PATIENT DECISION AIDS

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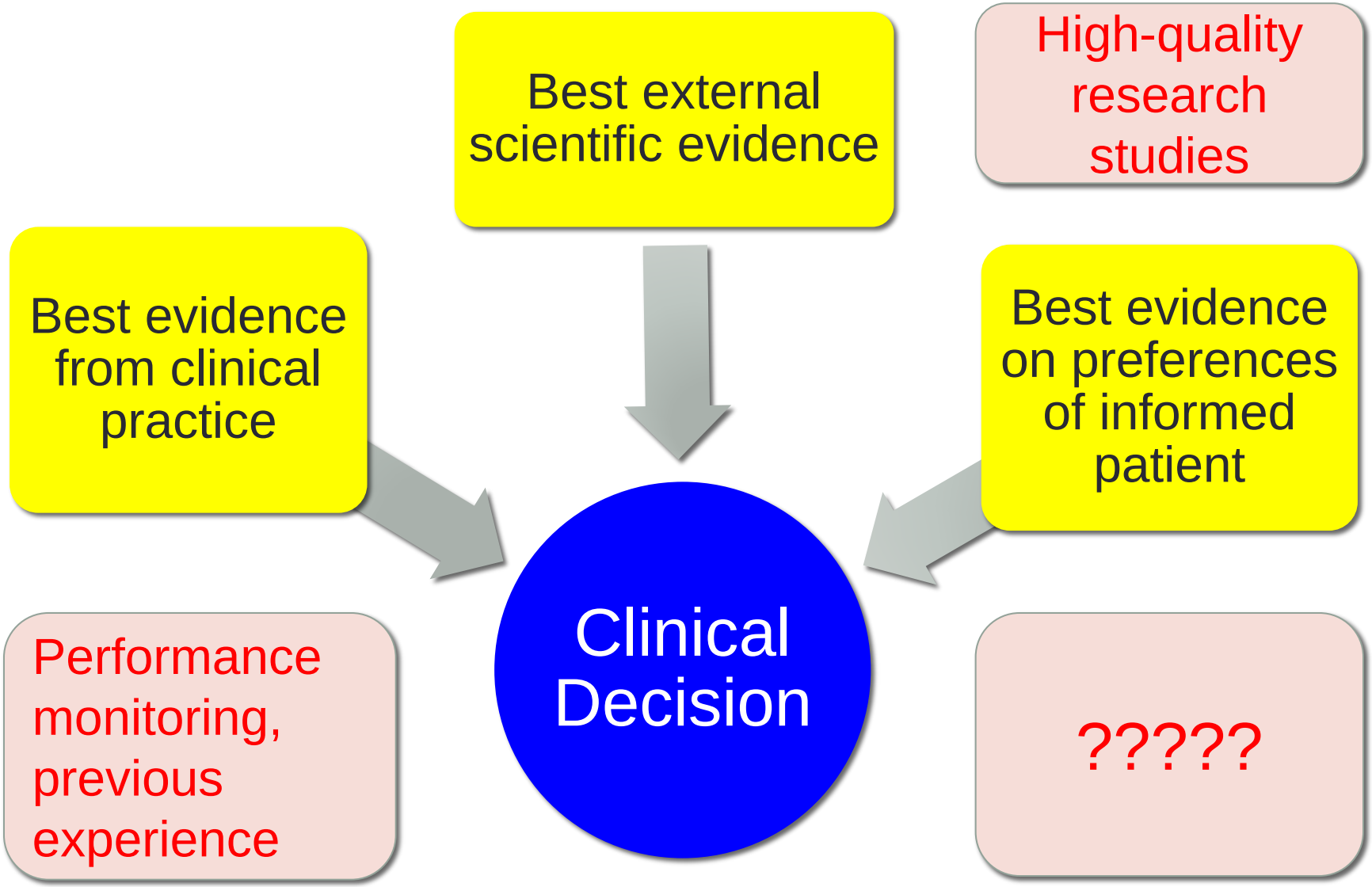
Disclosure slide

- I have **relevant relationships** in the products or services described, reviewed, evaluated or compared in this presentation.
- Financial relationships
  - Some of the concepts to be discussed today are included in *The Handbook for Evidence-Based Practice in Communication Disorders*, which I authored in 2007. I receive royalties from Brookes Publishing from its sale.
- Nonfinancial relationships
  - I have served as a volunteer on a number of ASHA committees, boards, and task forces concerning evidence-based practice.

Three evidence sources for EBP



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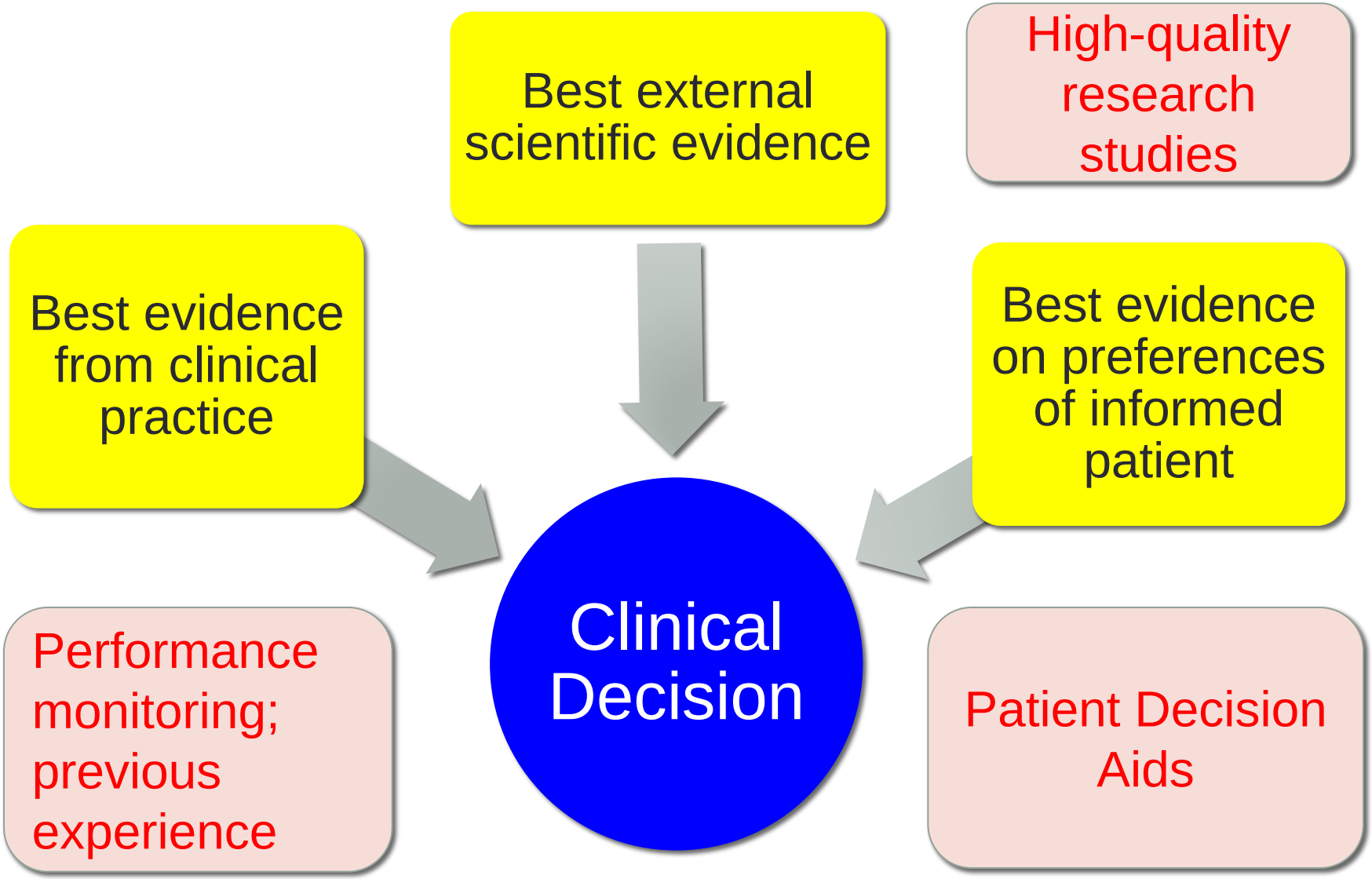
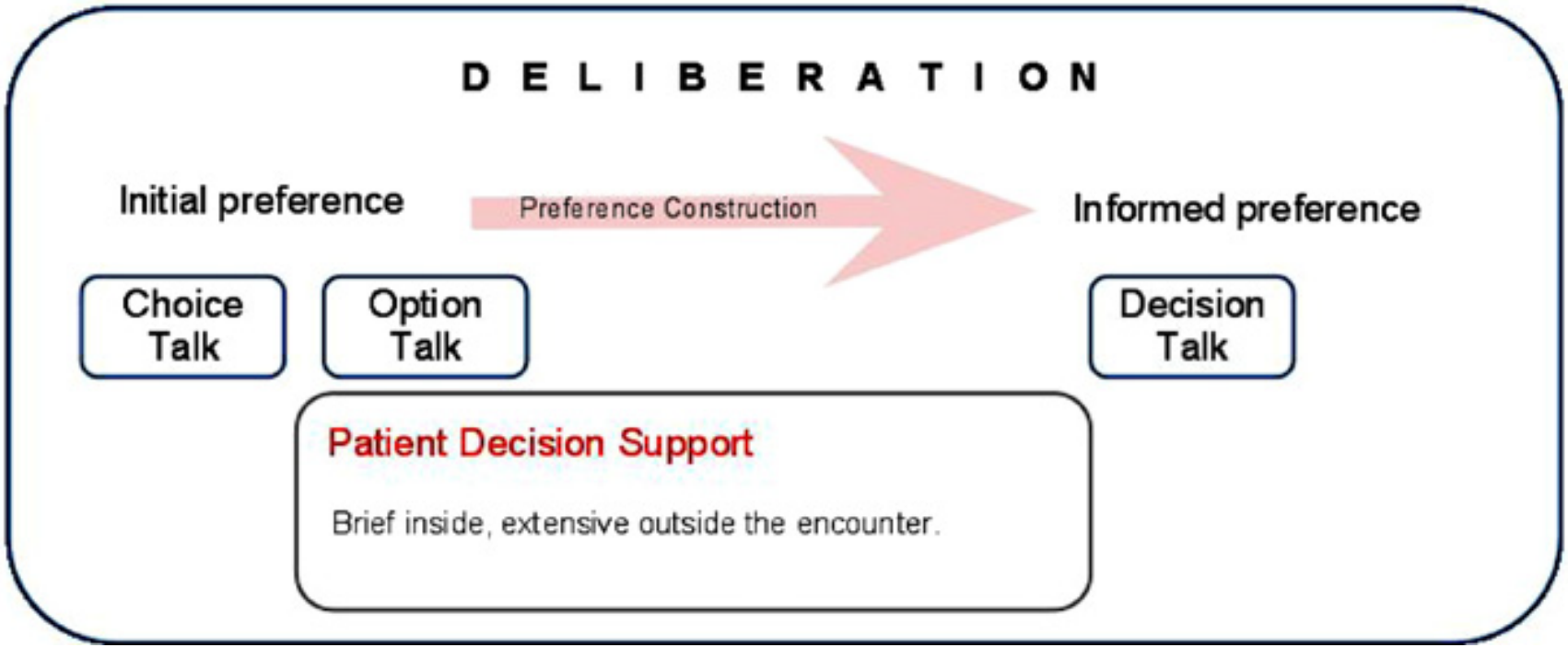


What are Patient Decision Aids?[a]

- Tools to help patients participate in decision-making about their care, by
  - Increasing their understanding of the clinically reasonable options for diagnosis or treatment
  - Clarifying their personal values and preferences as they consider pros and cons of the options
- Intended to complement, not replace, counseling by clinician
- Grounded in Shared Decision Making model of clinical practice

Shared Decision Making (SDM) model



Elwyn et al., 2013, p. 211

Phases of Elwyn et al. (2013) SDM model

- Choice talk (relatively brief encounter)
  - Make explicit the need for a decision about the patient's care and the patient's option to share in the decision-making
- Option talk(s) (more extensive encounter; PDAs helpful)
  - Information on clinically reasonable options
    - Benefits and risks given the patient's clinical condition
    - Non-medical impact on the lives of the patient and significant others (convenience, financial, etc.)
  - Values and preferences clarification
    - Patient considers and rates the importance to him or her of the pros and cons of each option
- Deliberation phase (length may vary)
- Decision talk

Why are Patient Decision Aids?

- Reasonable options exist for diagnosing and treating most clinical conditions
- Each option has good and bad features that people value differently; no single best option for everyone
- Matching the features that matter most to a patient with the clinical option that has these features could improve outcomes, including compliance and satisfaction (http://ipdas.ohri.ca)

Evidence on PDAs (tip of the )

- Individual randomized clinical trials of PDAs used in a variety of areas, e.g.
- Prenatal screening for Down Syndrome
  - (Bjorklund et al., 2012)
- Attention Deficit Hyperactivity Disorder
  - (Brinkman et al., 2013)
- Surgery for temporal lobe epilepsy
  - (Choi et al., 2011)
- Surgery for breast cancer
  - (Elwyn et al., 2013)

Evidence on PDAs (cont.)

- Several systematic reviews and meta-analyses
- Most recent: Stacey et al. (2011) meta-analysis for Cochrane Review
  - 86 RCTs
  - 20,209 patients
  - Use of PDAs in treatment vs treatment as usual

Stacey et al. (2011) meta-analysis showed PDAs effective in:

- Increasing patient knowledge
- Increasing patient-practitioner communication
- Increasing active participation by patients in decisions
- Increasing patient satisfaction with decisions
- Reducing patients' decisional conflict
- Reducing proportion of patients who remained undecided

Stacey et al. (2011) findings (cont.)

- No evidence of a difference in anxiety, general health outcomes, or the few specific health outcomes that could be examined
- Insufficient evidence to judge differences in adherence to decision, or in costs and resource use
- Effect of PDA on length of consultation varied from -8 to 23 minutes (median 2.5 minutes)

Evidence on PDAs

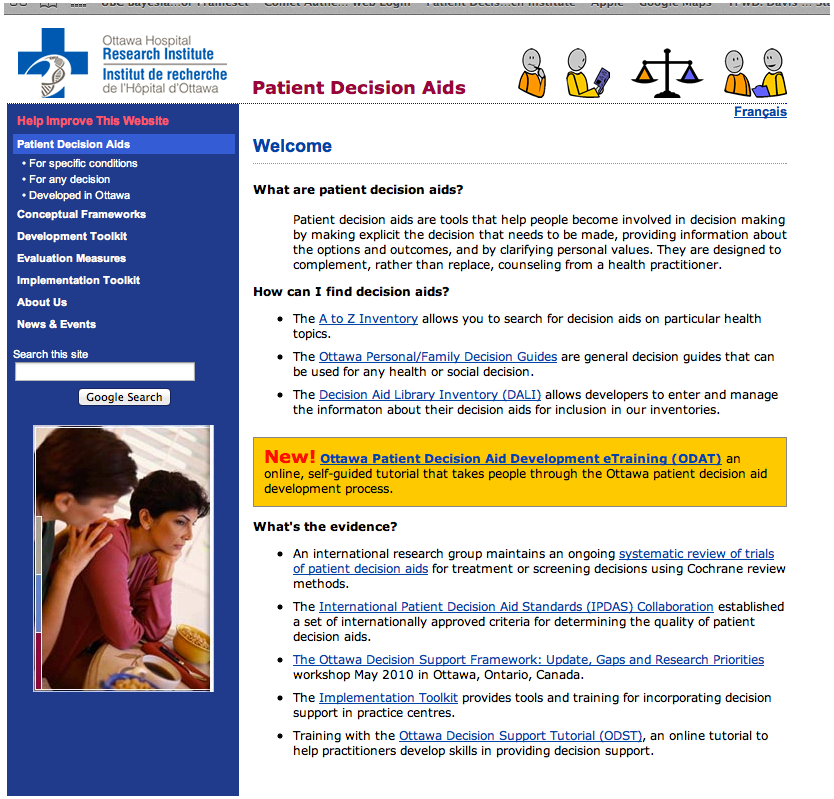
- PDAs have some advantages, but they also require at least a little more time
- Should you consider using them? *Ah – a decision needs to be made! A perfect opportunity to show how PDAs work.*

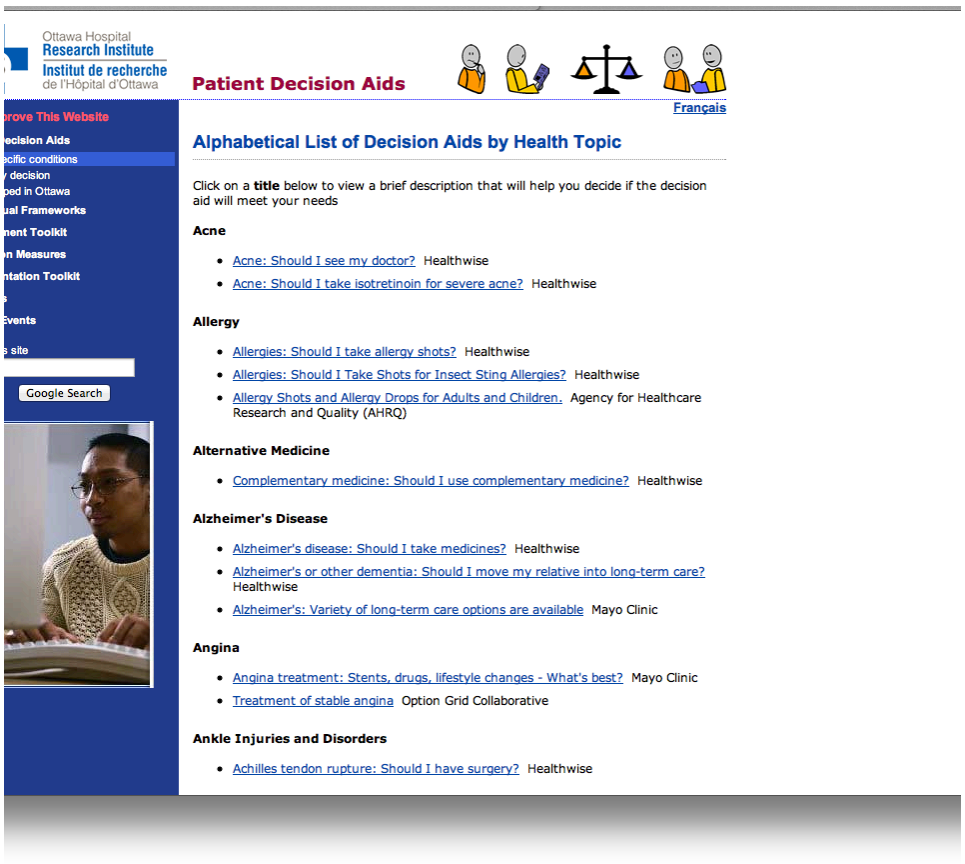
A general format for decision aids

- We'll use a general framework, the Personal Decision Guide (for individuals facing tough health or social decisions) from the Ottawa Hospital Research Institute (OHRI)
- OHRI website (http://decisionaid.ohri.ca) has a wealth of information and downloadable forms
- There's also a Family Decision Guide

Ottawa Hospital Research Institute

www.decisionaid.ohri.ca





Ottawa Personal Decision Guide

For People Facing Tough Health or Social Decisions

You will be guided through four steps: ❶ ❷ ❸ ❹

❶ 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?

- ☐ Not yet thought about the options
- ☐ Thinking about the options
- ☐ Close to making a choice
- ☐ Already made a choice

❷ 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 options with the risks that matter most to you.

	Reasons to Choose this Option (Benefits / Advantages / Pros)	How much it matters Use 0 to 5 ★s	Reasons to Avoid this Option (Risks / Disadvantages / Cons)	How much it matters Use 0 to 5 ★s
Option #1				
Option #2				
Option #3				

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

Support

Who else is involved?			
Which option do they prefer?			
Is this person pressuring you?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
How can they support you?			

What role do you prefer in making the choice?

- ☐ Share the decision with…
- ☐ Decide myself after hearing views of…
- ☐ Someone else decides…

Who?

❸ Identify your decision making needs.

 **Knowledge**	Do you know the benefits and risks of each option?	☐ Yes	☐ No
 **Values**	Are you clear about which benefits and risks matter most to you?	☐ Yes	☐ No
 **Support**	Do you have enough support and advice to make a choice?	☐ Yes	☐ No
 **Certainty**	Do you feel sure about the best choice for you?	☐ Yes	☐ No

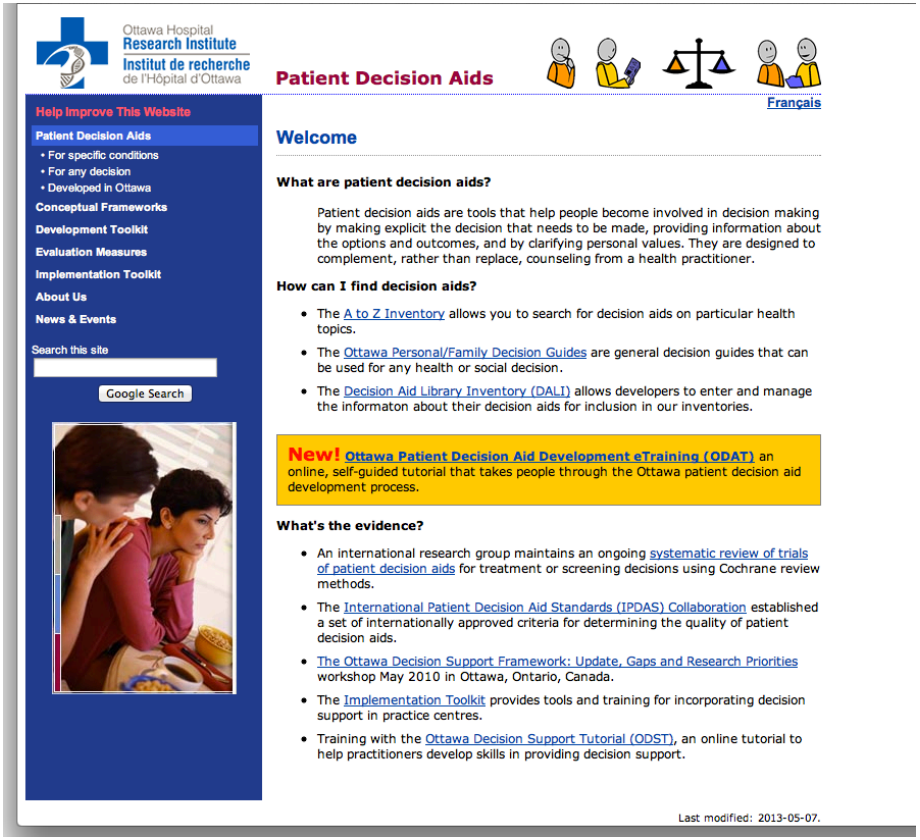
People who answer "No" to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. Therefore, it is important to work through steps two ❷ and four ❹ that focus on your needs.

❹ Plan the next steps based on your needs.

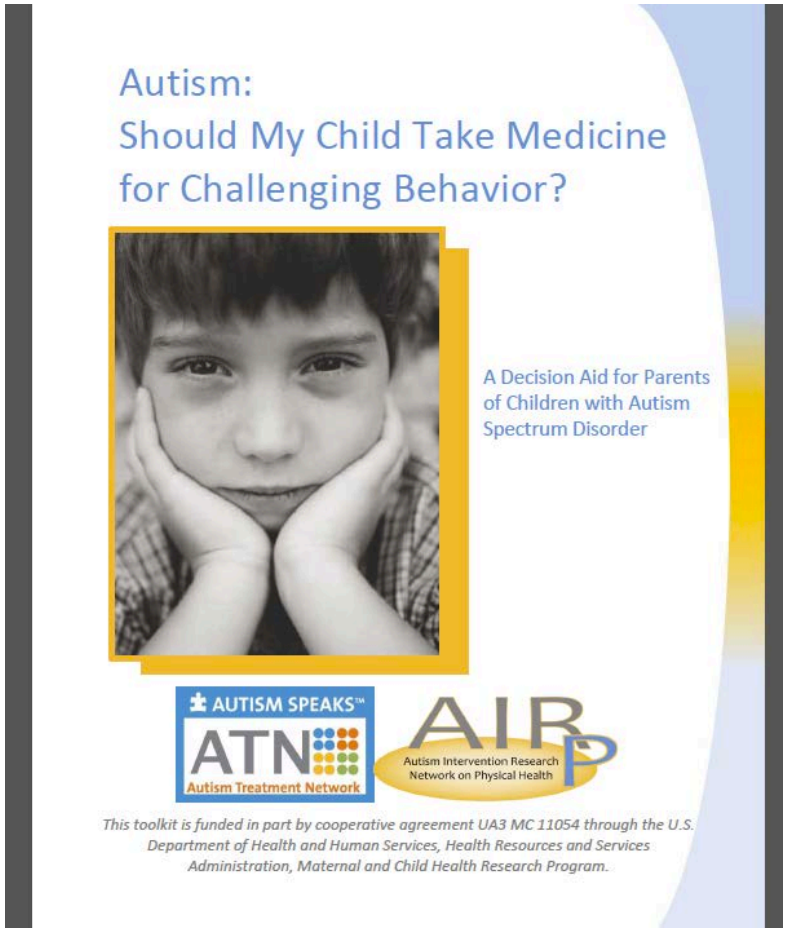
Decision making needs	✓ Things you would like to try
 **Knowledge**	
If you feel you do NOT have enough facts	☐ Find out more about the options and the chances of the benefits and risks. ☐ List your questions. ☐ List where to find the answers (e.g. library, health professionals, counsellors):
 **Values**	
If you are NOT sure which benefits and risks matter most to you	☐ Review the stars in the balance scale to see what matters most to you. ☐ Find people who know what it is like to experience the benefits and risks. ☐ Talk to others who have made the decision. ☐ Read stories of what mattered most to others. ☐ Discuss with others what mattered most to you.
 **Support**	
If you feel you do NOT have enough support	☐ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends). ☐ Find help to support your choice (e.g. funds, transport, child care).
If you feel PRESSURE from others to make a specific choice	☐ Focus on the opinions of others who matter most. ☐ Share your guide with others. ☐ Ask others to complete this guide. Find areas of agreement. When you disagree on facts, agree to get information. When you disagree on what matters most, consider the other person's opinion. Take turns to listen to what the other person says matters most to them. ☐ Find a neutral person to help you and others involved.
Other factors making the decision DIFFICULT	List anything else you need:

- I suspect that you need more information before making a decision about whether to consider using them
- Let’s look at a few examples, from among many PDAs that are available for patients facing specific screening, diagnostic, or treatment decisions
- Again, just the tip of the iceberg

www.decisionaid.ohri.ca for a searchable list of PDAs on specific conditions and an evaluation via IPDAS



OHRI links to a PDA by Autism Speaks and Autism Intervention Research Network on Physical Health



Autism Speaks PDA includes

- Sections on information content, including general information for parents on autism spectrum disorders (definitions, symptoms, treatment approaches, etc.)
- Personal stories of parents who have faced the decision
- Simple, clear tables showing standard medication choices, the behaviors they're intended to target, and their possible side effects

➢ Table of standard medication choices & potential side effects

Medicine Type	Target Behaviors	Possible Side Effects	
Stimulant Medicines			
• methylphenidate (Ritalin, Metadate, Concerta, Methylin, Focalin, Daytrana) • mixed amphetamine salts (Adderall) • dextroamphetamine (Dexedrine) • lisdexamfetamine (Vyvanse)	Hyperactivity Short attention span Impulsive behaviors	**Common:** Problems falling asleep Less appetite Irritability/emotional outbursts	**Less common:** Anxiety Depression Repeating behaviors/ thoughts Headaches Diarrhea Social withdrawal Changes in heart rate Tics
Alpha Agonist Medicines			
• guanfacine(Tenex,Intuniv) • clonidine (Catapres, Catapres TTS, Kapvay)	Hyperactivity Short attention span Impulsive behaviors Sleep problems Tics	**Common:** Sleepiness Irritability	**Less Common:** Aggression Less appetite Low blood pressure Constipation
Anti-Anxiety Medicines			
• fluoxetine (Prozac) • fluvoxamine (Luvox) • sertraline (Zoloft) • paroxetine (Paxil) • citalopram (Celexa) • escitalopram (Lexapro)	Depression Anxiety Repeating thoughts Repeating behaviors	**Common:** GI problems (nausea, vomiting, constipation, low appetite) Headaches Problems falling asleep Sleepiness Agitation Weight gain	**Less common:** Seizure Thoughts of harming self Suicide Serotonin syndrome
Second Generation/ Atypical Antipsychotics			
• risperdone (Risperdal) • olanzapine (Zyprexa) • quetiapine (Seroquel) • aripiprazole (Abilify) • ziprasidone (Geodon)	Irritability Aggression Self-injury Tantrums Sleep problems High activity level Repeating behaviors Tics	**Common:** Sleepiness Drooling Increased appetite/ weight gain	**Less common:** High blood sugar, diabetes High cholesterol Tardive dyskinesia (abnormal movements) Quetiapine – eye side effects Ziprasidone- heart side effects
Medicines For Seizures and Mood Problems			
• carbamazepine (Tegretol, Carbatrol) • valproic acid (Depakote, Depakene) • lamotrigine (Lamictal) • oxcarbazepine (Trileptal) • topiramate (Topamax)	Seizures Mood problems Aggression Self-injury	**Common:** Sleepiness Nausea / Vomiting	**Less common:** Dizziness Rashes Memory problems Hepatitis Liver failure Pancreatitis Bone marrow suppression Tremor

This toolkit is funded in part by cooperative agreement U83 MC 11054 through the U.S. Department of Health and Human

Autism Speaks PDA (cont.)

- Information content sections (cont.)
  - Description of alternative treatments that could be tried before medication is used

Besides Medicine, What Are The Other Options?

Some of the most important ways to treat challenging behavior do not involve medicine. Some of these things you can do yourself. You might need help for other things. You might be able to get help from your child's health care provider or school team. You might also be able to get help from local psychologists or social workers. If your child has a community helper or a service coordinator, ask that person.

Try some of these things:

- **Try and see what is causing the behavior.** Sometimes treating a health problem or changing a daily routine can improve behavior.
- **Work with your health care provider to find and treat health problems that might be part of the behavior problem.** For example, children who have pain from a tooth problem or from a stomach problem might have more tantrums. Children with allergies or constipation might be irritable. Children who do not sleep well at night might have problems with attention during the day. Treating these types of medical problems can help with behavior.
- **You can work with a behavior specialist** to figure out reasons for some behaviors. Some children have tantrums to get out of something that is hard to do. Some children hit other people as a way of telling them something when they are not able to talk. Sometimes the adults around children encourage problem behaviors without meaning to. A behavior specialist can help with ways to teach children better behaviors.
- **You can work with a child psychologist.** Some children with autism benefit from counseling or treatments such as Cognitive Behavioral Therapy (CBT). These treatments might help with anxiety, depression, social skills, and other difficulties. A psychologist can also help parents to learn ways to help their child. Some families find that working with a psychologist also helps them cope better.
- **Make a daily schedule.** Children have better behavior when they know what to expect. You might need to use pictures to help your child understand the schedule.
- **Get help in caring for your child.** Every parent needs a break sometimes. Finding good caregivers can be difficult. If respite care is available, use it.
  You can also ask for help from friends and family. Sometimes caregivers can be found through churches, colleges, and local disability agencies.

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Autism Speaks PDA (cont.)

- Information content sections (cont.)
  - A simple chart comparing the two basic options (Take Medication for Behavior/Do Not Take Medication for Behavior) on three dimensions
  - What is usually involved?
  - What are the benefits?
  - What are the risks?

COMPARING THE OPTIONS

	Take medicine (for behavior)	Don't take medicine (for behavior)
What is usually involved?	• You learn about the medicine. You learn what symptoms it can help with. You learn what side effects to watch for. • You give medicines every day. • You talk with the school team, health team, and others who work with your child to see how well the medicines are working. • You watch your child for side effects. • You meet with your health care provider regularly.	• You can work with your health care provider and others to determine if health problems or other factors might make behavior worse. • You can consider other ways to teach desired behavior and reduce problem behavior. • You can find other ways to reduce family stress. You can ask family or friends to help you. You can find respite or other community supports to help your child and family.
What are the Benefits? (Pros) ☺	• Your child might be less irritable. • Problem behaviors might improve. • Your child may function better at home, school, and in the community. • Your child and family might sleep better. • Your child may fit in better with other children. • You might feel that you are doing everything possible for your child.	• You avoid cost and possible side effect of medicines. • You won't have to feel worried about using medicines. • You avoid the uncertainty of trying medicines. • If behaviors continue to be a problem, you can always try medicines later. • You may find other treatments for problem behavior.
What are the Risks? (Cons) ☹	• Medicine will not cure autism. • Medicine may not help every child with autism. • Medicines can cost a lot. • Your child might have side effects from the medicine.	• Problem behavior might cause stress for family, school, and child. • Behavior may continue or get worse. • Your child may not be able to be included in as many family, school, or community opportunities. • Your child may not do as well in school. • Your child may have more difficulty with other children.

Are you interested in what other families decided to do? Many other families have faced this decision. These personal stories may help you.
CLICK HERE to read Personal Stories on page 18

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Autism Speaks PDA (cont.)

- Values clarification sections
  - Very similar to the ones on the general Personal Decision Guide
    - Reasons FOR giving medication, and how important each is
    - Reasons AGAINST giving medication, and how important each is

Clarifying Personal Values

➢ **First consider some of the reasons *FOR* giving your child medicine:**

	Very important to me ★★★★★	Slightly important to me ★★★	Not important to me ★
I think my child may feel better.	☐	☐	☐
I think that problem behaviors might improve.	☐	☐	☐
Medicine might help my child might do better at school.	☐	☐	☐
Medicine might help my child might do better at home.	☐	☐	☐
I think our family might have less stress.	☐	☐	☐
My child and our family might sleep better.	☐	☐	☐
My child might make friends with greater ease or might join in activities with other children.	☐	☐	☐
I can deal with side effects of medicine.	☐	☐	☐
I want to know that I am doing everything possible for my child, even if it means having him or her take medicine.	☐	☐	☐
Are there other reasons FOR using medicine that have not been listed? (open text)			

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Which Way Are You Leaning?

Leaning Away From Medicine | Uncertain | Leaning Towards Medicine

What Do You Need To Feel More Ready To Decide?

- ☐ Review Facts → CLICK HERE to review the Autism FAQ on page 13
- ☐ Review Options → CLICK HERE to read about Comparing Options on page 5
- ☐ Get More Support → From Whom? _____
- ☐ Take more time to think about the decision.

☐ **Other (open text):**

☐ **Questions (open text):**

☐ **Concerns (open text):**

Remember: The goal of this decision aid is to help you sort through your personal values and preferences so that you can communicate them to your provider

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What Are My Options?

➢ Now that I have reviewed the information, what are my options?

☐	I could work with my child's health care provider and have my child take medicine to treat behavior or emotional symptoms.
☐	I could discuss medicines and other treatment options more with my health care provider before making a decision.
☐	I could discuss medicines and other treatment options more with my partner and family before making a decision.
☐	I could decide not to have my child take medicines now and think about this option again in _____ months.
☐	I could decide against using medicines for challenging behaviors.

➢ How sure are you about your decision?

Not Sure At All — Somewhat Sure — Very Sure

Use this box to list questions, concerns, and next steps:

You might want to print this out for your records

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Considering Personal Benefits And Risks (Continued)

Medicines are usually used only when behaviors are causing a serious problem for your child. Behaviors can cause problems for your child in different ways, though. This might help you think about how behavior is affecting your child and family.

	Leaning toward choosing medicine	Don't know	Leaning away from medicine
Behavior Improvement?	My child's behavior is not getting better with non-medicine treatments.	My child's behavior is getting a little better with non-medicine treatments.	My child's behavior is getting better with non-medicine treatments.
Learning?	My child's behavior is making it very difficult for him/her to learn.	Behavior is making it a little difficult for my child to learn.	Behavior is not a problem for learning at all.
Problems at school?	My child's behavior is causing a lot of problems at school.	My child's behavior is causing a little problem at school.	My child's behavior is not causing problems at school.
Family stress?	My child's behavior is causing a lot of family stress.	My child's behavior is causing a little family stress.	My child's behavior is not causing any family stress.
Outings?	My child's behavior makes it very difficult to take him to stores, church and other places/ activities. I rarely take him/her out.	My child's behavior makes it a little difficult to take him/her out, but I still do it.	I can take my child out easily.
Bothersome to self?	My child's symptoms bother him/her a lot. He/she seems unhappy, uneasy or uncomfortable.	My child's symptoms bother him/her a little ***OR*** I don't know if they bother him/her	I do not think my child's symptoms bother him/her.
Other? (open text)			

You may want to share the information above with your child's health care provider. You or your child's teachers might be also asked to fill out behavior rating forms. This will help your child's team to know more about the behavior problems.

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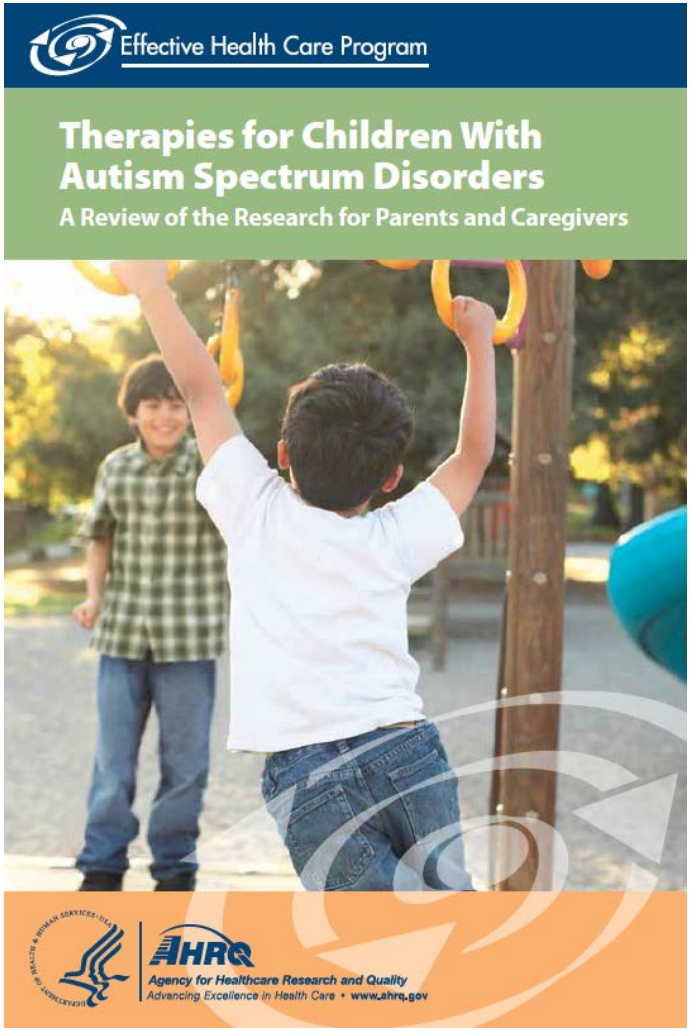
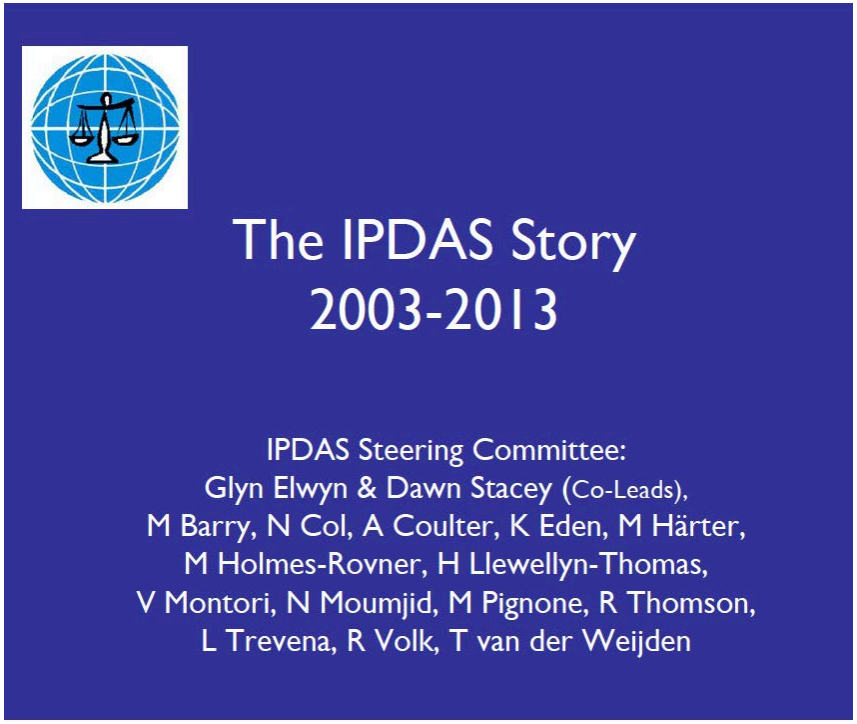
AHRQ (www.ahrq.gov) and other organizations are developing PDAs on various conditions, for professionals and for caregivers



Quality control for PDAs



International Patient Decision Aids Standards Collaboration Quality Criteria

12 Dimensions

Essential Content

- Information
- Probabilities
- Values clarification
- Guidance
- Patient Stories

Effectiveness Criteria

- Decision process
- Decision quality

Generic Criteria

- Development process
- Disclosure
- Internet delivery
- Balance
- Plain language
- Up to date evidence

Elwyn, et al., BMJ. 2006 Aug 26; 333(7565):417.
http://www.ncbi.nlm.nih.gov/pubmed/16908462

IPDAS standards: PDA CONTENT

- Sufficient information about options?
  - list options, including option of doing nothing
  - describe positive features of options (benefits)
  - describe negative features of options (harms, risks, disadvantages)
- Probabilities of outcomes presented in an unbiased and understandable way?
  - use event rates specifying population and time period
  - allow patient to select multiple methods (words, numbers, pictures) for viewing probabilities
  - place probabilities in the context of other events
- Include methods for clarifying and expressing values?
  - consider which positive and negative features matter most
  - suggest how to discuss what matters most with others

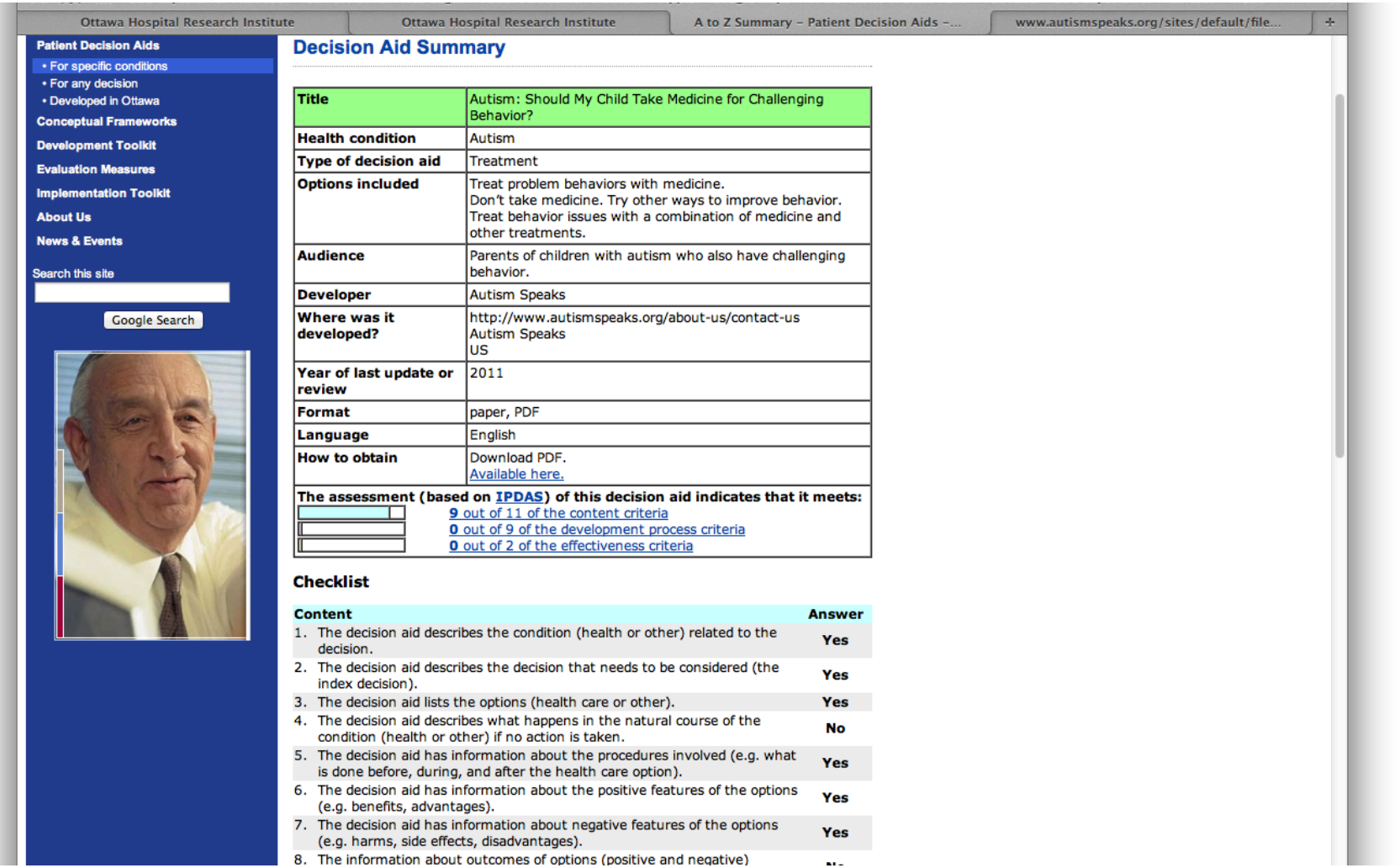
IPDAS standards: PDA DEVELOPMENT PROCESS

- Developed via a transparent and systematic Information provided in a balanced manner?
- Based on current, cited scientific evidence?
- Plain language?
- Potential conflicts of interest disclosed?

IPDAS standards: PDA EFFECTIVENESS

- Patients recognize that a decision needs to be made
- Patients know their options
- Patients understand that values will affect the decision
- Patients are clear about the features that matter most to them
- Patients discuss their values with others
- Patients become involved in preferred ways

www.decisionaid.ohri.ca rates each PDA it lists, using a checklist of IPDAS criteria



Improving PDAs: Studies of optimal approaches to communication of:

- General information
  - More detailed PDAs more effective than simpler PDAs in increasing people's knowledge (Stacey et al., 2011)
    - Three Bears Principle, however; e.g., Options Grid
  - Explicit probability statements expressed via natural frequencies result in more accurate risk perception than general/non-numeric statements
    - *Of 100 people who take the drug, 1 will develop the disease within five years. Of 100 people who don't take the drug,15 will develop the disease in five years* BETTER THAN *People who take the drug are less likely to develop the disease in five years.*

option grid

Breast cancer surgery

Use this grid to help you and your clinician decide whether to have mastectomy or lumpectomy with radiotherapy.

Frequently asked questions	Lumpectomy with Radiotherapy	Mastectomy
Which surgery is best for long term survival?	There is no difference between surgery options.	There is no difference between surgery options.
What are the chances of cancer coming back in the breast?	Breast cancer will come back in the breast in about 10 in 100 women in the 10 years after a lumpectomy.	Breast cancer will come back in the area of the scar in about 5 in 100 women in the 10 years after a mastectomy.
What is removed?	The cancer lump is removed with a margin of tissue.	The whole breast is removed.
Will I need more than one operation on the breast?	Possibly, if cancer cells remain in the breast after the lumpectomy. This can occur in up to 5 in 100 women.	No, unless you choose breast reconstruction.
How long will it take to recover?	Most women are home 24 hours after surgery	Most women are home 2-3 days after surgery.
Will I need radiotherapy?	Yes, for up to 6 weeks after surgery.	Unlikely, radiotherapy is not routine after mastectomy.
Will I need to have my lymph glands removed?	Some or all of the lymph glands in the armpit are usually removed.	Some or all of the lymph glands in the armpit are usually removed.
Will I need chemotherapy?	Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.	Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.
Will I lose my hair?	Hair loss is common after chemotherapy.	Hair loss is common after chemotherapy.

Elwyn et al., 2013, p. 209

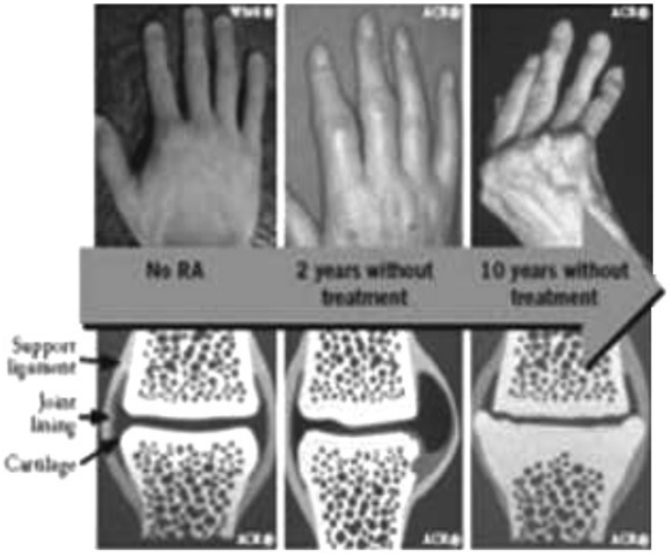
Studies of optimal approaches to communicating: (cont.)

- Numerical information and probabilities
  - e.g., Martin et al., 2012 compared formats for communicating the ability of a hypothetical drug to slow the rate of progression of joint damage in rheumatic arthritis
  - All groups underestimated the drug's benefit
  - The group that received the Narrative plus Graphic format (either speedometer or natural frequency pictograph) had more accurate recall than the Narrative-Only group

Narrative (N) statement alone

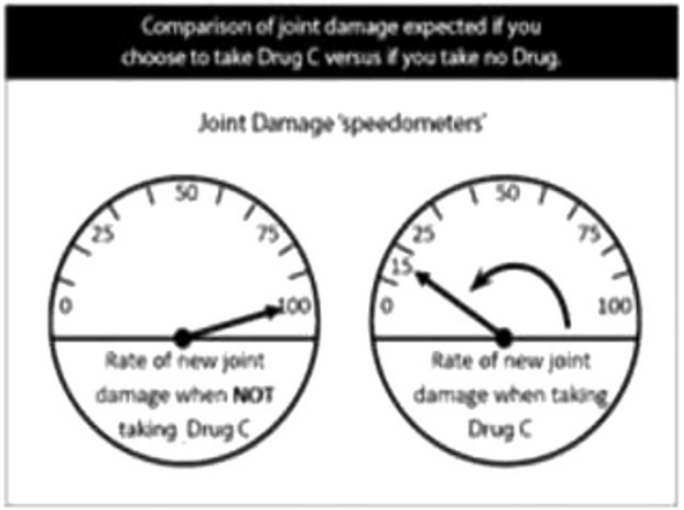
One benefit of Drug C is its power to slow further joint damage. Research has shown Drug C can reduce the rate of RA joint damage in most patients by about 85%.

N + graphic representation of progression of SJD



N + natural frequency pictogram

N + speedometer metaphor



Martin et al. 2012 p. 330

What's next?

http://af-design.com

Your thoughts on PDAs to develop for the decisions that your patients face?

PDAs and Clinical Practice Guidelines

- CPGs: Systematically developed statements to assist practitioners and patients in making decisions about appropriate health care for specific circumstances.
- Until recently CPGs have hardly acknowledged the issue of individual patient preferences (van der Weijden et al., 2012: 585)
- Strong CPG recommendations are inappropriate if
  - More than one single best option is available
  - Values and preferences differ widely among the target population
  - Benefits and downsides (including increased resource use) are finely balanced
- Stay tuned; the intersections of PDAs and CPGs is going to be very interesting

A few references and resources

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