Using Evidence & Experience to Inform Patients’ Involvement in Health Decisions

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Associate Professor
Director, Ottawa Patient Decision Aids Research Group

‘Festival of Evidence & Experience’ June 6, 2012
Outline

• Shared decision making
• Evidence to inform decision making
  – Ways to communicate evidence
  – Effect on decisions
• Experience to inform decision making
  – Patients’ own experiences
  – Experiences of others
• The intersection of evidence & experiences
Shared Decision Making

A process by which a healthcare choice is made between the patient and one or more health professionals.

Facilitated by:
- Patient decision aids
- Decision coaching

The crux of patient-centred care

(Legare et al., 2010; Makoul & Clayman 2006; Stacey et al. 2011; Weston, 2001)
Integrative Model of SDM

**Essential Elements**
- Inform: problem, options, benefits, risks, costs
- Check understanding
- Clarify: patient’s values, preferences, ability, self-confidence
- Clinician’s knowledge/recommendations
- Make/explicitly defer decision
- Arrange follow-up

**Ideal Elements**
- Unbiased information and evidence (probabilities)
- Role definition (desire for involvement)
- Mutual agreement

(Makoul & Clayman 2006)
Patient Decision Aids adjuncts to consultation

Inform
• facts, probabilities

Clarify values
• Experiences, ask what matters most

Support
• Guide in steps, worksheets
Formats for decision aids

1. Print
   - Passive or interactive

2. Linear DVD/Video
   - Passive

3. Online/computer-based
   - Passive or interactive
• Medical (n=25)
  - 10 HRT
  - 3 atrial fib anti-coag
  - 1 hypertension
  - 2 cardiovascular
  - 1 osteoporosis
  - 1 chemotherapy
  - 1 MS
  - 2 diabetes
  - 1 schizophrenia
  - 1 depression
  - 1 breast ca prevention
  - 1 osteoarthritis knee
  - 1 natural health products

• Surgical (n=20)
  - 4 mastectomy +1 reconstruction
  - 2 prophylactic BRCA1/2
  - 3 prostatectomy
  - 1 orchiectomy for prostate ca
  - 3 hysterectomy
  - 2 dental
  - 1 circumcision
  - 1 back
  - 2 coronary revascularization

• Screening (n=32)
  - 12 PSA
  - 8 BRCA1/2 genetic
  - 5 colon cancer
  - 1 colon ca genetic
  - 5 prenatal
  - 1 mammography

• Obstetrics (n=4)
  - 2 VBAC
  - 1 termination
  - 1 breech

• Vaccine (n=2) (Stacey et al., 2011)
  - 1 infant
  - 1 Hep B

• Other (n=2)
  - 1 autologous blood donation
  - 1 CF referral for transplant
Patient decision aids (86 trials)

- Improve decision quality
  - 14% higher knowledge
  - 74% more realistic expectations
  - 25% better match of values & choices

- Patients 39% less passive in decisions

- Reduce over-use
  - 20% surgery
  - 15% PSA
  - 27% HRT

- Potential to reduce under-use

(Stacey et al., 2011 Cochrane Review Patient Decision Aids)
Of 5 studies, using 3rd party observer measures... 2 had an impact

<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention 1</th>
<th>Intervention 2</th>
<th>Standard Effect Size</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stacey 2006</td>
<td><strong>Multifaceted intervention</strong> Patient-mediated intervention, educational meeting, audit and feedback</td>
<td>Usual Care</td>
<td>2.11</td>
<td>(1.30; 2.90)</td>
</tr>
<tr>
<td>Nannenga 2009</td>
<td><strong>Single intervention</strong> Patient-mediated intervention: Statin Choice decision aid</td>
<td><strong>Single intervention</strong> Patient-mediated intervention: Standard Mayo patient education pamphlet</td>
<td>1.06</td>
<td>(0.62; 1.50)</td>
</tr>
</tbody>
</table>

(Legare, Ratte, Stacey, et al. 2010, Cochrane review)
Interventions to increase SDM: a patient perspective

Of 21 RCTs, 3 had positive effect:

<table>
<thead>
<tr>
<th>Compared to</th>
<th>Bieber 2006</th>
<th>Krones 2008</th>
<th>Loh 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational meeting</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Pt mediated intervention</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Audit/feedback</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>74%</td>
<td>227%</td>
<td>P=0.003</td>
<td></td>
</tr>
</tbody>
</table>

(Legare, Turcotte, Stacey, Ratte, Kryworuchko, Graham 2012)
Decision coaching

- Develops patients’ skills in deliberating about options, preparing for a consultation, and implementing change.
- Trained facilitators are supportive but non-directive.
- Delivery: face to face, groups, telephone, email, internet.

(O’Connor et al., 2008; Stacey et al., 2008; 2012)
# Ottawa Personal Decision Guide

For People Facing Tough Health or Social Decisions

You will be guided through four steps:

1. Clarify your decision.
   - What decision do you face?
   - What is your reason for making this decision?
   - When do you need to make a choice?
   - How far along are you with making a choice?

2. Explore your decision.
   - Knowledge
     List the options and main benefits and risks you already know.
   - Values
     Use stars (★) to show how much each benefit and risk matters to you. 5 stars means that it matters “a lot”. No stars means “not at all”.
   - Certainty
     Consider the option with the benefits that matter most to you and are most likely to happen. Avoid the option with the risks that matter most to you.

<table>
<thead>
<tr>
<th>☀ BENEFITS</th>
<th>How much it matters</th>
<th>☀ RISKS</th>
<th>How much it matters</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<tr>
<td>Option #1</td>
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<tr>
<td>Option #2</td>
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<tr>
<td>Option #3</td>
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</tbody>
</table>

Which option do you prefer?  #1  #2  #3  Unsure

Support

Who else is involved?
Ottawa Family Decision Guide
For Families Facing Tough Health or Social Decisions

1. Clarify the decision.
   What decision do you face?
   What is your reason for making this decision?
   When do you need to make a choice?

2. Explore the decision.
   Knowledge
   List the options and main benefits and risks you already know.
   Values
   Use stars (★) to show how much each benefit and risk matters to you. 5 stars means it matters ‘a lot’. No stars means “not at all”.
   Certainty
   Consider the option with the benefits that matter most to you and are most likely to happen. Avoid the option with the risks that matter most to you.

<table>
<thead>
<tr>
<th>Reasons to Choose this Option</th>
<th>How much it matters</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Benefits / Advantages / Pros)</td>
<td>Use 0 to 5 ★'s!</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reasons to Avoid this Option</th>
<th>How much it matters</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Harms / Disadvantages / Cons)</td>
<td>Use 0 to 5 ★'s!</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option #1</th>
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<table>
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<tr>
<th>Option #2</th>
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</table>

<table>
<thead>
<tr>
<th>Option #3</th>
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<tbody>
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</tbody>
</table>

Which option do you prefer?

<table>
<thead>
<tr>
<th>#1</th>
<th>#2</th>
<th>#3</th>
<th>Unsure</th>
</tr>
</thead>
</table>

Support

Who else is involved?

Option you think this person prefers?

<table>
<thead>
<tr>
<th>#1</th>
<th>#2</th>
<th>#3</th>
<th>Unsure</th>
</tr>
</thead>
</table>

Option you think this person prefers?

<table>
<thead>
<tr>
<th>#1</th>
<th>#2</th>
<th>#3</th>
<th>Unsure</th>
</tr>
</thead>
</table>
Decision Coaching to Prepare Patients for Making Health Decisions: A Systematic Review of Decision Coaching in Trials of Patient Decision Aids

(10 trials)

Dawn Stacey, PhD. Jennifer Kryworuchko, PhD. Carol Bennett. MSc. Mary Ann Murray, PhD, Sarah Mullan, MSc, France Légaré, PhD

**Background.** Decision coaching is individualized, non-directive facilitation of patient preparation for shared decision making. Purpose. To evaluate the effectiveness of decision coaching compared to usual care in improving outcomes of patient decision making. Methods. A systematic review and meta-analysis of randomized controlled trials. Data Sources. A systematic search of Medline, Embase, and the Cochrane Library from 2000 to 2011. Inclusion criteria: randomized controlled trials comparing decision coaching to usual care or decision aids. Data Extraction. Two independent reviewers extracted data. Ten trials were included. Results. Compared to usual care, decision coaching improves knowledge. Improvement in knowledge similar when coaching compared to decision aids. Outcomes for other comparisons are more variable – some trials show positive effects and others report no difference. (Stacey et al., 2012, Med Dec Making)
22 Reviews: Clinical Decision Making Interventions

Examples of interventions:
- Patient decision aids
- Training clinicians in communication skills
- Question prompts / coaching to develop patients’ skills in preparing for consultations, deliberating about options, implementing change
Outline

• Shared decision making

• **Evidence** to inform decision making
  – Ways to communicate evidence
  – Effect on decisions

• Experience to inform decision making
  – Patients’ own experiences
  – Experiences of others

• The intersection of evidence & experiences
“Without numbers, consumers are left flying blind”

(Schwartz & Woloshin, Welch, 2009; p.184)
Step 1: What are the benefits and harms of each treatment option?

<table>
<thead>
<tr>
<th>Level</th>
<th>Options</th>
<th>Benefits</th>
<th>Serious Harms and Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 0</td>
<td>Chondroitin</td>
<td>In 100 people: 30 improve on their own 70 don't improve</td>
<td>The chance of serious harm is the same for treatment or placebo (fake treatment). Capsaicin can cause discomfort when applied to the skin.</td>
</tr>
<tr>
<td></td>
<td>Hot pepper cream (capsaicin)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Glucosamine</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Electrical treatment applied to the skin (TENS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level 1</td>
<td>Exercise</td>
<td>In 100 people: 30 improve on their own 64 don't improve</td>
<td>The chance of serious harm is the same for treatment or placebo (fake treatment). Exercise can cause people to stop due to pain. Acupuncture can cause bruising.</td>
</tr>
<tr>
<td></td>
<td>Healthy weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Acupuncture</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Acetaminophen (such as Tylenol)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level 2</td>
<td>NSAID creams (such as Pennsaid lotion)</td>
<td>In 100 people: 30 improve on their own 49 don't improve</td>
<td>The chance of serious harm is the same for treatment or placebo (fake treatment). NSAID creams can cause dry skin or rash. A common side effect from joint injection (viscosupplement) is a skin reaction at the joint site.</td>
</tr>
<tr>
<td></td>
<td>Insoles</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Joint injections with steroid or viscosupplement</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
IPDAS presenting probabilities

<table>
<thead>
<tr>
<th>The patient decision aid presents probabilities ...</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ...using event rates...</td>
</tr>
<tr>
<td>2. ...using the same denominator</td>
</tr>
<tr>
<td>3. ...over the same period of time</td>
</tr>
<tr>
<td>4. ...with uncertainty</td>
</tr>
<tr>
<td>5. ...using visual diagrams (e.g. faces, bar charts)</td>
</tr>
<tr>
<td>6. ...using the same scales</td>
</tr>
<tr>
<td>7. ...with more than 1 way of viewing probabilities (e.g. words, numbers, diagrams).</td>
</tr>
<tr>
<td>8. ...based on patient’s own situation (e.g. specific to their age or severity of their disease)</td>
</tr>
<tr>
<td>9. ...using both positive and negative frames</td>
</tr>
</tbody>
</table>

(Presenting Probabilities – Trevena et al. 2006 in J Eval Clin Practice)
<table>
<thead>
<tr>
<th>Level 3</th>
<th>NSAID pills (such as Advil)</th>
<th>In 100 people:</th>
<th>In 100 people under 60 years with no history of a heart disease:</th>
</tr>
</thead>
<tbody>
<tr>
<td>These options work better than a placebo. More people are harmed by the treatment than in level 2.</td>
<td>30 improve on their own</td>
<td>30 improve on their own</td>
<td>21 improve due to treatment</td>
</tr>
<tr>
<td>21 improve due to treatment</td>
<td>21 improve due to treatment</td>
<td>49 don't improve</td>
<td>49 don't improve</td>
</tr>
<tr>
<td>49 don't improve</td>
<td>1 gets a heart attack due to NSAID pills</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level 4</th>
<th>Opioid (narcotic) painkillers such as opioids, oxycontin, oxycodone, morphine, demerol</th>
<th>In 100 people:</th>
<th>Opioid painkillers can cause nausea, constipation, or withdrawal symptoms.</th>
</tr>
</thead>
<tbody>
<tr>
<td>These options work better than a placebo. More people are harmed by the treatment than level 3.</td>
<td>30 improve on their own</td>
<td>30 improve on their own</td>
<td>23 more people get withdrawal symptoms when their Opioid painkillers are reduced</td>
</tr>
<tr>
<td>21 improve due to treatment</td>
<td>21 improve due to treatment</td>
<td>49 don't improve</td>
<td>77 people avoid withdrawal symptoms</td>
</tr>
</tbody>
</table>

Number of heart attacks increase in older people or those with previous heart attacks
### Prescription Drug Facts: Lunesta (Eszopiclone)

**What is this drug for?**
To make it easier to fall or to stay asleep

**Who might consider taking it?**
Adults age 18 and older with insomnia for at least 1 month

**Who should NOT take it?**
People under age 18

**Recommended testing**
No blood tests, watch out for abnormal behavior

**Other things to consider doing**
Reducing caffeine (especially at night), exercise, regular bedtime, avoid daytime naps

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#### LUNESTA Study Findings

788 healthy adults with insomnia for at least 1 month – sleeping less than 6.5 hours per night and/or taking more than 30 minutes to fall asleep – were given LUNESTA or a sugar pill nightly for 6 months. Here’s what happened:

<table>
<thead>
<tr>
<th>What difference did LUNESTA make?</th>
<th>People given a sugary pill</th>
<th>People given LUNESTA (3 mg each night)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Did LUNESTA help?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LUNESTA users feel asleep faster (15 minutes faster)</td>
<td>45 minutes to fall asleep</td>
<td>30 minutes to fall asleep</td>
</tr>
<tr>
<td>LUNESTA users slept longer (37 minutes longer)</td>
<td>5 hours 45 minutes</td>
<td>6 hours 22 minutes</td>
</tr>
<tr>
<td><strong>Did LUNESTA have side effects?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life threatening side effects</td>
<td>None observed</td>
<td></td>
</tr>
<tr>
<td>No difference between LUNESTA and a sugar pill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom side effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More had unpleasant taste in their mouth (additional 20% due to drug)</td>
<td>6% 6 in 100 3% 3 in 100 3% 3 in 100 2% 2 in 100</td>
<td>26% 26 in 100 10% 10 in 100 9% 9 in 100 7% 7 in 100</td>
</tr>
<tr>
<td>More had dizziness (additional 7% due to drug)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More had drowsiness (additional 6% due to drug)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More had dry mouth</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Schwartz & Woloshin, Welch, 2009)
The Decision Box

This document prepares the health professional to discuss scientific data with the patient so they can make an informed decision.

Use statins for primary prevention of cardiovascular diseases?

Benefits and harms

Patient preferences

Yes

No

DECISION

Later

Presentation of statins to patients

What are statins for?

Statins are medications that lower cholesterol levels. They are prescribed to treat high cholesterol levels and prevent cardiovascular diseases.

Among persons who might consider:

- Adults with
- Le niveau de
- À titre d'exemple,

State of knowledge – March 2011
Selection of best available studies

Benefits of treatment

- Death from any causes
  No death from any cause is prevented in persons with established cardiovascular disease.

Risks of treatment

- Myopathy
  For each 1000 persons treated with statins during 4
Patient decision aids (86 trials)

- Improve decision quality
  - 14% higher knowledge
  - 74% more realistic expectations
- 25% better match of values & choices
- Patients 39% less passive in decisions
- Reduce over-use
  - 20% surgery
  - 15% PSA
  - 27% HRT
- Potential to reduce under-use

(Stacey et al., 2011 Cochrane Review Patient Decision Aids)
Accurate Risk Perceptions

<table>
<thead>
<tr>
<th>Study or Subgroup</th>
<th>Decision Aid</th>
<th>Control</th>
<th>Risk Ratio M-H, Random, 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Events</td>
<td>Total</td>
<td>Weight</td>
</tr>
<tr>
<td>Dodin 2001</td>
<td>33</td>
<td>52</td>
<td>21</td>
</tr>
<tr>
<td>Gattellari 2003</td>
<td>57</td>
<td>106</td>
<td>11</td>
</tr>
<tr>
<td>Kuppermann 2009</td>
<td>157</td>
<td>244</td>
<td>80</td>
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<tr>
<td>Laupacis 2006</td>
<td>14</td>
<td>47</td>
<td>5</td>
</tr>
<tr>
<td>Lerman 1997</td>
<td>90</td>
<td>122</td>
<td>108</td>
</tr>
<tr>
<td>Man-Son-Hing 1999</td>
<td>92</td>
<td>139</td>
<td>35</td>
</tr>
<tr>
<td>McAlister 2005</td>
<td>66</td>
<td>175</td>
<td>25</td>
</tr>
<tr>
<td>McBride 2002</td>
<td>109</td>
<td>265</td>
<td>82</td>
</tr>
<tr>
<td>O'Connor 1998a</td>
<td>58</td>
<td>81</td>
<td>39</td>
</tr>
<tr>
<td>Schapira 2000</td>
<td>82</td>
<td>122</td>
<td>62</td>
</tr>
<tr>
<td>Vandemheen 2009</td>
<td>46</td>
<td>70</td>
<td>23</td>
</tr>
<tr>
<td>Whelan 2003</td>
<td>47</td>
<td>82</td>
<td>34</td>
</tr>
<tr>
<td>Whelan 2004</td>
<td>73</td>
<td>94</td>
<td>62</td>
</tr>
<tr>
<td>Wolf 2000</td>
<td>189</td>
<td>266</td>
<td>72</td>
</tr>
</tbody>
</table>

Total (95% CI) 1865 1830 100.0% 1.74 [1.46, 2.08]

Total events 1113 659
Heterogeneity: Tau² = 0.08; Chi² = 77.13, df = 13 (P < 0.00001); I² = 83%
Test for overall effect: Z = 6.18 (P < 0.00001)

2011-14 RCTs showed RR 1.74 [1.46, 2.08] 2009 = RR 1.7 [1.3, 2.2]
But evidence is not enough!
Outline

- Shared decision making
- Evidence to inform decision making
  - Ways to communicate evidence
  - Effect on decisions
- Experience to inform decision making
  - Patients’ own experiences
  - Experiences of others
- The intersection of evidence & experiences
Patient experience in adult NHS services: improving the experience...

- Elements of high quality care that matter to patients
  - Their experience
  - Effectiveness of interventions
  - Safe delivery of healthcare

- Experience is complex and multi-factorial
  - Service factors: access, quality of information, shared decision making skills of health professionals
  - Individual factors: previous experience

- Uses client-centred care to define experience

- UK aiming to include patient experience as measureable outcome – but no robust measure (satisfaction inadequate)
Strategy

Improve the individual experience by providing exceptional care and service to customers that is consistent with both best practice and customer expectations.

Key 2010-11 Actions

- Develop and implement a provincial framework for patient- and family-centered care that will serve as an overarching guide for health care service delivery in Saskatchewan.
- Develop and implement a Shared Decision Making framework which will inform and engage patients in decisions about their treatment options, including surgical and non-surgical treatments.
### Identify your decision making needs.

<p>| | | | |</p>
<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge</strong></td>
<td>Do you know the benefits and risks of each option?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Values</strong></td>
<td>Are you clear about which benefits and risks matter most to you?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td>Do you have enough support and advice to make a choice?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Certainty</strong></td>
<td>Do you feel sure about the best choice for you?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

People who answer “No” to one or several questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. Therefore, it is important to work through steps **two** and **four** that focus on your needs.
Patients’ decision-focused ‘values’

“Detailed insight into the patient’s attitudes about the relative desirability of each of the possible benefits and harms - or attributes - inherent in each option”

(Llewellyn-Thomas, 2009, chpt 18)
Values Clarification Methods
(Llewellyn-Thomas 2009 chpt 18)

- Non-interactive / implicit
  - Patient testimonials
  - Decision aids that describe options
- Interactive / explicit
  - Utility-based
    - Classic decision analysis
  - Non-utility-based
    - Explicit social matching
    - Leaning scale
    - Balance techniques
- Threshold techniques - TTO
- Conjoint analysis
- Analytic hierarchy
- Analytic hierarchy

uOttawa
### IPDAS Clarifying Values (clarify what matters most)

The patient decision aid...

1. ...describes the procedures and outcomes to help patients imagine what it is like to experience their physical, emotional, and social effects.

2. ...asks patients to consider which positive and negative features matter most

Patient Decision Aids adjucts to counseling

Inform
• facts, probabilities

Clarify values
• Experiences, ask what matters most

Support
• Guide in steps, worksheets
Consider which positive and negative features matter most

<table>
<thead>
<tr>
<th>How important is it to you ...</th>
<th>Not Important</th>
<th>Very Important</th>
<th>Options to consider if this reason is important to you</th>
</tr>
</thead>
<tbody>
<tr>
<td>To get better pain relief</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td>Try other options in your current Level or move to the next Level.</td>
</tr>
<tr>
<td>To avoid taking pills?</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td>Try options in Level 1 or 2.</td>
</tr>
<tr>
<td>To avoid needles?</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td>Avoid acupuncture in Level 1 and joint injections in Level 2.</td>
</tr>
<tr>
<td>To avoid bleeding ulcers or heart attack?</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td>Avoid NSAID pills in level 3.</td>
</tr>
<tr>
<td>To avoid withdrawal symptoms?</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td>Avoid OPIOID painkillers in Level 4.</td>
</tr>
<tr>
<td>List other reasons</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Summary of Clinical Priority and Patient's Preference for Total Joint Replacement

Clinical Priority

- Worst Joint: Right Knee
- Symptoms Self-report WOMAC:
  - Total Score (%): 68%
  - Pain: 65%
  - Limited Function: 65%
  - Stiffness: 100%

If current pain remained as it is for the remainder of life, would feel: Unhappy

Surgical Priority (HKPT)

- Total Score (%): 50%

GP’s or physiotherapist’s assessment results

Patient’s preference with their level of (un)certainty

Knowledge test results

(✓ = correct; × = wrong)

Patient’s Preference & Decisional Needs

- Certainty: 75% correct answers
- Knowledge: 75% correct answers
- Values: 97% values predict surgical preference
- Reasons for Surgery:
  - Get pain relief
  - Return to normal activities
  - Avoid side effects of pain meds
- Reasons Against Surgery:
  - Avoid surgery
  - Avoid time off for recovery
  - Avoid side effects of surgery

Support: 75% feels has enough support and advice to make a choice

BMJ 2008;0:bmj.39520.701748.94v2-bmj.39520.701748.94

Stacey, D. et al.
Patient decision aids (86 trials)

- Improve decision quality
  - 14% higher knowledge
  - 74% more realistic expectations
- 25% better match of values & choices

- Patients 39% less passive in decisions
- Reduce over-use
  - 20% surgery
  - 15% PSA
  - 27% HRT
- Potential to reduce under-use

(Stacey et al., 2011 Cochrane Review Patient Decision Aids)
Outline

• Shared decision making
• Evidence to inform decision making
  – Ways to communicate evidence
  – Effect on decisions

• Experience to inform decision making
  – Patients’ own experiences
  – Experiences of others

• The intersection of evidence & experiences
Using Personal Stories/Narratives

- Narratives provide
  - others’ experiences relevant to the decision

- Narratives from a range of ‘others’ - carers, family, professionals
Personal stories during the consultation

• “Doctor what do you think I should do?”

• I don’t know it depends on what is most important to you
  - If you were like my mother, she is... and she would say...
  - If you were like my wife, she is ... and she would say...
  Or
  - Some women...
  - Other women...
Others’ experiences on Internet

The Health Experience Research Group has created a unique database of personal and patient experiences through in-depth qualitative research into over 50 different illnesses and health conditions. The results of our research are published on two websites – www.healthtalkonline.org and www.youthhealthtalk.org which are aimed at patients, their carers, family and friends, doctors, nurses and other health professionals. Our target is to complete at least 100 conditions within the next 5-10 years. The websites, formerly known as www.dipex.org are run by the DIPEX Charity.

For a PDF copy of our annual report, please click here.
Introduction

About Health Crossroads

If you’ve come to this Web site, you’re probably at a crossroad. You may be making a medical decision about whether or not to have a screening test, or you may be looking for the best way to participate in your care.

Each Crossroad on this Web site has been carefully researched and written to help you find the right path for you.

About This Crossroad

This Crossroad is intended for men who are considering whether to have a prostate-specific antigen (PSA) test, a blood test to determine the PSA level. The test may lead to a diagnosis of prostate cancer.

This Crossroad is not intended for men who already have prostate cancer.

Medical Editor: Richard Hoffman, MD
The patient decision aid…

...provides stories that represent a range of experiences (positive and negative)

...describes that the patients gave informed consent to include their stories

Personal stories in publicly available patient decision aids
Khangura, Bennett, Stacey, O’Connor 2008

<table>
<thead>
<tr>
<th>Characteristics of 56 patient decision aids</th>
<th>Developer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A (n = 8) (%)</td>
</tr>
<tr>
<td>Breadth</td>
<td>Median number of stories/PtDA (range)</td>
</tr>
<tr>
<td>Balance</td>
<td>IPDAS: stories in the PtDA represent a range of positive and negative experiences</td>
</tr>
<tr>
<td></td>
<td>Options: the PtDA contains an equal (±1) number of stories portraying choices favouring and against the most intensive option</td>
</tr>
<tr>
<td></td>
<td>Outcomes: the PtDA contains both stories portraying satisfaction and stories portraying dissatisfaction with the outcome/s</td>
</tr>
<tr>
<td>Consent</td>
<td>IPDAS: reports patients gave informed consent to include their stories</td>
</tr>
<tr>
<td>Financial disclosure</td>
<td>IPDAS: reports if there was some financial or other reason why patients decided to share their story</td>
</tr>
</tbody>
</table>

Using 2007 Cochrane A to Z Inventory: stratified by developer and randomly sampled
Exploring stories in decision aids

(Khangura et al., 2008)

<table>
<thead>
<tr>
<th>Characteristics of 260 personal stories</th>
<th>Developer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A (n = 59) (%)</td>
</tr>
<tr>
<td>Depth</td>
<td></td>
</tr>
<tr>
<td>Median number of words/story (range)</td>
<td>201 (35–551)</td>
</tr>
<tr>
<td>Demographics</td>
<td></td>
</tr>
<tr>
<td>Age of narrators</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>59.2</td>
</tr>
<tr>
<td>Range</td>
<td>49–72</td>
</tr>
<tr>
<td>Sex of narrators</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28 (47.5)</td>
</tr>
<tr>
<td>Female</td>
<td>31 (52.5)</td>
</tr>
<tr>
<td>Unidentified</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Ethnicity of narrators</td>
<td></td>
</tr>
<tr>
<td>Number identified</td>
<td>59 (100.0)</td>
</tr>
</tbody>
</table>
Outline

- Shared decision making
- Evidence to inform decision making
  - Ways to communicate evidence
  - Effect on decisions
- Experience to inform decision making
  - Patients’ own experiences
  - Experiences of others’
- The intersection of evidence & experiences
Evidence-based clinical decisions
(Guyatt, Haynes, DiCenzo from McMaster University)

Clinical state, setting, & circumstances

Patient preferences & actions

Healthcare Professionals

Research evidence

Healthcare resources
Summary & questions

• Communicating probabilities is important BUT with what evidence?
  – Systematic reviews
  – Local hospital data

• Patients own life experiences influence their preferences BUT how are they acknowledged in decision making?

• Patients want to hear of others’ experiences BUT how do we synthesize (qualitative systematic reviews?) and communicate experiences while reducing potential bias?

• Interventions (e.g. patient decision aids, decision coaching, shared decision making) incorporate evidence and experience BUT how do we ensure they are not biasing the patient?
Patient Decision Aids

Welcome

What are patient decision aids?

Patient decision aids are tools that help people become involved in decision making by providing information about the options and outcomes and by clarifying personal values. They are designed to complement, rather than replace, counseling from a health practitioner.

How can I find decision aids and learn about their quality?

- The A to Z Inventory allows you to search for decision aids on particular health topics.
- The Ottawa Personal Decision Guide a general decision guide that can be used for any health or social decision.

How do I develop a decision aid?

- The Development Toolkit provides information for developers and researchers interested in producing decision aids using the Ottawa Decision Support Framework.
- The Decision Aid Library Inventory (DALI) allows developers to enter and manage the information about their decision aids for inclusion in our inventories.

What’s the evidence?

- An international research group maintains an ongoing systematic review of trials of patient decision aids for treatment or screening decisions using Cochrane review methods.
- The International Patient Decision Aid Standards (IPDAS) Collaboration established a set of internationally approved criteria for determining the quality of patient decision aids.