UNDERSTANDING THE IMPORTANT ELEMENTS THAT DEFINE QUALITY PATIENT DECISION AIDS

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Practice Transformation Manager
Washington State Health Care Authority
Objectives

- Identify a high quality patient decision aid, applying a set of evidence-based certification criteria
- Evaluate the differences between a patient decision aid and patient education materials
- Understand the value of certification in ensuring PDA quality, and expectations for a certified aid
- Recognize the key elements in a PDA which are most critical to supporting good shared decision making

What is Shared Decision Making?

A process in which clinicians and patients work together to make decisions and select tests, treatments and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values.

Why SDM is important

A tool used by providers in shared decision making to engage patients in decisions that affect their health care by providing them with information they need to make an informed choice.

PDAs come in many forms:
- A written document
- A link to an interactive website
- Videos
- Visual aids
Shared Decision Making: The Role of Patient Decision Aids

Patient Decision Aids support good shared decision making

PDA versus Educational Materials

<table>
<thead>
<tr>
<th>PDA</th>
<th>Educational Material</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides information about more than one option to help patients choose the right one for them</td>
<td>Typically provides information about one option and what the patient can expect</td>
</tr>
<tr>
<td>Assumes there is a choice that needs to be made</td>
<td>Assumes there not a choice to be made or one has already been made</td>
</tr>
<tr>
<td>Helps patients and clinicians compare features of available options, including benefits and risks of each</td>
<td>May provide information about one treatment, including benefits and risks</td>
</tr>
<tr>
<td>Helps patients clarify their values, or what matters most to them, for outcomes of options</td>
<td>Often provides information needed to consent to a treatment, rather than exploring reasons to make one choice vs another</td>
</tr>
<tr>
<td>Is used as part of a shared decision making process to engage patients in a two-way discussion process</td>
<td>Can provide valuable information but engagement is minimal, as information is provided in a one-way format</td>
</tr>
</tbody>
</table>
The Role of the Clinician in SDM

But I already DO shared decision-making with my patients...

Of course it is totally up to you, but if it was me, I’d choose to have the surgery.

Used with permission, Dr. Matt Handley, Group Health Cooperative.

What drives your decisions?

• Convenience
• Cost
• Loyalty
• Quality
How do you define quality?

As PDAs become more widely used, standards become critical

Ensures quality
  - Accuracy and appropriateness of information
  - Supports patient in exploring values

Minimizes bias

Addresses conflicts of interest

In Washington, enhanced liability protections are activated in part by PDA certification
In the early 2000s, Jack Wennberg presented to legislature and governor on clinical variation across regions of the state.
- Response was legislation to support SDM, with goal of reducing variation without restricting choice.
- Goal was appropriate utilization based on patient preferences, rather than decreased utilization.
  - Evidence suggests SDM decreases overutilization, but helps correct underutilization.

Health Care Authority role in SDM

- Certification of Patient Decision Aids
- Leverage our role as purchaser (1.8M Medicaid lives, 200K PEB) to support clinicians in the use of SDM and PDAs.
- Providing training and support to clinicians.
- Convening statewide discussion around spread and sustainability.
The Certification Criteria

- Based on standards established by the International Patient Decision Aids Standards Collaboration (IPDAS)
- Aimed at ensuring accurate, unbiased, up to date, understandable information
- Addresses values/preferences clarification
- The criteria may be adjusted over time

For a full list of criteria go to: https://www.hca.wa.gov/assets/program/2017-pda-criteria.pdf

Review process

- Full review panel
  - Review/score application, PDA, supporting document against certification criteria
- Evidence-based Practice Center
  - Review/score PDA and evidence table against current science
- Chief Medical Officer
  - Reviews full application, PDA, and evidence considering input from panel and SMEs for final determination
Current certified PDAs

- 2016: Maternity Care
  - Certified 5 PDAs
- 2017: Total Joint Replacement and Spine Care
  - Certified 7 PDAs
- 2017 - 2018: End of Life Care
  - Certified 24 PDAs
- Fall 2018 Cardiac Care

Lessons learned

- “Adequately met”
- Balance
- Bias
- Consistency
- Capacity
- Time
1. Describe the health condition or problem
2. Explicitly state the decision under consideration
3. Identify the eligible or target audience
4. Describe the options available for the decision, including non-treatment
5. Describe the positive features of each option (benefits)
6. Describe the negative features of each option (harms, side effects, disadvantages)

7. Help patients clarify their values for outcomes of options by a) asking patients to consider or rate which positive and negative features matter most to them AND/OR b) describing each option to help patients imagine the physical, social (e.g. impact on personal, family, or work life), and/or psychological effects
8. Make it possible to compare features of available options
9. Show positive and negative features of options with balanced detail
What influences your views?

- Do you have a view on this decision?
  - What influences your views on this decision?
- Have you, a family member, or friend experienced this decision?
  - If yes, was the outcome positive or negative?
- How might your views influence your judgment when certifying a PDA?

1. Describe the health condition or problem

1.1 Explanation

Clear description of the condition, disease, treatment, procedure, or investigation for which the index decision is required.

Permits PDA users to identify
- clinical context
- intended audience
1. Describe the health condition or problem

**What Is Spinal Stenosis?**

To understand your treatment options, it helps to know what *spinal stenosis* is, how it occurs, and how it causes pain. This chapter explains some parts of the spine and what happens as a person ages.

**Anatomy of the Spine**

The spine is made up of bones called *vertebrae*. The vertebrae are stacked on top of one another and supported by muscles and ligaments.

The vertebrae form a canal (or tube) that houses and protects the *spinal cord*. The spinal cord ends in the upper part of the lower back. Nerves branching out from the spinal cord pass between the vertebrae.

Between the vertebrae are *discs* that have a tough outer covering and a jelly-like center. The discs provide cushioning, absorb shock, and allow the back to move.

©Health Dialog, Spinal Stenosis, Choosing the right treatment for you, February 2018

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2. Explicitly state the decision under consideration

2.1 Explanation

**Decision (i.e., the focus of the PDA) is clearly stated**
2. Explicitly state the decision under consideration

2.2 Examples

Who is this decision aid for?
This patient decision aid is for adults with osteoarthritis who are thinking about total hip replacement surgery. It can help you think about whether you want to:

* have surgery at this time
* not have surgery at this time, and continue to manage your symptoms with non-surgical treatments

There is no right or wrong choice. This booklet provides information, and helps you compare options and think about what is most important to you. You and your health care provider can decide together about your next steps.

Is hip replacement surgery right for me? a decision aid for people with osteoarthritis
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3. Identify the eligible or target audience

3.1 Explanation

Clearly states who the PDA is intended for, to help the user determine whether it is applicable to them
3. Identify the eligible or target audience

3.2 Example (PDA by Mathers et al., UK)

4. Describe the options available for the decision, including non-treatment

4.1 Explanation

“It is important that PtDAs present all the relevant options and the information about those options in a complete, unbiased and neutral manner that is sustained throughout the PtDA's content and format.”

If potentially relevant options are missing, such as "no treatment", it’s important to provide a rationale for why.

(Abhyankar et al., BMC Medical Informatics and Decision-Making; 2013)
4. Describe the options available for the decision, including non-treatment

4.2 Example

Overview of Treatment Options

<table>
<thead>
<tr>
<th>Will my pain and cancer symptoms be treated?</th>
<th>Non-Treatment</th>
<th>Hospice</th>
<th>Supportive Care Only</th>
<th>Supportive Care + Anticancer Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, you would have chosen not to come back for care</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No, you have chosen not to come back for care</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No, you would have chosen not to come back for care</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No, you have chosen not to come back for care</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>How often will I need to come in to the hospital or clinic?</td>
<td>Never</td>
<td>Only if comfort measures can’t be given at home</td>
<td>About once every 1 to 3 months and when you have problems</td>
<td>Can vary, sometimes as often as weekly, but typically every 3 weeks.</td>
</tr>
<tr>
<td>How often will I need blood tests?</td>
<td>Never</td>
<td>Never</td>
<td>This varies. If you have symptoms suggesting a blood abnormality, and for some doctors, at each visit (every 1 to 3 months)</td>
<td>Before treatments or if you have symptoms suggesting abnormal blood tests</td>
</tr>
<tr>
<td>How often will I need x-rays or CAT scans?</td>
<td>Never</td>
<td>Never</td>
<td>The need for scans is driven by symptoms</td>
<td>Every 2 or 3 months to assess if the treatment is working</td>
</tr>
</tbody>
</table>

7. Values Clarification

7.1 Helps patients clarify their values for outcomes of options by:

a) asking patients to consider which positive/negative features matter most to them; and/or

Explanation: Interactive methods and/or exercises to help patients think about the desirability of options or attributes of options within a specific decision context, in order to identify which option he/she prefers.

b) describing each option to help patients image the physical, social (e.g. impact on personal, family, or work life) and/or psychological effects
7. Values Clarification

7.2 Example

What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and show how you feel about the following statements.

<table>
<thead>
<tr>
<th>Reason to take medicine</th>
<th>Reason not to take medicine</th>
</tr>
</thead>
<tbody>
<tr>
<td>I'm worried about my risk of heart attack and stroke, and I want to do everything I can to reduce it.</td>
<td>I'm not very worried about my risk of heart attack and stroke.</td>
</tr>
<tr>
<td>More important</td>
<td>More important</td>
</tr>
<tr>
<td>I don't mind taking medicine if it will reduce my risk of heart attack and stroke.</td>
<td>I hate the idea of taking a pill every day.</td>
</tr>
<tr>
<td>More important</td>
<td>More important</td>
</tr>
<tr>
<td>I'm not worried about the side effects of these medicines.</td>
<td>I am worried about the side effects of these medicines.</td>
</tr>
<tr>
<td>More important</td>
<td>More important</td>
</tr>
<tr>
<td>I've already done everything I can to reduce my risk through heart-healthy habits.</td>
<td>I could do more to reduce my risk by improving my habits.</td>
</tr>
<tr>
<td>More important</td>
<td>More important</td>
</tr>
</tbody>
</table>

Practice Activity

Working with others at your table, answer the following questions:

- Does the PDA:
  - 1. Describe the health condition or problem
  - 2. Explicitly state the decision under consideration
  - 3. Identify the eligible or target audience
  - 4. Describe the options available for the decision, including non-treatment
  - 5. Helps patients clarify their values for outcomes of options
4. Describe the options available for the decision, including non-treatment

**Cardiopulmonary Resuscitation (CPR) Decision Aid**
For people with serious illness (like heart or lung disease or cancer) facing a decision about attempting CPR.

What can you want if your heart and breathing stop? This decision aid will help you consider your options for CPR and your personal values. You may change your choice at any time. Review the information on both sides of this decision aid. Talk with your doctor about what to expect.

<table>
<thead>
<tr>
<th>What are your options?</th>
<th>Attempt CPR</th>
<th>Do Not Attempt CPR</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is it?</strong></td>
<td>CPR is done for you by someone else and can include:</td>
<td>CPR is not provided.</td>
</tr>
<tr>
<td></td>
<td>• Pressing on your chest</td>
<td>You will receive other care to treat your symptoms and keep you comfortable.</td>
</tr>
<tr>
<td></td>
<td>• A tube to help you breathe</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Electrical shock and drugs</td>
<td>Not attempting CPR allows a natural death.</td>
</tr>
<tr>
<td><strong>What does it do?</strong></td>
<td>CPR attempts to restart your heart and breathing.</td>
<td>Not attempting CPR avoids machines.</td>
</tr>
<tr>
<td></td>
<td>Not attempting CPR avoids the burden of CPR.</td>
<td></td>
</tr>
<tr>
<td><strong>What are the benefits?</strong></td>
<td>Discuss the facts (on the back) about the chances of CPR restarting your heart and breathing.</td>
<td>You will die.</td>
</tr>
<tr>
<td><strong>What are the short-term burdens?</strong></td>
<td>You will need to be on a breathing machine for a time. You will need to be in the intensive care unit (ICU), you may have damaged or broken ribs.</td>
<td></td>
</tr>
<tr>
<td><strong>What are the long-term burdens?</strong></td>
<td>You may have risk to severe brain damage. You may no longer be able to live alone.</td>
<td></td>
</tr>
<tr>
<td><strong>Which option best matches your values?</strong></td>
<td>Your Values:</td>
<td></td>
</tr>
<tr>
<td><strong>Your Values</strong></td>
<td>You prefer a natural death. You are unwilling to accept the fact that CPR may not restart your heart and breathing. You are unwilling to accept the burden of CPR.</td>
<td></td>
</tr>
<tr>
<td><strong>Your Values</strong></td>
<td>You are willing to accept the fact that CPR may not restart your heart and breathing. You are willing to accept the burden of CPR.</td>
<td></td>
</tr>
</tbody>
</table>

8. Can compare features of available options

8.1 Explanation

Are the features of available options presented in equal detail and equal presentation?

Consider:
- font type and size
- color
- format
8. Can compare features of available options

8.2 Example

9. Show positive and negative features of options with balanced detail

9.1 Explanation

“The complete and unbiased presentation of the relevant options and the information about those options—in content and in format—in a way that enables individuals to process this information without bias”

Consider if information is presented using similar fonts, sequence, presentation of statistical information.

(Abhyankar et al., BMC Medical Informatics and Decision-Making; 2013)
9. Show positive and negative features of options with balanced detail

9.2 Example

<table>
<thead>
<tr>
<th>Summary of the 3 choices</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Choice 1:</strong> Make no change</td>
</tr>
</tbody>
</table>
| Average blood sugar (Hba1c) is ......%.
Advantages:  
* Keep to your daily routine  
* No insulin injections  
* No side effects of insulin  
Disadvantages:  
* Continue to have diabetic symptoms |
Your chance of getting complications in 5 years is:

| **Choice 2:** Follow the diabetes advice more regularly |
| Average blood sugar (Hba1c) is ......%.
Advantages:  
* No insulin injections  
* No side effects of insulin  
Disadvantages:  
* Your diabetic symptoms may improve  
* Have to make changes to your daily routine and follow the diabetic advice more regularly |
Your chance of getting complications in 5 years is:

| **Choice 3:** Add insulin |
| Average blood sugar (Hba1c) is ......%.
Advantages:  
* Your diabetic symptoms will improve  
* Have to make changes to your daily routine  
* Slight discomfort with the insulin injection  
Disadvantages:  
* Have to check your blood sugar regularly  
* May put on 6 to 8 pounds in the first year  
* May have ‘hypos’ 3 to 5 times a year  
Your chance of getting complications in 5 years is: |

(PDA by Mathers et al., UK)

9.3 Example

**Think About Your Choices**

There is a lot to think about before choosing hospice.

<table>
<thead>
<tr>
<th><strong>Hospice Care</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Many people who choose hospice care feel it is important to focus on quality of life and comfort.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Non-Hospice Care</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Many people who do not choose hospice care want to pursue more procedures with the hope of cure or extending life even at the risk of more pain and suffering.</td>
</tr>
</tbody>
</table>

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16. There is evidence that the patient decision aid follows plain language guidelines, to ensure understanding of people with low literacy and/or low health literacy skills* 

16.1 Evidence

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.¹

- Example of phrases that are confusing to those with poor health literacy:
  - “Take the medicine three times a day”
  (How should the times be spaced?)


16.2 Example

<table>
<thead>
<tr>
<th>Try VBAC</th>
<th>Plan C-Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>What’s the risk of uterine rupture?</td>
<td>A planned C-section lowers the small risk that an old scar could break open during labor. This will happen to about 3 out of 10,000 women who plan a C-section. The chance of a baby dying from a uterine rupture is even rarer than with VBAC.</td>
</tr>
<tr>
<td>There’s a very small chance that an old C-section scar on your uterus will break open (uterine rupture) during labor. This can be very serious. About 50 out of 10,000 women who try VBAC will have a scar break open. From those 50 women, about 1 baby will die as a result. That means about 1 woman out of 10,000 who plans a VBAC will lose a baby because of a uterine rupture.</td>
<td></td>
</tr>
</tbody>
</table>
Questions?

Contact:
Laura Pennington
laura.Pennington@hca.wa.gov
360-725-1231
or
shareddecisionmaking@hca.wa.gov

More Information:

How Decision Aids Can Promote Person-Centered Care for Serious Illness

Linda Briggs, MSN, MA RN
Director, Program Development and Research
Knowing and Honoring Preferences and Decisions

Care that is respectful of and responsive to individual patient preferences, needs, and values, ensuring that patient values guide all clinical decisions

Person-Centered and Family-Oriented Care

Advance Care Planning
Preparation for future healthcare decisions

Person-Centered Decision Making

Shared Decision Making in Serious Illness
Making current healthcare decisions
Desired Outcome of Person-Centered Decision Making

To know and honor individuals’ well-informed preferences and decisions by...

- Creating an effective process to plan for future decisions
- Making plans available to treating health professionals
- Assuring plans are incorporated into current medical decisions


SDMSI Versus Common Approach to Decision Making: What’s Different?

**Common Approach**
- First, identify all options.
- Present options for intervention to patient.
  - FAQs
  - Risk: Benefit statistics
- Work with patient to make a treatment decision.

**SDMSI Approach**
- First, identify and understand patient’s priorities and goals for care.
- Present options consistent with patient’s goals.
- Frame “benefits and burdens” in context of patient’s views of unacceptable outcomes.
- Explore non-intervention as a viable option.
“...shared decision making respects autonomy and builds relationships based on respect for and curiosity about the patient as a person...relies on fundamental communication skills—developing trust, understanding, empathy, and patient enablement to facilitate decision making.”

Decision Aid Development

Phase I
Development

Phase II
Certification Application

Phase III
Program Integration

Phase IV
Dissemination and Evaluation

Decision Aid Development

Standard Operating Procedure (SOP)
- Guiding principles
- Common definitions and terms
- General policy standards
- Standard DA development procedure
- Standard templates and forms
- Research and references
Phase I Development

Internal subject matter experts
• Identify treatment decision
• Target population
• Create draft DA
• Internal team feedback, review, revise

External subject matter experts
• Patient focus groups
• Clinical experts
• Special interest groups
• Feedback, review, revise

Cardiopulmonary Resuscitation (CPR) Decision Aid
For people with serious illness (like heart or lung disease or cancer) facing a decision about attempting CPR.

What care do you want for your heart and breathing stop? This decision aid will help you consider your options for CPR and your personal values. You may change your choice at any time. Review the information on both sides of this decision aid. Talk with your doctor about what to expect.

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<td>• Electrical shock and drugs</td>
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<td><strong>What does it do?</strong></td>
<td>CPR attempts to restart your heart and breathing.</td>
</tr>
<tr>
<td><strong>What are the benefits?</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Review the facts (on the back) about the chances of CPR restoring your heart and breathing.</td>
</tr>
<tr>
<td><strong>What are the short-term burdens?</strong></td>
<td>CPR may restart your heart and breathing.</td>
</tr>
<tr>
<td></td>
<td>You will need to be on a breathing machine for a time.</td>
</tr>
<tr>
<td></td>
<td>You will need to be in the intensive care unit (ICU).</td>
</tr>
<tr>
<td></td>
<td>You may have damaged or broken ribs.</td>
</tr>
<tr>
<td><strong>What are the long-term burdens?</strong></td>
<td>You may have mild to severe brain damage.</td>
</tr>
<tr>
<td></td>
<td>You may no longer be able to live alone.</td>
</tr>
</tbody>
</table>

Which option best matches your values?

Your Values

You want the chance to live.
You are willing to accept the fact that CPR may not restore your heart and breathing.
You are willing to accept the burdens of CPR.

Your Values

You prefer a natural death.
You are unwilling to accept the fact that CPR may not restore your heart and breathing.
You are unwilling to accept the burdens of CPR.
### Phase I Development

<table>
<thead>
<tr>
<th>Internal subject matter experts</th>
<th>External subject matter experts</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identify treatment decision</td>
<td>• Patient focus groups</td>
</tr>
<tr>
<td>• Target population</td>
<td>• Clinical experts</td>
</tr>
<tr>
<td>• Create draft DA</td>
<td>• Special interest groups</td>
</tr>
<tr>
<td>• Internal team feedback, review, revise</td>
<td>• Feedback, review, revise</td>
</tr>
</tbody>
</table>

### CPR in the hospital vs. CPR outside the hospital

<table>
<thead>
<tr>
<th>Adults with serious illness who get CPR and live</th>
<th>Adults living in the community who get CPR and live</th>
<th>Adults living in a residential setting who get CPR and live</th>
</tr>
</thead>
<tbody>
<tr>
<td>At most, 15 out of 100 leave the hospital and may live an average of 6 months²</td>
<td>5 out of 100 leave the hospital and may live up to 1 year²</td>
<td>2 out of 100 leave the hospital and may live up to 1 year²</td>
</tr>
</tbody>
</table>


Questions I have for my doctor after reviewing this CPR information:

My values most align with:  
- [ ] Attempting CPR  
- [ ] Not attempting CPR

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Phase II Certification Application

- Identify treatment decision
- Target population
- Create draft DA
- Internal team feedback, review, revise

Internal subject matter experts

External subject matter experts

- Patient focus groups
- Clinical experts
- Special interest groups
- Feedback, review, revise

Certification Process

- Application
- Revision
- Certification

Phase III Program Integration

- DA webinar and user guide
- Integrate into existing programs
- Additional decision aids
CPR Video

Key Learning

- Team approach
- Time and resources
- Development of content
- Next steps
Questions
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sschellinger@respectingchoices.org

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