- Chart prompt

Responders n = 313

Potential Participants n= 776

Control random assignment of intervention groups.
Hypotheses

• **Primary Outcomes**
  – Treatment Group patients will have higher knowledge (endpoint-baseline survey)
  – Treatment Group patients will have lower decisional conflict (endpoint survey)

• **Secondary Outcomes**
  – Treatment Group patients will have more complete informed decision making (IDM) (audio-recorded encounter)
  – Treatment Group patients will have lower screening (medical records)
## Characteristics of Patients in the Study (N=313)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Site</td>
<td>A</td>
<td>157</td>
<td>(50.2)</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>156</td>
<td>(49.8)</td>
</tr>
<tr>
<td>Age</td>
<td>50-59 years</td>
<td>216</td>
<td>(69.0)</td>
</tr>
<tr>
<td></td>
<td>60-69 years</td>
<td>97</td>
<td>(31.0)</td>
</tr>
<tr>
<td>Race</td>
<td>White</td>
<td>176</td>
<td>(56.4)</td>
</tr>
<tr>
<td></td>
<td>Nonwhite</td>
<td>136</td>
<td>(43.6)</td>
</tr>
<tr>
<td>Education</td>
<td>HS or Less</td>
<td>101</td>
<td>(32.6)</td>
</tr>
<tr>
<td></td>
<td>Greater than HS</td>
<td>209</td>
<td>(67.4)</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married</td>
<td>197</td>
<td>(63.3)</td>
</tr>
<tr>
<td></td>
<td>Not Married</td>
<td>114</td>
<td>(36.7)</td>
</tr>
</tbody>
</table>
Baseline Independent Variables - **Patients** (N=313)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>3.7</td>
<td>± 2.0</td>
</tr>
<tr>
<td>- 10 “true-false” items</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived Susceptibility</td>
<td>1.6</td>
<td>± 1.0</td>
</tr>
<tr>
<td>- two items w/ 0-4 Likert response set</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belief in Cure</td>
<td>3.5</td>
<td>± 0.7</td>
</tr>
<tr>
<td>- two items w/ 0-4 Likert response set</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Salience and Coherence</td>
<td>3.6</td>
<td>± 0.4</td>
</tr>
<tr>
<td>- four items w/ 0-4 Likert response set</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>3.4</td>
<td>± 0.8</td>
</tr>
<tr>
<td>- four items w/ 0-4 Likert response set</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worries and Concerns</td>
<td>1.4</td>
<td>± 1.0</td>
</tr>
<tr>
<td>- four items w/ 0-4 Likert response set</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td>3.7</td>
<td>± 0.6</td>
</tr>
<tr>
<td>- two items w/ 0-4 Likert response set</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Characteristics of Physicians in the Study (N=22)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Site</td>
<td>A</td>
<td>14</td>
<td>(63.2)</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>8</td>
<td>(36.6)</td>
</tr>
<tr>
<td>Age</td>
<td>Less than 50 years</td>
<td>18</td>
<td>(81.8)</td>
</tr>
<tr>
<td></td>
<td>60-69 years</td>
<td>4</td>
<td>(19.2)</td>
</tr>
<tr>
<td>Race</td>
<td>White</td>
<td>20</td>
<td>(90.9)</td>
</tr>
<tr>
<td></td>
<td>Nonwhite</td>
<td>2</td>
<td>(9.1 )</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>197</td>
<td>(63.3)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>114</td>
<td>(36.7)</td>
</tr>
<tr>
<td>Experience</td>
<td>Less than 10 years</td>
<td>16</td>
<td>(72.7)</td>
</tr>
<tr>
<td></td>
<td>Greater than HS</td>
<td>6</td>
<td>(27.3)</td>
</tr>
</tbody>
</table>
### Baseline Independent Variables - Physicians (N=22)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of Screening Guidelines</td>
<td>8.9</td>
<td>± 1.1</td>
</tr>
<tr>
<td>- 10 “true-false” items</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Awareness of Screening Controversy</td>
<td>3.4</td>
<td>± 0.5</td>
</tr>
<tr>
<td>- three items w/ 0-4 Likert-type response set</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commitment to Understanding Patient Views</td>
<td>2.8</td>
<td>± 0.7</td>
</tr>
<tr>
<td>- three items w/ 0-4 Likert-type response set</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confidence in Shared Decision Making</td>
<td>2.6</td>
<td>± 0.6</td>
</tr>
<tr>
<td>- five items w/ 0-4 Likert-type response set</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Decision Counseling Session: Information

- Introduction
- Learn about the prostate
- Common prostate problems
- Prostate cancer screening tests
- For men in the general population, what happens?
- Early and late prostate cancer
- To sum up
Most men will have problems with their prostate gland as they grow older. One of those problems may be prostate cancer. A screening exam can find prostate cancer at an early stage.

Medical experts disagree about whether or not men should have a prostate cancer screening exam. It is important for men to make an informed decision about whether or not to be screened.

Please read on to learn what is known and what is not known about prostate cancer and screening.
Learn about the prostate

- The prostate is a sex gland.
- The prostate is about the size of a walnut.
- The prostate is located in front of the rectum.
- The prostate helps make the fluid that carries sperm.
Common prostate problems

Problems that are not cancer
Prostatitis and Benign Prostatic Hypertrophy (BPH) are common prostate problems that can occur.

These problems can cause:
- An enlarged or swollen prostate gland, and this alone is not cancer.
- An infected or inflamed prostate gland, and this alone is not cancer.

Prostate cancer
- Cells begin to grow too fast.
- Cell growth is uncontrolled.
- There may be no symptoms.
- Cancer can be life threatening.

Prostate cancer risk
Many men will develop prostate cancer in their lifetime, but most men die of something other than prostate cancer.

Prostate cancer risk is higher for men who are older, have a family history of prostate cancer, or are African American.
Prostate cancer screening tests

A screening exam (a digital rectal exam and a PSA blood test) can be done to find out if you have signs that may indicate prostate cancer.

Digital Rectal Exam
Using a gloved finger, the doctor can feel if the gland is hard or has lumps.

PSA Blood Test
A medical lab will test a sample of your blood for something called prostate specific antigen (PSA).
For 100 men who decide to screen, what happens?

Among men 55 to 74 years of age who screen:

- **86 will have a normal screening result.**
  - 68 will **NOT** have prostate cancer. **True (-) 68%**
  - 18 will have prostate cancer that is missed. **False (-) 18%**

- **14 men will have an abnormal screening result and follow-up testing.**
  - 13 will **NOT** have prostate cancer. **True (+) 13%**
  - 1 will have prostate cancer that is found. **False (+) 01%**

Results for men who screen
Early and late prostate cancer

Early prostate cancer (localized to the prostate)

Treatment options for early prostate cancer include:
- Surgery (radical prostatectomy)
- Radiation (external beam radiation therapy or radiation seed implantation, called brachytherapy)
- Watchful Waiting (periodic PSA testing)

Many men who have surgery or radiation are likely to have problems with sexual function; fewer are likely to have problems with urinary function.
Early and late prostate cancer

Late prostate cancer (prostate cancer that has spread to other parts of the body)

Among men who have prostate cancer detected by screening, less than one-third will have late prostate cancer.

Treatment options for late prostate cancer include:

- Androgen deprivation therapy (the use of certain hormones)
- Chemotherapy

Most men who have androgen deprivation therapy will experience problems with sexual function. Some will experience hot flashes.
To sum up

- It is common for men to develop prostate cancer, but they are not likely to die of this disease.

- Prostate cancer screening can find early prostate cancer. But it is not known whether finding and treating early prostate cancer can save lives. Research studies are underway to find out.

- Most men who screen have a normal screening result. But some men who have an abnormal screening result will be advised to have follow-up diagnostic tests unnecessarily.

- Men who screen and are treated for prostate cancer may have sexual and/or urinary dysfunction.

- Medical experts disagree about whether or not men should have a prostate cancer screening exam.
Decision Counseling: Preference Clarification

- Review prostate cancer screening brochure
- Identify top decision factors (pros and cons)
- Rank factors and determine factor weights
- Compute preference score (0.000-1.000)
- Assess agreement with preference measure
## Computing a Decision Preference Score

<table>
<thead>
<tr>
<th>Decision Factor Direction and Level of Factor Influence</th>
<th>Score</th>
<th>Preference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Con</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overwhelming</td>
<td>1.9</td>
<td>0.000 – 0.333</td>
</tr>
<tr>
<td>Very Much</td>
<td>1.7</td>
<td>0.334 - 0.356</td>
</tr>
<tr>
<td>Much</td>
<td>1.5</td>
<td>0.357 - 0.383</td>
</tr>
<tr>
<td>Somewhat</td>
<td>1.3</td>
<td>0.384 - 0.416</td>
</tr>
<tr>
<td>A little</td>
<td>1.1</td>
<td>0.417 - 0.454</td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
<td>1.0</td>
<td>0.455 - 0.545</td>
</tr>
<tr>
<td><strong>Pro</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little</td>
<td>1.1</td>
<td>0.546 - 0.583</td>
</tr>
<tr>
<td>Somewhat</td>
<td>1.3</td>
<td>0.584 - 0.616</td>
</tr>
<tr>
<td>Much</td>
<td>1.5</td>
<td>0.617 - 0.643</td>
</tr>
<tr>
<td>Very Much</td>
<td>1.7</td>
<td>0.644 - 0.666</td>
</tr>
<tr>
<td>Overwhelming</td>
<td>1.9</td>
<td>0.667 - 1.000</td>
</tr>
</tbody>
</table>
Patient Decision Factors

• Pros
  – “I think it’s important to know if I am OK.”
  – “I want to be screened, so that I won’t die from prostate cancer.”
  – “I want to screen, so I have peace of mind.”
  – “I want to be around for my grand children.”
  – “My doctor thinks I should be tested.”

• Cons
  – “I don’t want to know if I have a problem.”
  – “The test would be embarrassing and inconvenient.”
  – “If it ain’t broke, don’t mess with it.”

81% Pros
19% Cons
# Results: Patient Knowledge*

<table>
<thead>
<tr>
<th>Study Group</th>
<th>Baseline Mean (SD)</th>
<th>Endpoint Mean (SD)</th>
<th>Difference from Baseline to Endpoint (SD)</th>
<th>Change (95% CI)**</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>3.6 (2.1)</td>
<td>4.4 (2.1)</td>
<td>+0.8 (1.9)</td>
<td>+0.8 (0.5, 1.2)</td>
<td>0.001</td>
</tr>
<tr>
<td>Treatment</td>
<td>3.8 (2.0)</td>
<td>5.3 (2.0)</td>
<td>+1.5 (2.1)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*10-point scale based on total number correct; **Analysis of change adjusted for site, patient background characteristics, and study group-physician interaction; Control Group (N=142) and Treatment Group (N=144).
# Results: Patient Decisional Conflict*

<table>
<thead>
<tr>
<th>Study Group</th>
<th>Endpoint Mean (SD)</th>
<th>Difference (95% CI)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>0.32 (0.49)</td>
<td></td>
<td>0.620</td>
</tr>
<tr>
<td>Treatment</td>
<td>0.30 (0.34)</td>
<td>-0.02 (-0.12, 0.07)</td>
<td></td>
</tr>
</tbody>
</table>

*Decisional conflict score based on 16 items measured on a 0-4 scale, with higher scores indicative of higher conflict; Control Group (N=142) and Treatment Group (N=144).
## Results: Informed Decision Making (IDM)

<table>
<thead>
<tr>
<th>Study Group</th>
<th>IDM Rate</th>
<th>Rate Ratio* (95% CI)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>2.4</td>
<td>1.00 (reference)</td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td>3.0</td>
<td>1.30 (1.03, 1.64)</td>
<td>0.029</td>
</tr>
</tbody>
</table>

*9-point scale; IDM rate computed for 15-minute intervals; analyses adjusted for study site, patient characteristics, physician characteristics, and study site*race interaction; Control Group (N=60) and Treatment Group (N=74).
### Results: Screening

<table>
<thead>
<tr>
<th>Study Group</th>
<th>N</th>
<th>(%)</th>
<th>OR (95% CI)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>81</td>
<td>59.1</td>
<td>1.00 (reference)</td>
<td>0.004</td>
</tr>
<tr>
<td>Treatment</td>
<td>62</td>
<td>45.2</td>
<td>0.37 (0.19, 0.73)</td>
<td></td>
</tr>
</tbody>
</table>

*Model adjusted for study site, patient characteristics, physician characteristics, and study group*physician knowledge interaction; Control Group (N=137) and Treatment Group (N=137).
• Decision Counseling (Mediated Decision Support)
  ▪ Increased patient knowledge about prostate cancer and screening
  ▪ Had no effect on patient decisional conflict
  ▪ Increased the completeness of informed decision making in physician-patient encounters
  ▪ Lowered screening use
So, where to we go from here with decision support?
Decision Counseling

Guided interaction between a trained decision counselor and a patient intended to review information about and clarify personal preference for health behavior options

Anett Petrich, RN, MSN; David Patricola, Jeff-IT
Research in the Center focuses on informed/shared decision making; patient, provider, and population response to mediated decision support; and the impact of decision counseling on patient behavior, provider practice patterns, population health, disparities in cancer care, and patient-centered outcomes.
Center for Health Decisions

Population Science
Decision Counseling Program

Campus Key: 
Password: 
Submit

Maintained by Jefferson Information Technologies
Copyright© Thomas Jefferson University. All Rights Reserved.

The Thomas Jefferson University web site, its contents and programs, is provided for informational and educational purposes only and is not intended as medical advice nor is it intended to create any physician-patient relationship. Please remember that this information should not substitute for a visit or a consultation with a health care provider.
The views or opinions expressed in the resources provided do not necessarily reflect those of Thomas Jefferson University, Thomas Jefferson University Hospital, or the Jefferson Health System or staff.
Please read our Privacy Statement

Jefferson
Kimmel Cancer Center
NCI-designated

NCI:CC
A Cancer Center Designated by the National Cancer Institute
Example: Initiating a Decision Counseling Session: Colon Cancer Vaccine Study

Division of Population Science
Decision Counseling Program

Welcome Anett Petrich

Initiate Session

To initiate a Session, highlight a Decision below and click the start session button. Decisions are grouped under their Domain (in bold).

Prevention
Colon Cancer Vaccine Study
Colonoscopy completion
Completion of home stool blood test
GERA

Recall Session

Three ways to recall information:
1. Recall session by participant ID
2. Recall preference report by participant ID
3. Recall all sessions by decision situation

Recall session by participant ID:

Recall preference report by participant ID:
-Select Participant ID-
go

Recall all sessions by decision situation:
-Select a Decision Situation- go
Define Decision Options & Review Information

In this decision making process, we are looking at your preference to join or not to join the Colon Cancer Vaccine Study.

Please enter the Participant ID: 03192012  Check if Unique

Your Participant ID is ok to use.

Selected Decision to be Made: Colon Cancer Vaccine Study

Option 1: Join the Study

Option 2: Not to join the Study

The following are optional selections.

- Review Information with patient? View Information
- Checklist complete? View Checklist

Colorectal Cancer Vaccine Study

Division of Population Science
Link Participant to Decision Condition/Domain

pause session  log out
Decision Counseling Report: Colon Cancer Vaccine Study

Decision to be Made - **Option 1**: Join the Study or **Option 2**: Not to join the Study

Session results indicate that you prefer to join the study.

<table>
<thead>
<tr>
<th>Option</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0.732</td>
</tr>
<tr>
<td>2</td>
<td>0.268</td>
</tr>
</tbody>
</table>

Top Decision Factors and Direction of Influence:

<table>
<thead>
<tr>
<th>Factor</th>
<th>Direction</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am worried that I might develop colon cancer</td>
<td>Pro</td>
</tr>
<tr>
<td>I am worried about insurance coverage and cost</td>
<td>Con</td>
</tr>
<tr>
<td>I just don’t trust researchers</td>
<td>Con</td>
</tr>
</tbody>
</table>

Comments:

Address Mr. Doe’s concern about cost and insurance coverage

I understand and agree with the Decision Counseling Report results shown above.

Participant ID: 03192012
Decision Counselor: NAME
Participant First Name: John
Participant Last Name: Doe
Participant Signature: ___________________
Decision Counseling Program Data Flow

- Patient/Client ID, Name, and Contact Information
- Decision Domain
- Decision Situation
- Specified Factors Influencing Decision
- Comparisons of Factor Relative Importance
- Primary, Secondary, & Tertiary Factor Strengths
- Score, Validation Status, Comments and Notes
- Demographics

DCP Data Repository
So, what else can decision support do?
RCTs of Decision Support Interventions in Cancer

- Reviewed 44 randomized, controlled trials of decision aids in breast, colon & prostate cancer (2000-2011)
  - Screening (n=24)
  - Risk Assessment (n=9)
  - Treatment (n=11)
- Outcome measures: knowledge, anxiety, decisional conflict, interest/intention, and behavior
## Decision Support in Cancer Screening (n=24)

<table>
<thead>
<tr>
<th>Effect</th>
<th>Knowledge (n=19)</th>
<th>Anxiety (n=6)</th>
<th>Decisional Conflict (n=9)</th>
<th>Intention (n=15)</th>
<th>Behavior (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3*</td>
</tr>
<tr>
<td>Decrease</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>7</td>
<td>4**</td>
</tr>
<tr>
<td>No Effect</td>
<td>4</td>
<td>6</td>
<td>3</td>
<td>5</td>
<td>7**</td>
</tr>
</tbody>
</table>

*Colorectal cancer screening; **Prostate cancer screening
### Measured Outcomes*

<table>
<thead>
<tr>
<th>Effect</th>
<th>Knowledge (n=8)</th>
<th>Anxiety (n=3)</th>
<th>Decisional Conflict (n=3)</th>
<th>Intention (n=9)</th>
<th>Behavior (N=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Decrease</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>No Effect</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

*Breast cancer risk assessment
## Decision Support in Cancer Treatment (n=11)

### Measured Outcomes

<table>
<thead>
<tr>
<th>Effect</th>
<th>Knowledge (n=6)</th>
<th>Anxiety (n=3)</th>
<th>Decisional Conflict (n=6)</th>
<th>Intention (n=1)</th>
<th>Behavior (N=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Decrease</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>4*</td>
</tr>
<tr>
<td>No Effect</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>0</td>
<td>2**</td>
</tr>
</tbody>
</table>

* Patients with early stage breast cancer and mastectomy (n=1); Patients with low-risk breast cancer (small tumor size, node (-), ER (-)) and adjuvant chemotherapy (n=2); patients with prostate cancer and orchiectomy (n=1).

** Patients with late stage colorectal cancer and multiple treatment options; patients with node(-) breast cancer and chemotherapy.
Going forward…

- Develop new decision support methods and clarify appropriate measures of success
- Conduct research on mediated decision support related to patient-centered outcomes
- Implement high quality decision support methods that conform to international quality standards (IPDAS criteria)
- Health care reform legislation may facilitate decision support research, implementation, and dissemination
Patient-Centered Outcomes Research

• The Patient Centered Outcomes Research Institute (PCORI) was created by Patient Protection and Affordable Care Act (PPACA) of 2010 to advance comparative effectiveness research (CER).

• Priorities:
  – Compare options for prevention, diagnosis, and treatment
  – Improve health care systems
  – Support communication and dissemination research
  – Address disparities among patient populations and health outcomes
  – Accelerate patient-centered outcomes and methodological research.
Translating Research Findings into Routine Care: The Way It Has Been

Public/Private Support

Research

Basic Science
Clinical Science
Population Science

Best Practices for Improving Patient/Population Outcomes

Routine Care

Health Systems
Clinical Practices
Community Settings
Translating Research Findings into Routine Care: The Way It May Be

Public/Private Funding

Research

Basic Science

Clinical Science

Population Science

NIH/AHRQ/PCORI Funding

Best Practices for Improving Patient/Population Outcomes

Routine Care

Health Systems

Clinical Practices

Community Settings
Questions and Comments