

Engaging patients and their family in shared decision making



@d_stacey

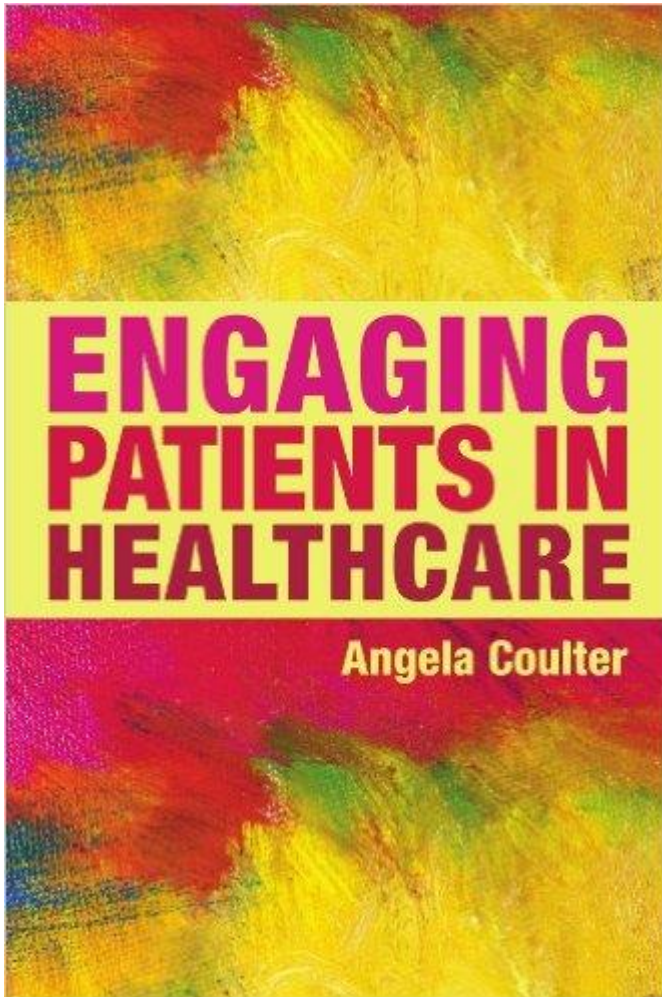
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- *“Working together to promote and support active patient and public **involvement** in health and healthcare and*
- *to strengthen their influence on healthcare decisions, at both the individual and the collective level”*

HealthAffairs

Robert Wood Johnson Foundation



Health Policy Brief

FEBRUARY 14, 2013

Patient Engagement. People actively involved in their health and health care tend to have better outcomes—and, some evidence suggests, lower costs.

WHAT'S THE ISSUE?

A growing body of evidence demonstrates that patients who are more actively involved in their health care experience better health outcomes and incur lower costs. As a result, many public and private health care organizations are employing strategies to better engage patients, such as educating them about

their medical conditions. What's more, the US health care system often has seemed indifferent to patients' desires and needs. Many practitioners fail to provide the information that patients need to make the best decisions about their own care and treatment. And even when patients do receive detailed information, they can be overwhelmed or lack confidence in their own choices. Those with low levels of



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(James, 2013; Health Affairs)

Multidimensional Framework For Patient And Family Engagement In Health

Continuum of engagement →

Levels of engagement

Consultation

Involvement

Partnership and shared leadership

Policy making

Public agency conducts focus groups with patients to ask opinions

Patients' research priorities are used to make funding decisions

Patients participate to decisions about how to allocate resources

Organizational design and governance

Organization surveys patients about their care experiences

Patients as advisory council members

Patients co-lead safety and quality improvement committees

Research

Focus groups with patients to ask opinions

Patients suggest research question

Patients as co-partners on the team

Direct Care

Patients receive information about a diagnosis

Patients are asked about their preferences

Decisions are made based on patients' preferences, evidence, and clinical judgement

Factors influencing engagement:

- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)

Shared decision making (SDM)

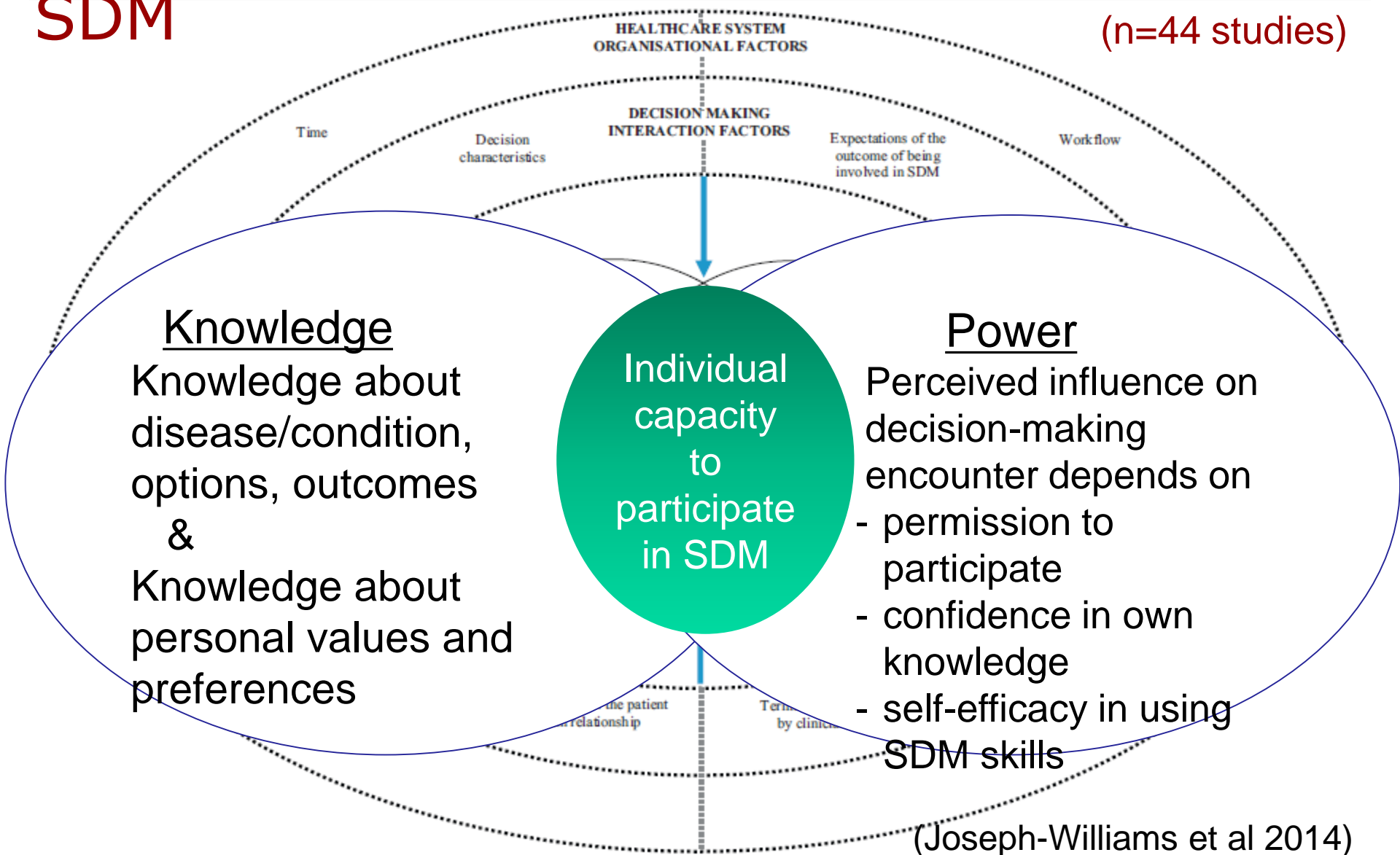


A process by which decisions are made by the patient and the clinician using the best available evidence and patients informed preferences.



Patient identified barriers & facilitators to SDM

(n=44 studies)



(Joseph-Williams et al 2014)

Fig. 2. Knowledge and power: patient-reported influences on individual capacity to participate in shared decision making.

SDM can be learned

Healthcare professional training

COMBINED WITH

Patient-mediated interventions such as patient decision aids

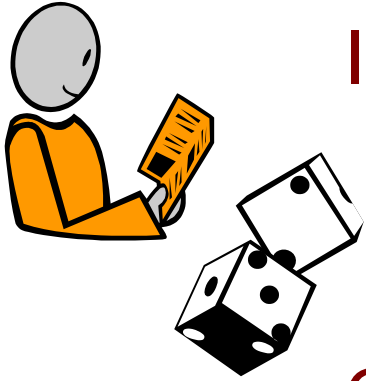
Interventions for improving the adoption of shared decision making by healthcare professionals (Review)

Légaré F, Stacey D, Turcotte S, Cossi MJ, Kryworuchko J, Graham ID, Lyddiatt A, Politi MC, Thomson R, Elwyn G, Donner-Banzhoff N



(Légaré et al. 2014)

Patient Decision Aids adjuncts to counseling



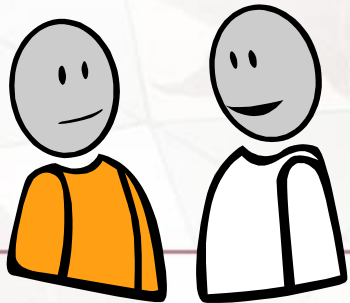
Inform

- Provide facts
Condition, options, benefits, harms
- Communicate probabilities



Clarify values

- Ask which benefits/harms matters most
- Share patient experiences



Support

- Guide in steps in deliberation/communication
- Worksheets, list of questions

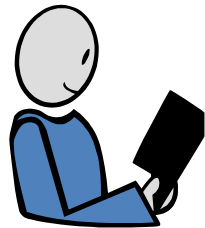


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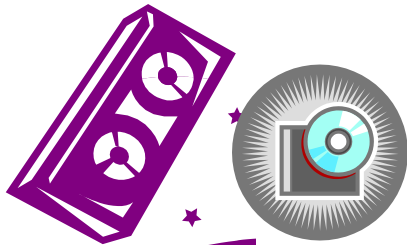
(Stacey et al., Cochrane Library, 2017)

Formats for patient decision aids

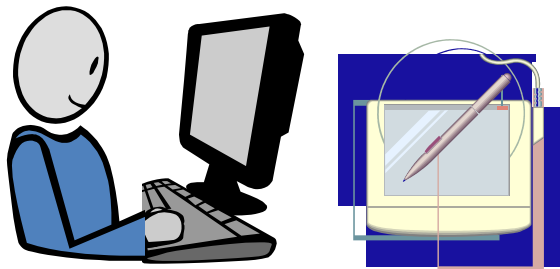
(used prior to or within consultations)



1. Print



2. DVD/Video



3. Online/computer-based

Against comparators, PtDAs (105 RCTs)...



Improve decision quality with...

- ✓ 13% higher knowledge****
- ✓ 110% more accurate risk perception***
- ✓ 106% better match between values & choices **

GRADE quality:

**** high	** low
*** moderate	* very low

- ✓ Reduce decisional conflict (-9% uninformed; -9% unclear values)****
- ✓ Help undecided to decide (36%)
- ✓ Support patients to be less passive in decisions (32%) ***
- ✓ Improve patient-practitioner communication (9/10; 1 no diff)
- ✓ Potential to reduce over-use
 - ✓ -16% elective surgery
 - ✓ -12% PSA – prostate screening
 - ✓ +65% new diabetes medicine

Do Interventions Designed to Support Shared Decision-Making Reduce Health Inequalities? A Systematic Review and Meta-Analysis

Marie-Anne Durand^{1*}, Lewis Carpenter¹, Hayley Dolan¹, Paulina Bravo², Mala Mann³, Frances Bunn⁴, Glyn Elwyn⁵

1 Centre for Lifespan and Chronic Illness Research, University of Hertfordshire, Hatfield, United Kingdom, **2** School of Nursing, Pontificia Universidad Catolica de Chile, Santiago, Chile, **3** Support Unit for Research Evidence, Cardiff University, Cardiff, United Kingdom, **4** Centre for Research in Primary and Community Care, University of Hertfordshire, Hatfield, United Kingdom, **5** The Dartmouth Center for Health Care Delivery Science, Dartmouth College, Hanover, United States of America

Abstract

Background: Increasing patient engagement in healthcare has become a health policy priority. However, there has been concern that promoting supported shared decision-making could increase health inequalities.

Objective: To evaluate the impact of SDM interventions on disadvantaged groups and health inequalities.

Design: Systematic review and meta-analysis of randomised controlled trials and observational studies.

19 studies* showed:

- significantly better outcomes for disadvantaged patients
- maybe more beneficial to disadvantaged patients than for those with higher literacy/ socioeconomic status

(*small sample sizes and various study quality)



International Patient Decision Aid Standards (IPDAS) Collaboration since 2003



To enhance the quality and effectiveness of patient decision aids by establishing a shared evidence-informed framework for improving their content, development, implementation, and evaluation.

IPDAS Steering Committee: Dawn Stacey, R Volk (co-leads),
M Barry, N Col, A Coulter, M Härter,
V Montori, N Mounjid, M Pignone,
R Thomson, L Trevena, T van der Weijden

BMC Medical Informatics and Decision Making 2013, 13 (Suppl 2).
<http://www.biomedcentral.com/bmcmmedinformdecismak/supplements/13/S2>



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To find decision aids

Google: 'decision aid'



[Français](#)

Search Results - A to Z Inventory of Decision Aids

Your search: **cancer** found the following decision aids (see list below).

Click on a **title** to view a brief description that will help you decide if the decision aid will meet your needs, or try another keyword search to look for other decision aids.

Search again:

Found 67 matches.

Breast and Ovarian Cancer

- [BRCA1 and BRCA2: Cancer Risk and Genetic Testing](#). National Cancer Institute
- [Breast Cancer Risk: Should I Have a BRCA Gene Test?](#) Healthwise
- [The BRCA1/2 gene mutation test to evaluate the risks of breast and ovarian cancer ; Le dépistage des mutations génétiques BRCA1/2 pour évaluer les risques de cancer du sein et de l'ovaire](#) Université Laval
- [Understanding genetic tests for breast and ovarian cancer that runs in the family: Information and decision aid](#). Centre for Genetics Education, NSW Health

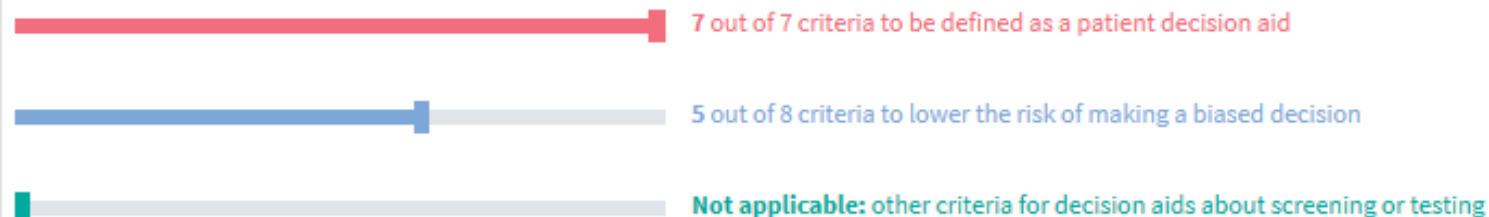
Breast Cancer

- [A Patchwork of Life - One Woman's Story, For Women Making Breast Cancer Treatment Decisions](#). Dan L. Duncan Cancer Center at Baylor College of Medicine

Decision Aid Summary

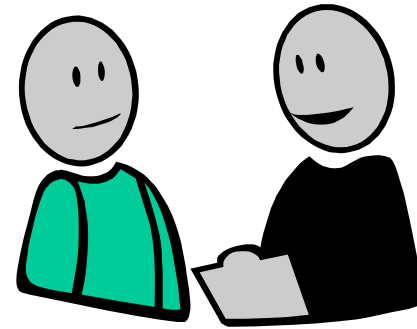
Title	Radiotherapy for Head and Neck Cancer: A Summary for Adults and Their Caregivers.
Audience	People diagnoses with head and neck cancer considering radiation therapy.
Options included	Three-Dimensional Conformal Radiation Therapy (3DCRT). Intensity-Modulated Radiation Therapy (IMRT). •Stereotactic Body Radiation Therapy (SBRT). Proton-Beam Radiation Therapy (PBRT).
Year of last update or review	2015
Format	Web, paper, audio, PDF
How to obtain	Click here to view the decision aid on the developer website
Developer	Agency for Healthcare Research and Quality (AHRQ)
Where was it developed?	http://www.ahrq.gov/info/customer.htm Agency for Healthcare Research and Quality (AHRQ) US
Health condition	Radiation Therapy
Type of decision aid	Treatment
Language	English, Spanish

Based on **IPDAS criteria (International Patient Decision Aid Standards)** this decision aid (and/or supporting materials) meets:



What is decision coaching?

- Trained healthcare professional who is non-directive and provides support that aims to develop patients skills in:
 - thinking about the options
 - preparing for discussing the decision in a clinician consultation
 - implementing the chosen option
- Delivered face to face or using telephone



(O'Connor et al., 2008; Stacey et al., 2008)

Decision Coaching to Prepare Patients for Making Health Decisions: A Systematic Review of Decision Coaching in Trials of Patient Decision Aids

*Dawn Stacey, PhD, Jennifer Kryworuchko, PhD, Carol Bennett, MSc,
Mary Ann Murray, PhD, Sarah Mullan, MSc, France Légaré, PhD
Medical Decision Making, 2012*

Background. Decision coaching is individualized, nondirective facilitation of patient preparation for shared decision making. **Purpose.** To explore characteristics and effectiveness of decision coaching evaluated within trials of patient decision aids (PtDAs) for health decisions. **Data Sources.** A subanalysis of trials included in the 2011 Cochrane Review of PtDAs. **Study Selection.** Eligible trials allowed the effectiveness of decision coaching to be compared with another intervention and/or usual care.

process without any difference in knowledge or participation in decision making. Coaching plus PtDA compared with PtDA alone ($n = 4$) had no difference in knowledge, values-choice agreement, participation in decision making, or satisfaction with the process. Decision coaching plus PtDA was more cost-effective compared with PtDA alone or usual care ($n = 1$). **Limitations.** Methodological quality, number of trials, and description of decision coaching. **Conclusions.** Compared with usual care, deci-

Coaching (n=10 trials):

- improved knowledge compared to usual care
- improved knowledge similar to decision aid group
- improved or no difference on other outcomes
(values-choice agreement, satisfaction, participation, costs)

Ottawa Personal Decision Guide

For People Making Health or Social Decisions



1 Clarify your decision.

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with making a choice?

- ☐ Not thought about it
☐ Thinking about it

- ☐ Close to choosing
☐ Made a choice

2 Explore your decision.



Knowledge

List the options and benefits and risks you know.



Values

Rate each benefit and risk using stars (★) to show how much each one matters to you.



Certainty

Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0 ★ not at all 5 ★ a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0 ★ not at all 5 ★ a great deal
Option #1				
Option #2				
Option #3				

Which option do you prefer?

☐ Option #1

☐ Option #2

☐ Option #3

☐ Unsure



Support

Who else is involved?

Which option do they prefer?

To find Google: 'generic decision aid'



Ottawa Personal Decision Guides

The Ottawa Personal Decision Guide (OPDG) and Ottawa Personal Decision Guide for Two (OPDGx2) are designed for any health-related or social decisions.

They can help people identify their decision making needs, plan the next steps, track their progress, and share their views about the decision. See this [video example of the OPDG being used to coach someone making a decision](#).

A screenshot of the Ottawa Personal Decision Guide (OPDG) form. It is a two-page interactive PDF with various sections for decision-making, including a table for listing options and a section for tracking progress.

[Ottawa Personal Decision Guide](#)

(Two-page interactive PDF. Fill in, save your answers, and print using [Adobe Reader](#).)

[French](#)

[Spanish](#)

[Swedish](#)

[German](#)

[Dutch](#)

[Japanese](#)

A screenshot of the Ottawa Personal Decision Guide for Two (OPDGx2) form. It is a two-page interactive PDF designed for two people to complete together, with sections for decision-making and progress tracking.

[Ottawa Personal Decision Guide for Two](#)

(Allows 2 people involved in the decision to complete the guide.)

[French](#)

You may use any of these guides without requesting permission. These guides are protected by copyright but are freely available for you to use, provided you: a) cite the reference in any documents or publications; b) do not charge for or profit from them; and c) do not alter them except for prefilling them for a specific condition/decision as necessary.

Multidimensional Framework For Patient And Family Engagement In Health

Continuum of engagement



Levels of
engagement

Consultation

Involvement

Partnership and
shared leadership

Direct Care

To Engage Patients/Families:

- Create health policies that support patient engagement
- Establish a culture of patient engagement
- Provide training
- Develop or gather tools for facilitating patient engagement
- Focus research on priorities established with patients/public

Policy making

Factors influencing engagement:

- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)



Patient Decision Aids

For specific conditions

For any decision

Developed in Ottawa

Other KT Tools

Decision Coaching

Conceptual Frameworks

Development Toolkit

Development Methods

International Standards

Systematic Review

Decision Aid Library Inventory

Evaluation Measures

Implementation Toolkit

Step 1: Identify the decision

Step 2: Find patient decision aids

Step 3: Identify barriers

Step 4.1: Implementation

Step 4.2: Provide training

Step 5: Monitor and evaluate

Welcome

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

How can I find decision aids?

- [A to Z Inventory](#) allows you to search for decision aids on particular health topics.
- [Ottawa Personal/Family Decision Guides](#) can be used for any health or social decision.
- [Decision Aid Library Inventory \(DALI\)](#) allows developers to enter information about their decision aid inventories.

Where are the online tutorials?

- The [Ottawa Decision Support Tutorial \(ODST\)](#), to help practitioners develop knowledge in shared decision support.
- The [Ottawa Patient Decision Aid Development eTraining \(ODAT\)](#) to help people create a patient decision aid development process.
- The [Implementation Toolkit](#) provides tools and training for incorporating decision support in practice.

What's the evidence?

- An international research group updates the [systematic review of trials of patient decision aids](#) for patient decision aids.
- The [International Patient Decision Aid Standards \(IPDAS\) Collaboration](#) established a set of international standards for patient decision aids.

<http://decisionaid.ohri.ca>