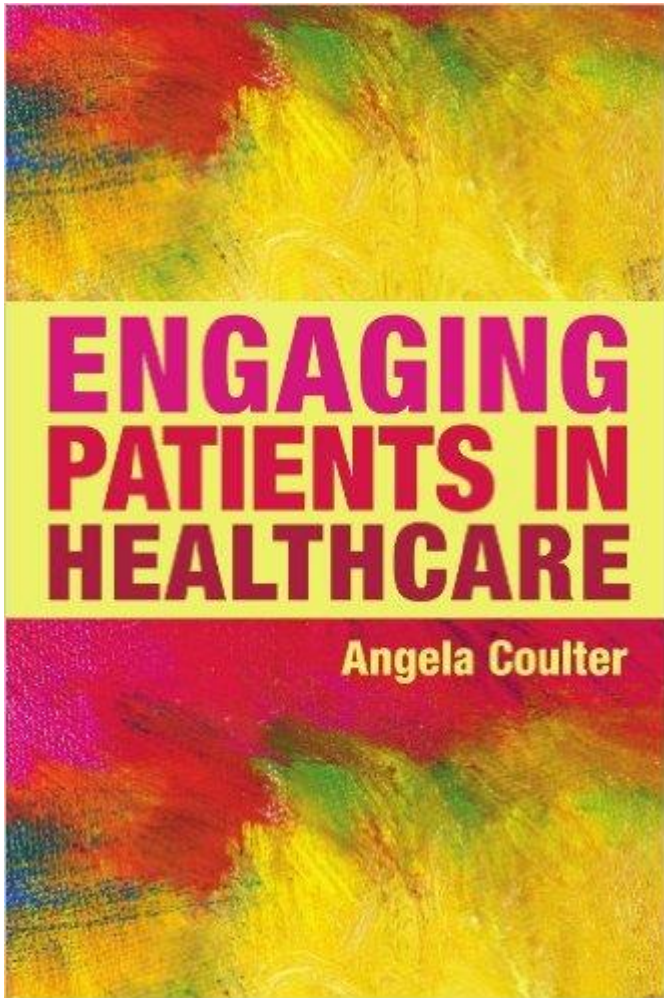


*Patient/User Involvement:
where are we, what do we know,
where can we go?*

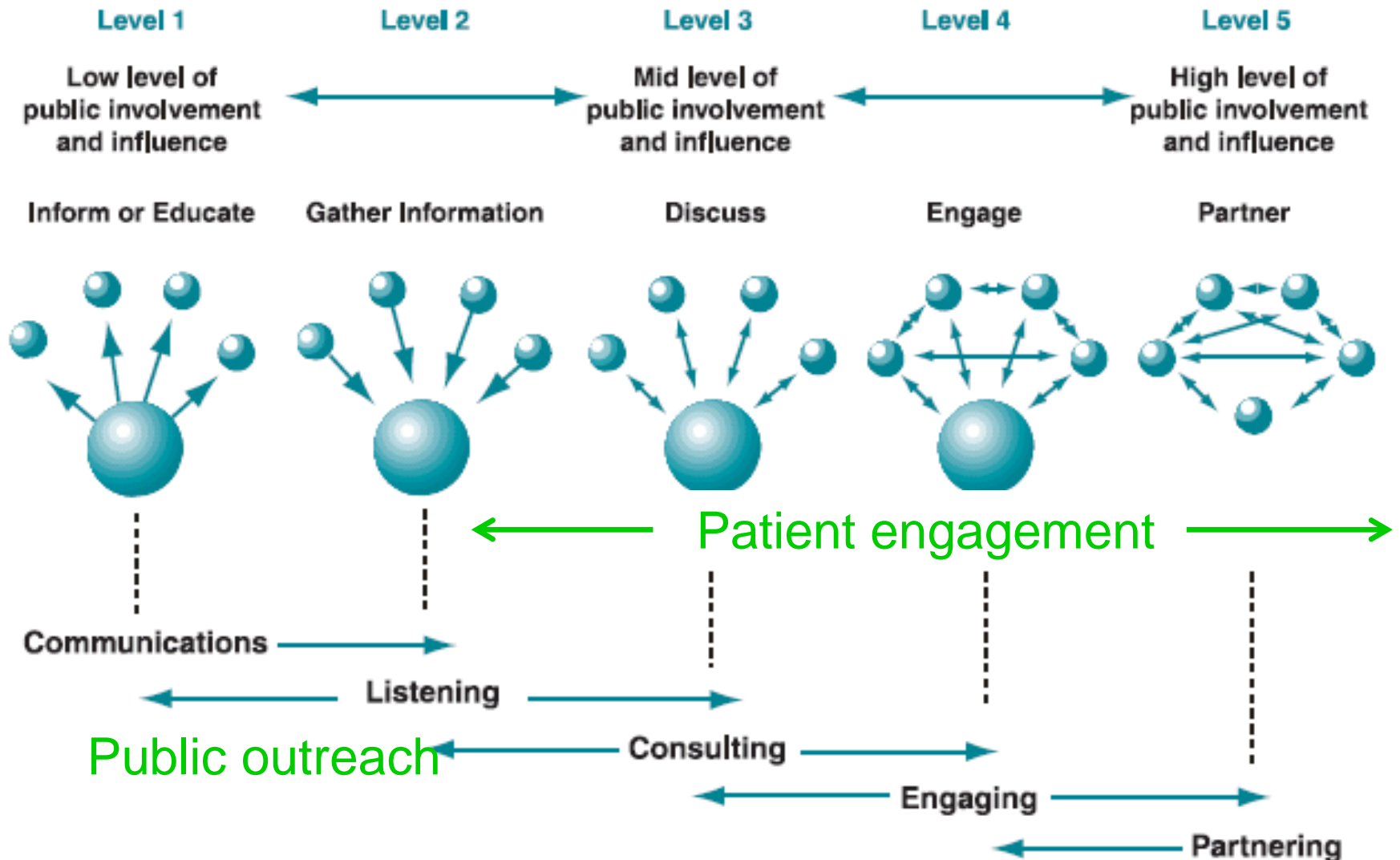


Dawn Stacey RN, PhD
Research Chair, Knowledge Translation to Patients
Professor, University of Ottawa
Senior Scientist, Ottawa Hospital Research Institute



- *“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”*

What does involvement mean?



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

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

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

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

Factors influencing engagement:

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

Cancer research priorities



- 105 patients attending UK cancer treatment centres participated
- Patients' top priority areas:
 - impact cancer has on life
 - how to live with cancer and related support issues
 - risk factors and causes of cancer
 - early detection and prevention
- **Mismatch between patient priorities and UK research portfolio priorities**

Engaging Patients In Research Prioritization



Welcome to the James Lind Alliance website

The James Lind Alliance (JLA) is a non-profit making initiative which was established in 2004. It brings **patients, carers and clinicians** together to identify and prioritise the **Top 10 uncertainties**, or 'unanswered questions', about the effects of treatments that they agree are most important.

The aim of this is to help ensure that those who fund health research are aware of what matters to **both patients and clinicians**. The method, described in the JLA Guidebook, is designed to lead to changes in the way research funding is granted, with a view to raising awareness of research questions which are of direct relevance and potential benefit to patients and the clinicians who treat them.

<http://www.lindalliance.org/>

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Canadian Institutes of Health Research



Canada

 Search

- Funding ▾
- Institutes ▾
- Strategies ▾
- Initiatives ▾
- Collaboration ▾
- Health research in action

[Home](#) → [Strategies](#) → [Strategy for Patient-Oriented Research](#)

Strategy for Patient-Oriented Research

Networks

SUPPORT units

Developing capacity

Improving our competitiveness in conducting clinical trials

Patient engagement

National Steering Committee

News

Publications

Patient engagement

What is patient engagement and why do it?

- **Patients meaningfully and actively collaborate in:**
 - the governance, priority setting, and conduct of research
 - summarizing, distributing, sharing, and applying its resulting knowledge
- Makes investments in research more accountable and transparent, provides new insights that could lead to innovative discoveries and ensures that research is relevant to patients' concerns
- Involving them in planning and design of studies leads to better outcomes



Search

Funding Opportunities

What We Mean by Engagement



WHAT & WHO WE FUND

HOW TO APPLY

APPLICANT TRAINING

WHAT WE MEAN BY ENGAGEMENT

PCORI'S STAKEHOLDERS

Engagement in Research

- Meaningful involvement of patients, caregivers, clinicians and other healthcare stakeholders throughout the research process – from topic selection through design and conduct of research to dissemination of results.
- More likely to be patient centered, useful, and trustworthy and lead to greater use and uptake of research results by the patient and broader healthcare community.

Systematic review of patient engagement in research (N=142 studies)



- Feasible in most settings
- Most commonly done in the beginning of research (agenda setting and protocol development)
- Less commonly done during execution and translation of research
- Increased study enrollment rates and aided researchers in securing funding, designing study protocols, and choosing relevant outcomes
- Common challenges were related to logistics (extra time and funding needed) and to an overarching worry of a tokenistic engagement

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Evidence for patient engagement – Organizational Design & Governance



- When consumers were involved with developing healthcare policy and research, clinical practice guidelines, and patient information
 - Information materials were more relevant, readable and understandable without affecting anxiety (2 trials, moderate quality)
- Need for more research



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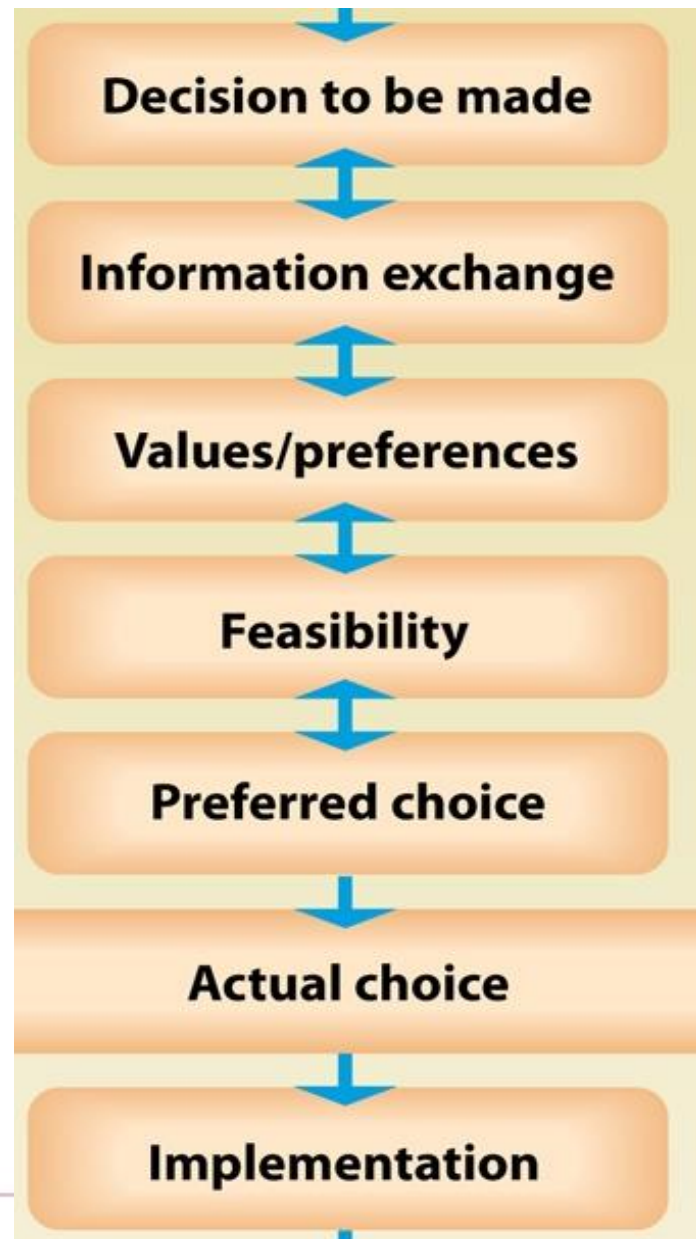
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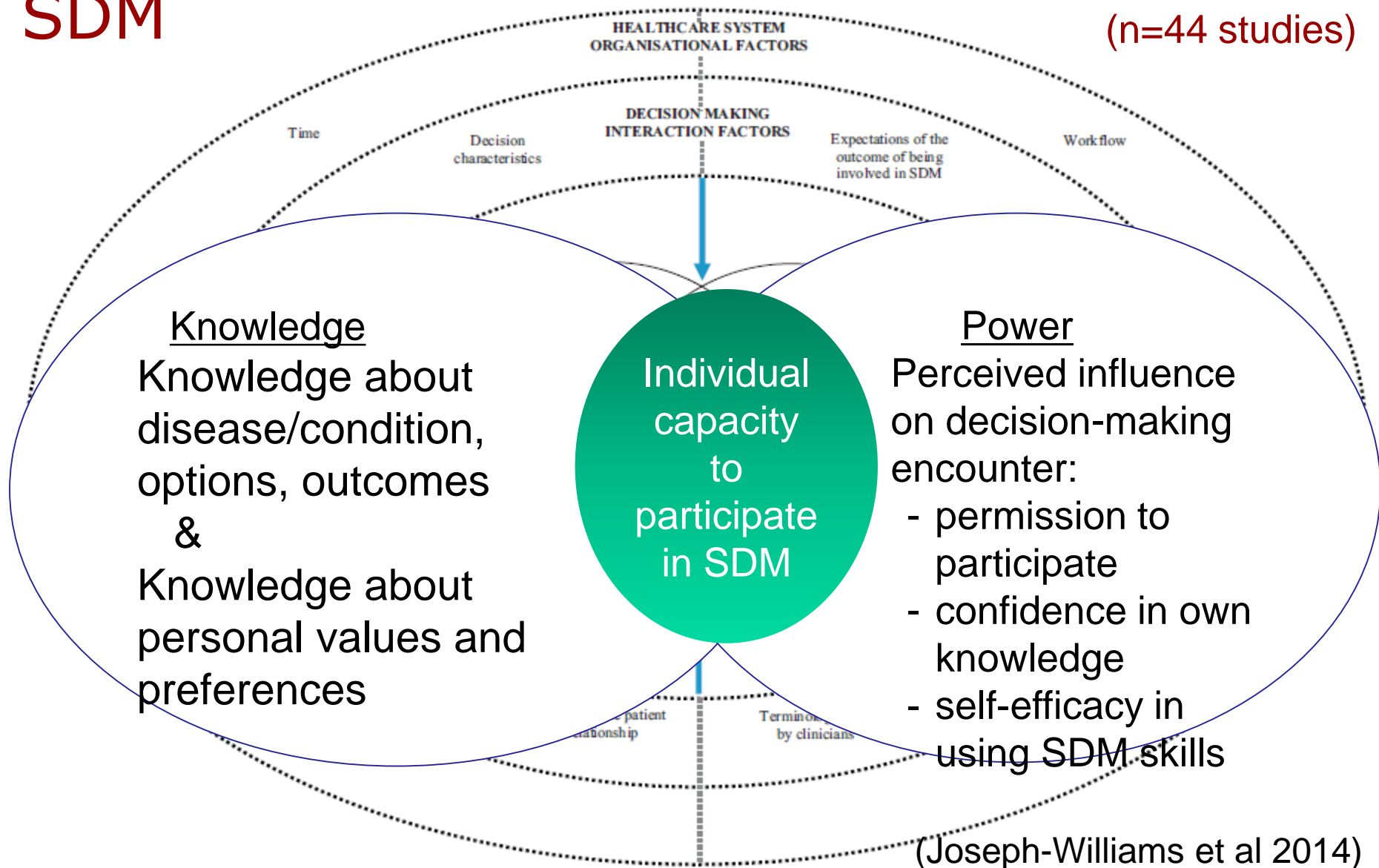
Shared decision making

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



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



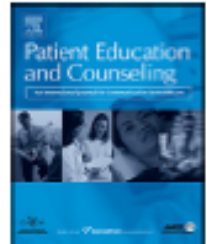
Légaré et al. Cochrane review
September 15th 2014



Contents lists available at SciVerse ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Review

Training health professionals in shared decision-making: An international environmental scan

France Légaré^{a,*}, Mary C. Politi^b, Renée Drolet^a, Sophie Desroches^a, Dawn Stacey^c, Hilary Bekker^d
the SDM-CPD team¹

^a Centre Hospitalier Universitaire de Québec Research Centre, Hospital St-François D'Assise, Québec, Canada

^b Health Communication Research Laboratory, George Warren Brown School of Social Work, Washington University in St-Louis, USA

^c School of Nursing, Faculty of Health Sciences, University of Ottawa, Ottawa, Canada

^d Leeds Institute of Health Sciences, School of Medicine, University of Leeds, Leeds, United Kingdom

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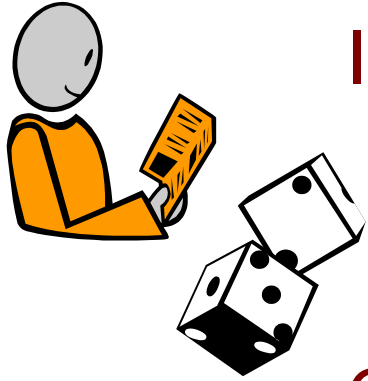
Implementation

Patient centered care

- 54 programs in 14 countries, 10 languages
 - Use interactive teaching methods
 - 17 published evaluation findings
- Competencies: relational & risk communication
(Legare, 2013)

<http://www.decision.chaire.fmed.ulaval.ca/en/list-of-sdm-programs/>

Patient Decision Aids adjuncts to counseling



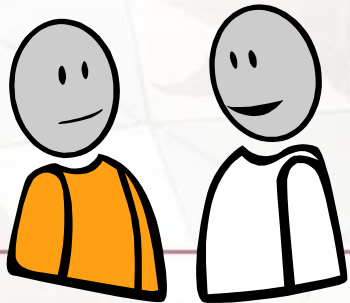
Inform

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



Clarify values

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



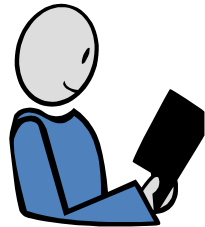
Support

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

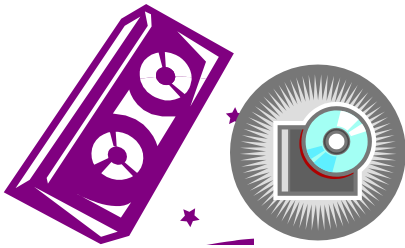


Formats for patient decision aids

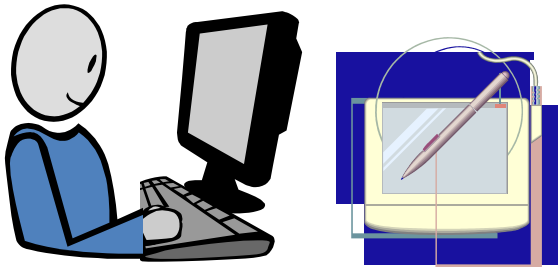
(used prior to or within consultations)



1. Print



2. DVD/Video



3. Online/computer-based

Topics in Decision Aid Trials (N=115)



- **Medication** (n=36)
 - **10 hormone replacement therapy**
 - 3 atrial fibrillation anti-coagulants
 - 3 cardiovascular
 - 3 diabetes
 - 2 osteoporosis
 - 2 chemotherapy
 - 2 breast cancer prevention
 - 2 osteoarthritis knee
 - hypertension
 - multiple sclerosis
 - schizophrenia
 - depression
 - natural health products
 - ovarian risk management
 - acute respiratory infection
 - contraceptives
 - coronary angiogram access site
- **Screening** (n=46)
 - **15 Prostate Specific Antigen**
 - 7 BRCA1/2 genetic
 - 11 colon cancer
 - 6 prenatal
 - 2 mammography
 - 2 diabetes
 - Colon cancer genetic
 - Cervix cancer
 - Stress testing for chest pain
- **Surgery** (n=23)
 - 4 mastectomy +1 reconstruction
 - **4 prostatectomy**
 - 4 hysterectomy
 - 2 prophylactic BRCA1/2
 - 2 coronary revascularization
 - dental
 - orchiectomy for advanced prostate ca
 - back
 - bariatric
 - vasectomy
 - long term feeding tube placement
- **Obstetrics** (n=6)
 - **2 vaginal birth after cesarean**
 - termination
 - breech
 - labour analgesia
 - embryo transplant
- **Other** (n=4)
 - Hepatitis B vaccine
 - influenza vaccine
 - Autologous blood donation
 - Cystic Fibrosis Transplant Referral

(Stacey et al., 2014 Cochrane Review)

Compared to usual care, decision aids...



Improve decision quality with...

- ✓ 13% higher knowledge****
- ✓ 82% more accurate risk perception***
- ✓ 51% better match between values & choices **

- ✓ Reduced decisional conflict (6%) (uninformed; unclear values)****
- ✓ Helps undecided to decide (41%)
- ✓ Patients 34% less passive in decisions***
- ✓ Improved patient-practitioner communication (7/8 trials)
- ✓ Potential to reduce over-use
 - ✓ -20% surgery
 - ✓ -14% PSA – prostate screening
 - ✓ -27% Hormone replacement therapy

GRADE quality:

**** high

** low

*** moderate

* Very low

(Stacey et al., 2014 Cochrane Review)

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: Glyn Elwyn & Dawn Stacey (Co-Leads),
M Barry, N Col, A Coulter, K Eden, M Härter, M Holmes-Rovner,
H Llewellyn-Thomas, V Montori, N Mounjid, M Pignone,
R Thomson, L Trevena, R Volk, T van der Weijden

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



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To find decision aids

Google: 'decision aid'



Patient Decision Aids



[Français](#)

Search Results - A to Z Inventory of Decision Aids

Your search: **breast screen** 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 4 matches.

Breast Cancer

- [Breast Cancer Screening and Dense Breasts: What Are My Options?](#) Healthwise
- [Breast Cancer Screening: When Should I Start Having Mammograms?](#) Healthwise
- [Should I Continue Having Mammograms to Screen for Breast Cancer? A decision aid for women aged 70 and older at their next screening mammogram.](#) University of Sydney
- [Should I Start Having Mammograms to Screen for Breast Cancer?](#) University of Sydney



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To find decision aids go to...

MED-DECS De internationale verzamelaarsplaats voor hulp bij medische keuzen



“Kan ik meebeslissen
in de keuze van de
arts?”

“Wat voor behandelingsmethoden zijn
er eigenlijk voor prostaatkanker?”



HOME

OVER MED-DECS

WAT IS EEN KEUZEHULP?

BETROUWBAARHEID

CONTACT

Medische behandeling

Artritis

Chirurgie voor gewrichtsklachten
en blessures

Med-Decs helpt u bij het kiezen van uw
medische behandeling

Med-Decs is een verzamelaarsplaats
van keuzehulpen uit de hele wereld.
Deze keuzehulpen kunnen u helpen



Een Europees project

Med-Decs is een Europees
initiatief dat nog steeds in
ontwikkeling is. Het doel van
Med-Decs is het beschikbaar



<http://www.med-decs.org/nl>

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

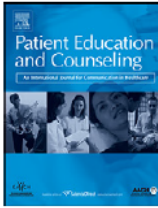
Unsure



Support

Who else is involved?

Which option do they prefer?



Question Prompts

Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial

Heather L. Shepherd^{a,b,*}, Alexandra Barratt^a, Lyndal J. Trevena^a, Kevin McGeechan^a, Karen Carey^f, Ronald M. Epstein^g, Phyllis N. Butow^c, Chris B. Del Mar^e, Vikki Entwistle^h, Martin H.N. Tattersall^d

Ask 3 questions:

1. What are my options?
2. What are the possible benefits and harms of those options?
3. How likely are the benefits and harms of each option to occur?

Conclusion:

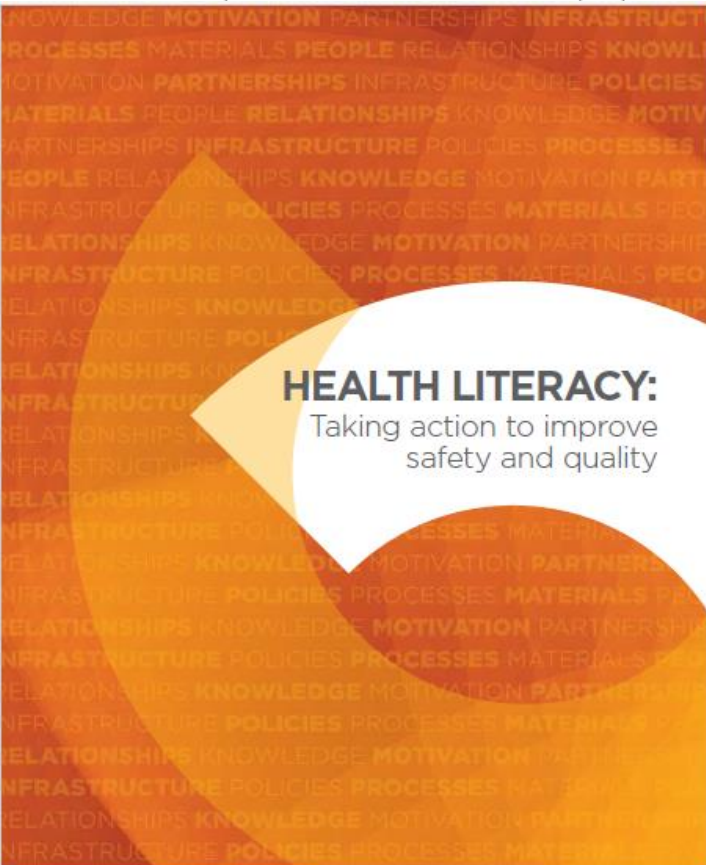
Asking 3 questions:

- improved information given by family physicians;
- increased physician facilitation of simulated patient involvement.



Improve the individual experience by providing exceptional care and service to

- 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.



HEALTH LITERACY:
Taking action to improve safety and quality



Patient Decision Aid Certification Criteria

Does the patient decision aid adequately:

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



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, 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 shared decision making](#) for shared decision making using Cochrane review methods.
- The [International Patient Decision Aid Standards \(IPDAS\) Collaboration](#) established a set of international standards for patient decision aids.

<http://decisionaid.ohri.ca>

Multidimensional Framework For Patient And Family Engagement In Health

Continuum of engagement



Partnership and

Levels of
engagement

Direct Care

Organizational
design and
governance

Research

Policy making

Opportunities for user involvement:

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

Factors influencing engagement:

- **Patient** (beliefs about patient role, health literacy, education)
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