Tested, Approved, and Still Useless?

What late-stage testing misses in decision aids design

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INTELLUS WORLDWIDE INSTITUTE

Where
Great Minds Meet

Sept 10-12, 2025   Hyatt New Brunswick, NJ, USA   In-Person Event

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TESTED, APPROVED, AND STILL USELESS?

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Why attend this session?

Patient Decision Aids (PDAs) are increasingly adopted but often fall short in real-world use. In this session, we will share field-tested insights on what makes PDAs usable, accessible and relevant to different patient groups, and actionable.

We will start with brief typology of Decision Aids, emphasize how simple design changes and patient-centered validation methods drive better decisions, and wrap up with Next Gen of Decision Aids for 2025.

> This session continues the discussion started in 2023 at Intellus Summit on Empowering Patients through Shared Decision-Making.

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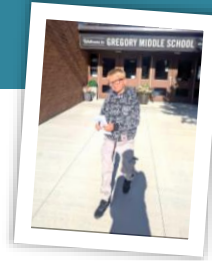
Many categories

Many brand names
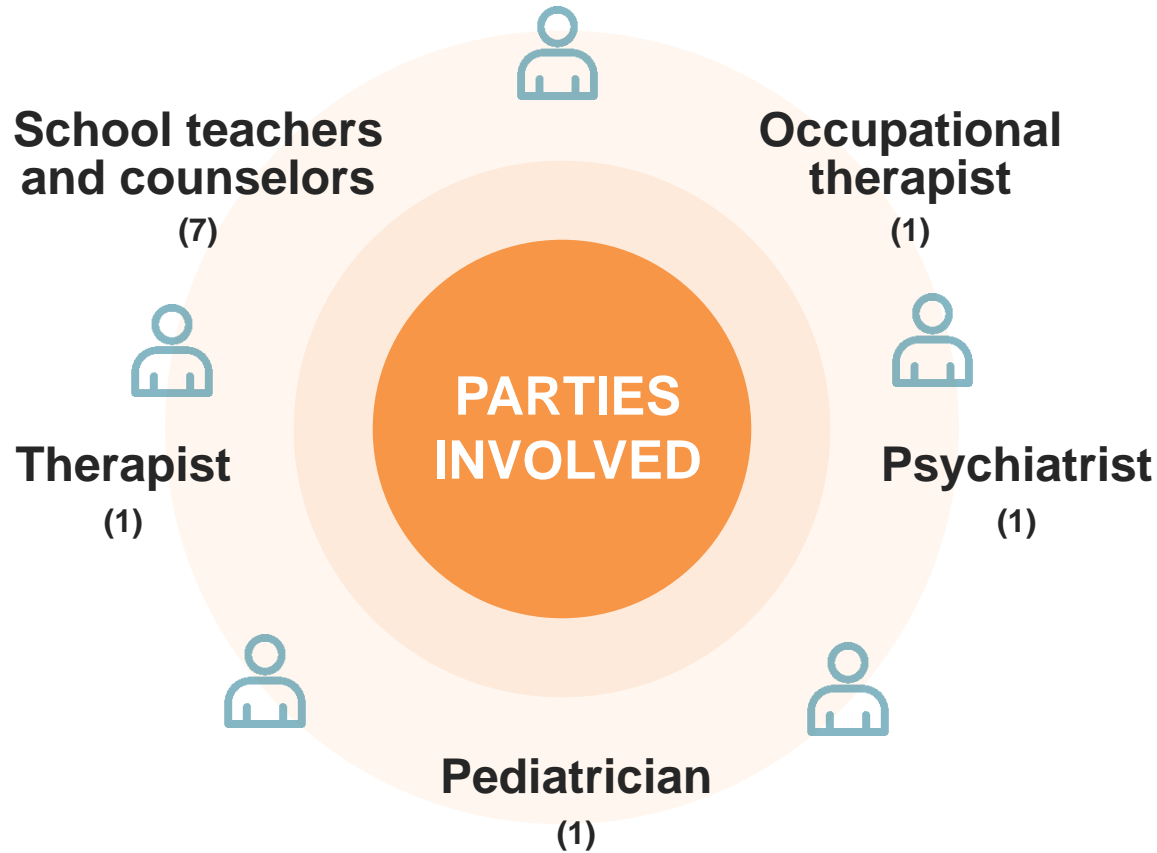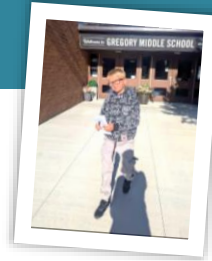
Group or individual?

At school or outside?
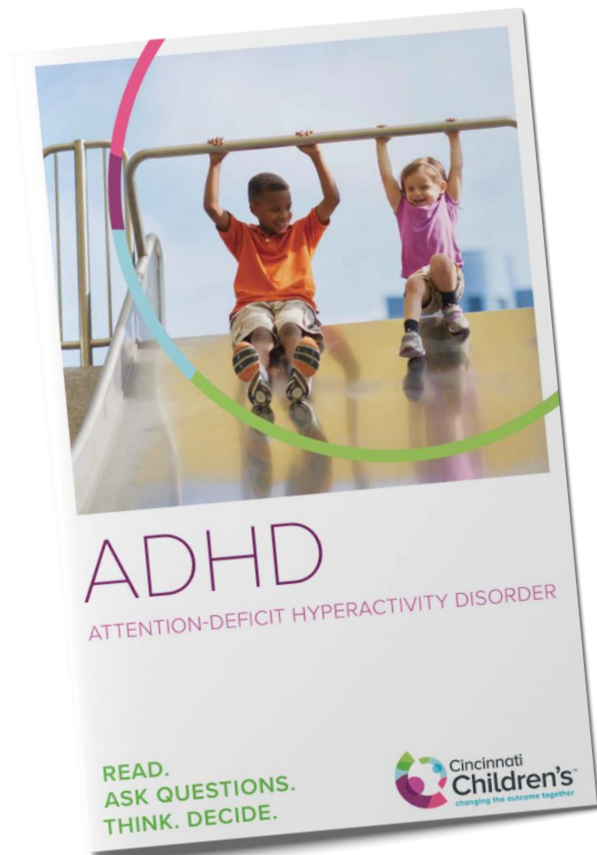
MEDICATION

THERAPY

Some generics

Executive functioning or behavioral?

PARTIES INVOLVED

School teachers and counselors (7)

Occupational therapist (1)

Therapist (1)

Psychiatrist (1)

Pediatrician (1)

What are ADHD Treatment Options?

Every effort should be made to manage symptoms and direct your child to helpful paths. There are treatment options to consider.

- Watchful Waiting

- Behavioral Treatment

- Medicine

- Combined Treatment (BOTH Behavioral Treatment AND Medicine)

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Comparing Treatment Choices

Here is our best guess of what will happen to **100 children** with ADHD who have a good response to an ADHD medicine and keep taking it.
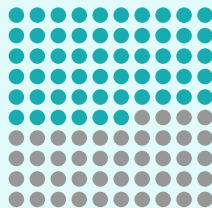
BEHAVIOR THERAPY
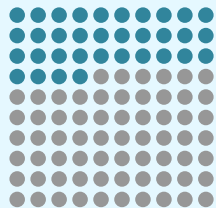
34 Number who have self-control and focus as well as the average child their age who doesn't have ADHD

66 Number who don't improve to that level

MEDICATION

56 Number who have self-control and focus as well as the average child their age who doesn't have ADHD

44 Number who don't improve to that level

COMBINED TREATMENT

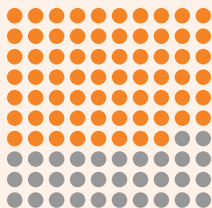**68** Number who have self-control and focus as well as the average child their age who doesn't have ADHD
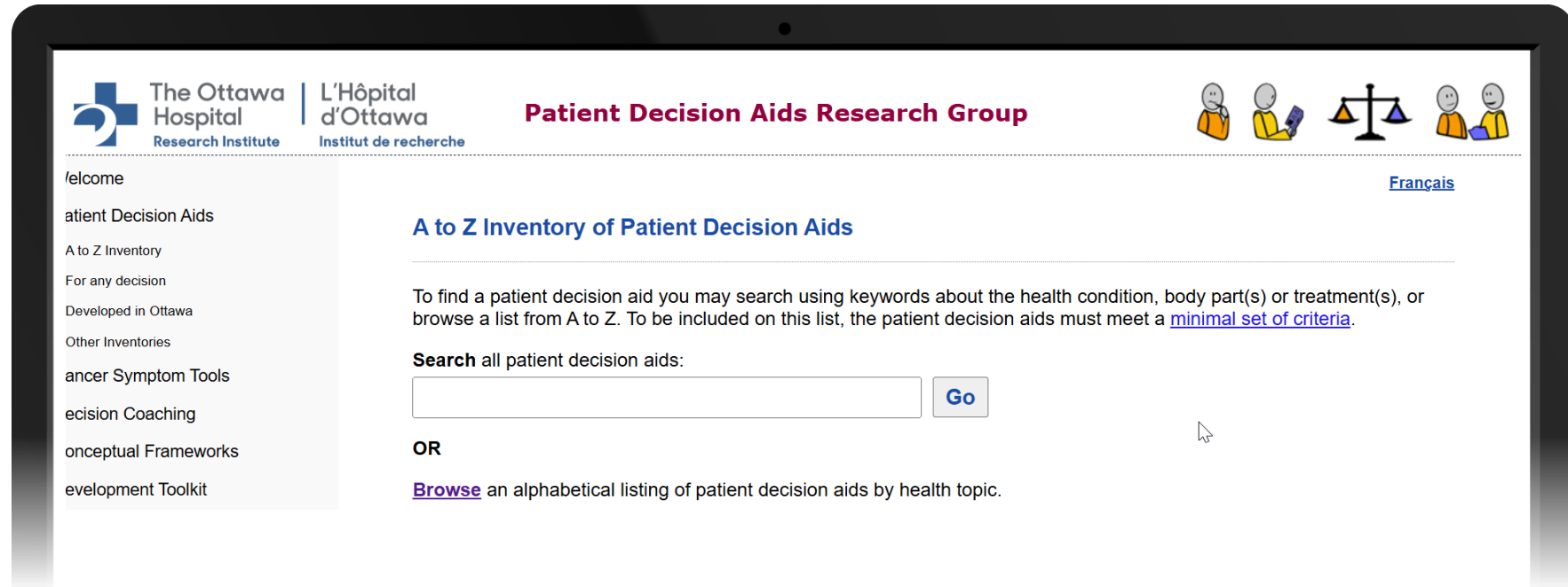
32 Number who don't improve to that level

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500 DAs developed, validated and available

The Ottawa Hospital | L'Hôpital d'Ottawa
Research Institute | Institut de recherche

Patient Decision Aids Research Group

- elcome
- atient Decision Aids
  - A to Z Inventory
  - For any decision
  - Developed in Ottawa
  - Other Inventories
- ancer Symptom Tools
- ecision Coaching
- onceptual Frameworks
- evelopment Toolkit

A to Z Inventory of Patient Decision Aids

To find a patient decision aid you may search using keywords about the health condition, body part(s) or treatment(s), or browse a list from A to Z. To be included on this list, the patient decision aids must meet a minimal set of criteria.

Search all patient decision aids:

[   ] [Go]

OR

Browse an alphabetical listing of patient decision aids by health topic.

https://decisionaid.ohri.ca/azinvent.php

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PDA's prominent examples

Mayo Clinic has developed multiple high quality decision aids for clinical use

[Depression Medication Choice DA](.).

Health systems like Mass General Brigham are implementing PDAs at scale:

MGH Decision Sciences – 100K Decision Aids

100K Decision Aids

Decision aids are interventions or tools designed to facilitate shared decision making and patient participation in health care decisions. We celebrated the delivery of our 100,000th decision aid at Mass General Brigham (MGB).

We are currently at...

100288

Data:

Here is a snapshot of monthly DA delivery across MGB by clinical specialty in the past year.
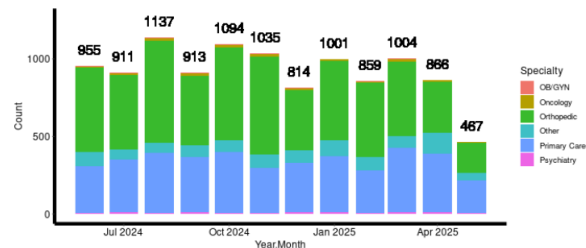
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Business Issue – Not More, but Better Tools

>80%
IN 2025
of U.S. hospitals report using some decision support tools, but depth and quality vary widely.

The next milestone is **not more tools, but better-designed, better-integrated tools** that meet patients where they are, across literacy, culture, and clinical workflows.

We explore what happens at the design and implementations stages of PDAs roll-out. Based on actual testing across multiple therapeutic areas, this session offers actionable guidance on how to make PDAs more effective and implementable.

Which Steps are Involved in Developing a Decision Aid?

To develop a Patient Decision Aid several key steps must be followed.

1 Identifying the Need for a Decision Aid

2 Defining Content and Format Requirements

3 Drafting the Decision Aid

4 Testing Usability and Understanding

5 Evaluating the Decision Aid

6 Implementing

7 Continuous Review and Update
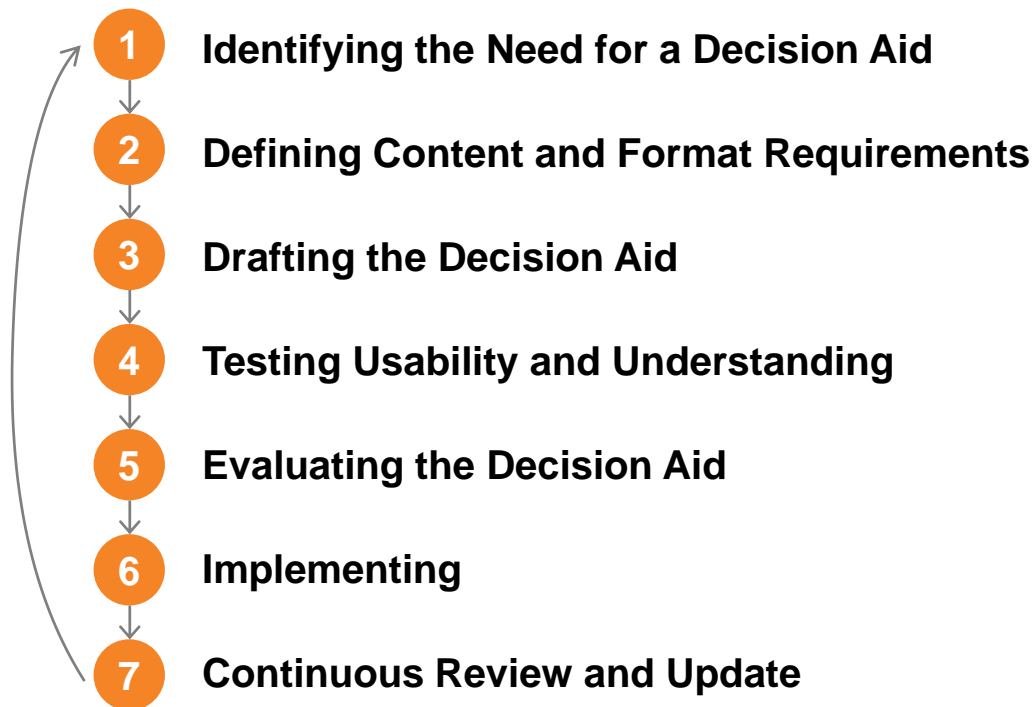
Could Pharma-Sponsored DA be Trusted? YES, if the development is rigorous

Prototype 1

Initial Draft of the Decision Aid.

Steering Committee 1

Review by steering committee to discuss decision needs, & decision aid development process.

Alpha Testing 1 (PACE Committee)

Testing of initial prototype with N=10 physicians to check for comprehensibility and usability.

Prototype 2

Revised Decision Aid.

Needs Assessment

Assess Physician Views of Educational & Treatment Decision Needs.

Wave 1

Needs Assessment and Conjoint Testing

Assess Patient Views of Educational & Treatment Decision Needs. Conjoint testing – specific tests for decision analysis with patients. N=50

Alpha Testing 2 (Prototype 2)

Testing & depth interviews with clinicians and patients to check acceptability and usability of all decision aid content (N=10).

Steering Committee 2

Reviews research results and provides input on process/findings.

Prototype 3

Revised Decision Aid based on patient & physician testing.

Wave 2

Beta testing (Prototype 3)

1:1 cognitive interviews to assess changes to usability and acceptability with physicians and patients (all of whom previously completed cycle 1 testing).

Beta testing (Prototype 3)

Quantitative online interviews with 25 patients

Steering Committee 3

Reviews research results and provides input on process/findings.

Prototype 4

Revised Decision Aid ready for roll-out.

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Example Pharma-sponsored PDA development

An Independent **Steering Committee**

- **Coordinators** (independent or from sponsor)
- **Sponsor** (Pharma or Health Organization)
- **Content developers**
- **Usability evaluators with no clinical background**
- **Market researchers**
- **Patient advocates**
- **Clinicians**
- **Patients**

Usability

Relevance

Updatability to match new treatments

People do not know these exist

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Randomized vignettes to test how patients interpret different framings (inclusion of patient stories)

Usability heuristics checklists

Choice experiments (e.g., conjoint) that help patients to understand their internal values

Use health literacy review tools (SHeLL, PEMAT) to simplify the language

Stories help, but they must be used carefully.

RANDOMIZED VIGNETTES

I include stories, but am very careful. I never use them to say 'I had this treatment and it was great'. I use them to convey things difficult to put in formal text.

For example, we had a testimonial about the worries of buying diapers or having accidents after prostate cancer treatment... Or someone saying, 'I never liked numbers, but I knew I had to understand risks and benefits, so I took time to study.

It breaks up dry text. But I'm careful to use names that resonate across race and ethnicity.

Angie Fagerlin,
Professor & Chair, Population Health
Sciences, University of Utah

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Three types of usability heuristics – Usability Heuristics Checklists

USABILITY HEURISTICS CHECKLISTS

General Heuristics

- Consistency
- Error message clarity
- Appropriate language use

Usability experts identified key issues and generated actionable recommendations to improve the prototype.

Ankolekar et al, 2019

Readability Heuristics

- Typeface and text size
- Color contrast
- Icon / button style and size

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Preference Elicitation Through Conjoint

CHOICE EXPERIMENTS

Conjoint Exercise to Elicit Preferences

Bazis Americas implemented interactive trade-off techniques to elicit patient preferences.

Often patients feel overwhelmed by available clinical evidence and treatment factors to consider.

Building a conjoint analysis methodology (such as Adaptive Conjoint Analysis, or Best-Worst Scaling Conjoint) into a decision aid helps patients clarify and articulate factors that carry the highest importance in their treatment choice.

Your Treatment Decision Survey / Page 16 / 23

Choice task 8 out of 12

If these treatments were identical in all other ways, which would you prefer?

5% risk of serious infection
Taken/administered every 4 weeks
Slight improvement in hemoglobin levels

or

15% risk of serious infection
Taken/administered every day
No improvement in hemoglobin levels

Strongly prefer the option presented on the left

No preference

Strongly prefer the option presented on the right

Back   Next

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Personalized Report with Symptoms Summary and Preferences

Decision aids provided patients with tailored Personalized Report that summarized:

- Individual treatment preferences determined through the trade-off exercise
- Side-by-side comparison of available treatments against patient preferences
- Summary of symptoms and their impact on daily life

Importance of Treatment Characteristics when making Decisions

Top 3 most important factors

1. Improvement in hemoglobin levels	2. Time in between dosing	3. How a medication is given	4 Risk of serious infection	5. Rick of blood clots
34	27	16	12	6

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Scales and Instruments to Assess Personal Perceptions

CHOICE EXPERIMENTS

Validated scales and instruments to assess personal perceptions such as:

- Shared Decision Making Questionnaire (SDM-Q)

- Beliefs about Medicines Questionnaire (BMQ)

Beliefs about Medicines Questionnaire (BMQ)

	Strongly disagree		Strongly agree		
	1	2	3	4	5
Without my medication I would be very ill				●	
My life would be impossible without my medication				●	
My health, at present, depends on my medication					●
My health in the future will depend on my medication					●
My medication protects me from becoming worse					●
I sometimes worry about becoming too dependent on my medication				●	
My medication disrupt my life				●	
My medication is a mystery to me		●			
Having to take medication worries me				●	

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End-user perspective

Tested and validated Decision Aids have strong impact on decision clarity and often on treatment outcomes.

- Increased patient preparedness and **reduced decisional conflict**
- **Better alignment** between treatment chosen and patient values

What **patients** said about decision aids in our interviews

This is the first time a tool helped me understand my priorities and not just medical facts. I finally felt prepared to talk to my doctor.

What **providers** said about patient decision aids in our interviews

It serves as some sort of way to reach, if not a conclusion, a starting point for the discussion on the treatment options, because it's capturing what a person is thinking, how they perceive their illness and therapy… one can use it as a starting point to discuss further.

Lessons Learned and Best Practices

Lesson 1.

Start usability testing early with designers and providers, then with just 5 to 10 patients. Some issues are invisible to developers and even HCPs, but **easily spotted by patients.**

Lesson 2.

Simplify, simplify, and simplify again. Use plain language tools like SHeLL or PEMAT. With diverse populations, plan for **multiple formats** (reliance on one format is the most frequent mistake!)

Lesson 3.

Integrate preference elicitation to clarify values (i.e. conjoint). **Conjoint methods help clarify preferences** better than statements or one-way recommendations.

Lesson 4.

Plan for 3-6 months updates when discussing costs to roll-out: clinical content and tools evolve fast.

TATIANA BARAKSHINA

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Tatiana is a co-founder of BazisAmericas⁷ —
international marketing research agency specialized in healthcare research.

A healthcare market research firm specializing in patient-centered insights. Her work focuses on decision heuristics and biases, clear health communication, health literacy, and shared decision making.

Tatiana is a member of the Clear Health Communication Taskforce, an award-winning group of volunteer researchers, and a frequent presenter at Intellus Worldwide.

She serves as a reviewer for Patient Education and Counseling, is part of the Core Course Certification Program faculty at Society for Medical Decision Making, and teaches at University of Illinois at Chicago and at Loyola University, Chicago business schools.

Her research spans across shared decision-making, health literacy, and patient-centered medicine.

PDA, HL and Plain Language Resources

1 **International Patient Decision Aid Standards (IPDAS) website**

https://decisionaid.ohri.ca/IPDAS/index.html

2 **PDA materials**

http://ipdas.ohri.ca/resources.html

3 **Inventory of decision aids, published by The Ottawa Hospital Research Institute**

https://decisionaid.ohri.ca/AZinvent.php

4 **Plain Language**
https://www.plainlanguage.gov/

5 **Sydney Health Literacy Lab (SHeLL) editor**
https://www.sydneyhealthliteracylab.org.au/health-literacy-editor

6 **Patient Education Materials Assessment Tool (PEMAT)**

https://www.ahrq.gov/health-literacy/patient-education/pemat.html

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