



# IPDAS Deliverables, Impact, & Next Steps 2003-2017

IPDAS Steering Committee:  
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# International Patient Decision Aid Standards (IPDAS) Collaboration

## Purpose:

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.



# International Patient Decision Aid Standards (IPDAS) Collaboration

## Steering Committee Functions:

1. Oversee process for maintaining/revising IPDAS criteria
2. Provide guidance to enhance reporting of research on PtDAs
3. Facilitate stakeholder involvement in IPDAS
4. Disseminate and implement IPDAS criteria by overseeing and setting principles for:
  - use and refinement of the IPDASi instrument
  - production of quality-assured IPDAS training materials
5. Monitor progress of IPDAS working groups
6. Approve consensus statements and publication of IPDAS



# International Patient Decision Aid Standards (IPDAS) Collaboration

[IPDAS@listserv.dartmouth.edu](mailto:IPDAS@listserv.dartmouth.edu)

This IPDAS email list is used:

- 1) as a membership register
- 2) to communicate
- 3) to agree on a process to convene a Steering Group
- 4) for future research / development of the IPDAS criteria

To be added, ask a current member to introduce you by citing your interest and expertise relevant to IPDAS. If you don't know a member, see Who's Involved on the IPDAS website at <http://ipdas.ohri.ca>



# IPDAS Phases

- |           |   |
|-----------|---|
| 2003-2006 | IPDAS Checklist                                 |
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| 2009-2013 | IPDAS Minimal Standards                         |
| 2011-2013 | Updated evidence underlying the IPDAS Checklist |
| 2014-2017 | Reporting guidelines                            |



# International Patient Decision Aid Standards (IPDAS) Collaboration

## Objective:

To establish internationally approved criteria to determine the quality of patient decision aids. These criteria are helpful to individuals and organizations that use and/or develop patient decision aids:

- Patients
- Practitioners
- Developers
- Researchers
- Policy makers or payers

>100 participants  
from 14 countries

To learn more, visit: [ipdas.ohri.ca](http://ipdas.ohri.ca)



## 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>



# Summarized evidence to inform voters

## I. Using a systematic development process

What is this criterion? The logical steps taken to build a patient decision aid.

Steps may include:

- To form groups to develop decision aids (decision experts, patient users, practitioner users);
- To identify the needs of potential users;
- To draft, review, field test, and revise the decision aid;
  
- To have the decision aid reviewed by outside experts who were not involved in its development and field testing.

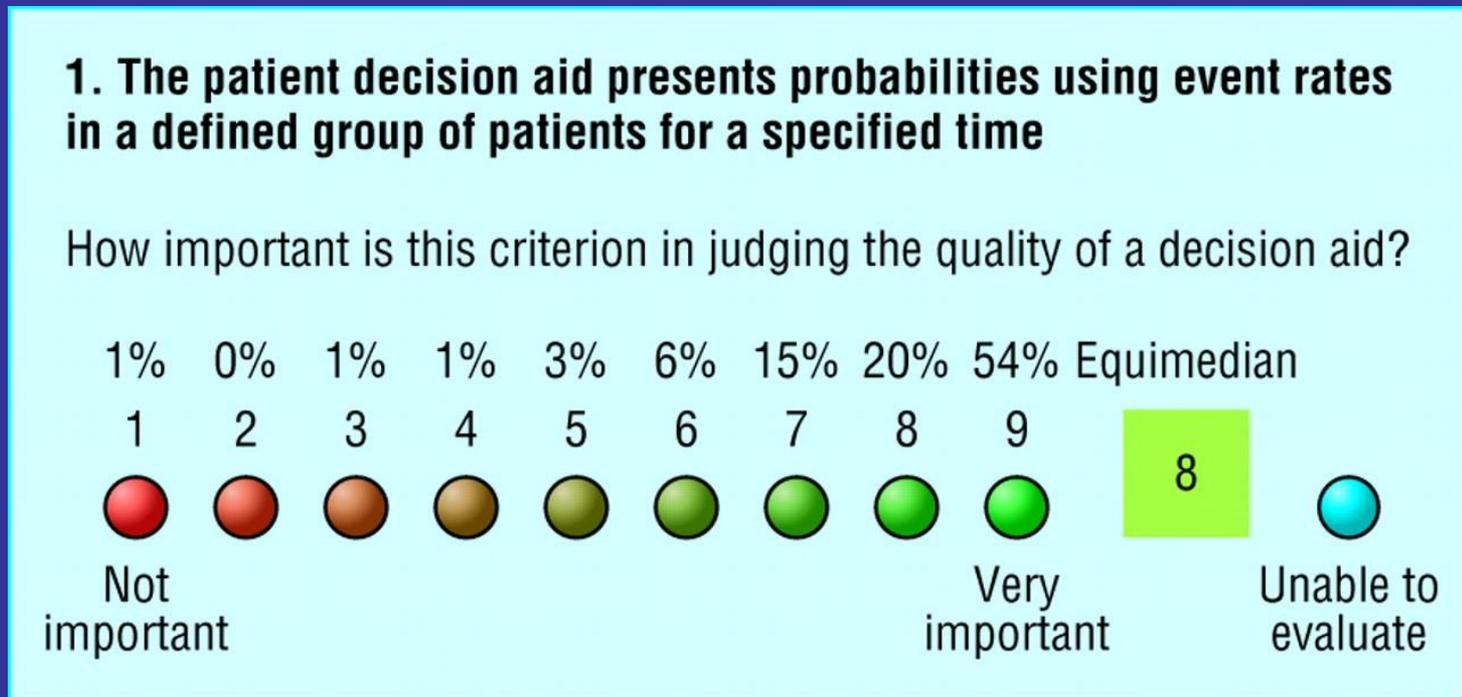
How might this affect the quality of decision making? In theory, decision aids may lead to poor decisions if they are developed by people who do not have the knowledge and skills to understand the decision situation and to help patients make decisions. Even qualified people may not design a good decision aid, if they do not take the time to develop it to meet the needs of the patients who face the specific decision and the practitioners who counsel them about the options. Outside experts may also help to identify things that were missed during development.

What is the evidence to support including or excluding this criterion? The Cochrane Collaboration review team examined the way 19 decision aids were developed. Of these, 17 reported the credentials of the developers (e.g. MD, RN, PhD), and 11 reported on the steps taken to develop the decision aid. There were no studies comparing different ways of developing patient decision aids.



# Modified Delphi Consensus Voting for developing the IPDAS Checklist (n=83 criteria from 12 dimensions)

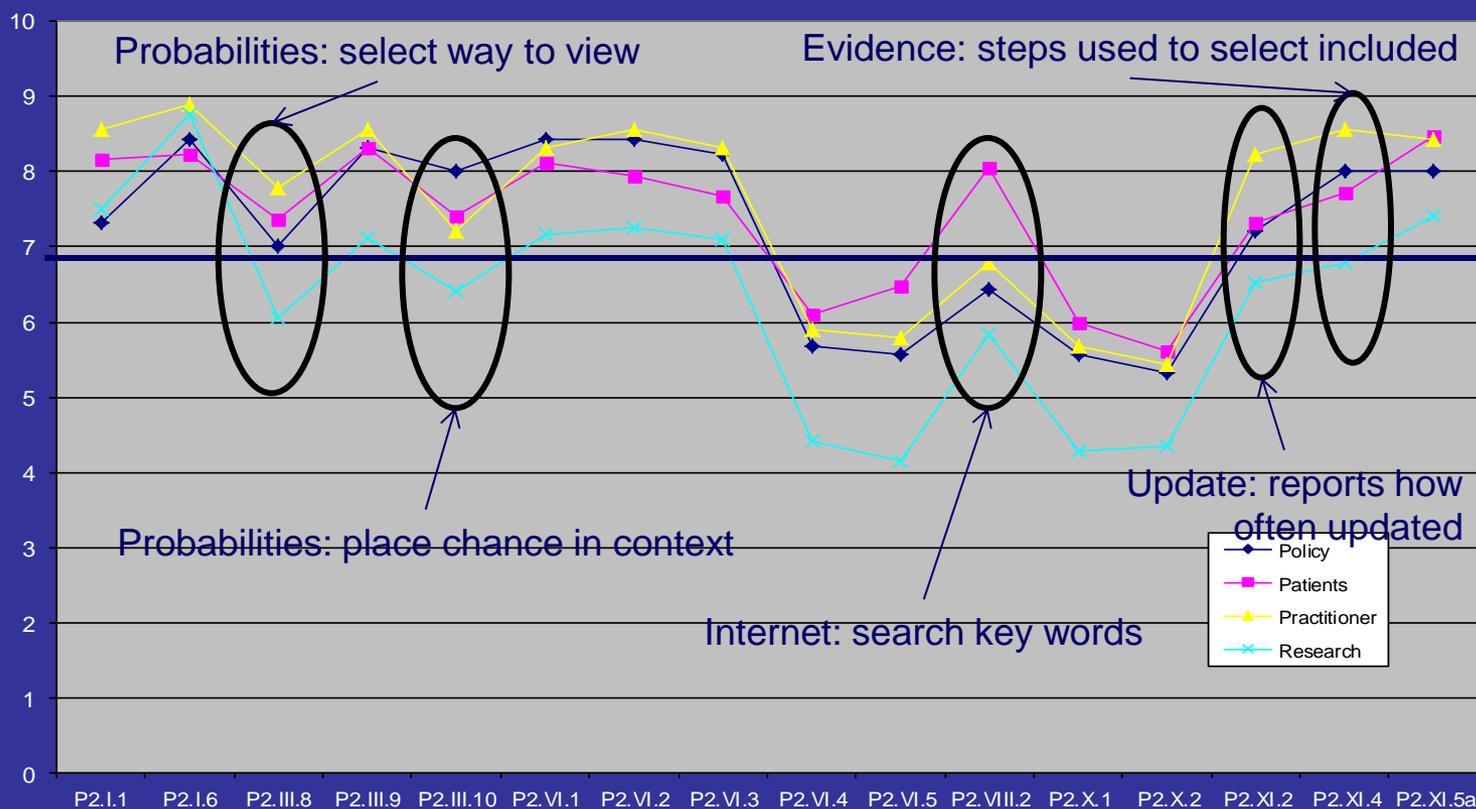
Example of a voting screen for one criterion





# Results

Only 5/16 criteria with differences between stakeholders, had medians that straddled threshold for inclusion





# IPDAS Checklist

74 items in 11 dimensions checked Yes/No  
(based on equimedean rating of 7 to 9 without disagreement)

**Table 3. IPDAS Patient Decision Aid Checklist for Users**

## **I. Content: Does the patient decision aid ...**

### **Provide information about options in sufficient detail for decision making?**

- describe the health condition 2.1
- list the options 2.2
- list the option of doing nothing 2.3
- describe the natural course without options 2.4
- describe procedures 2.5
- describe positive features [benefits] 2.6
- describe negative features of options [harms / side effects / disadvantages] 2.7
- include chances of positive / negative outcomes 2.8

### **Additional items for tests**

- describe what test is designed to measure 2.9
- include chances of true positive, true negative, false positive, false negative test results 2.10
- describe possible next steps based on test result 2.11
- include chances the disease is found with / without screening 2.12
- describe detection / treatment that would never have caused problems if one was not screened 2.13

### **Present probabilities of outcomes in an unbiased and understandable way?**

- use event rates specifying the population and time period 3.1
- compare outcome probabilities using the same denominator, time period, scale 3.2, 3.3, 3.6
- describe uncertainty around probabilities 3.4
- allows the patient to select a way of viewing probabilities [words, numbers, diagrams] 3.8
- allow patient to view probabilities based on their own situation [e.g. age] 3.9
- place probabilities in context of other events 3.10

## Developing a quality criteria framework for patient decision aids: online international Delphi consensus process

Glyn Elwyn, Annette O'Connor, Dawn Stacey, Robert Volk, Adrian Edwards, Angela Coulter, Richard Thomson, Alexandra Barratt, Michael Barry, Steven Bernstein, Phyllis Butow, Aileen Clarke, Vikki Entwistle, Deb Feldman-Stewart, Margaret Holmes-Rovner, Hilary Llewellyn-Thomas, Nora Moumjid, Al Mulley, Cornelia Ruland, Karen Sepucha, Alan Sykes, Tim Whelan, on behalf of the International Patient Decision Aids Standards (IPDAS) Collaboration

### Abstract

**Objective** To develop a set of quality criteria for patient decision support technologies (decision aids).

**Design and setting** Two stage web based Delphi process using online rating process to enable international collaboration.

**Participants** Individuals from four stakeholder groups (researchers, practitioners, patients, policy makers) representing 14 countries reviewed evidence summaries and rated the importance of 80 criteria in 12 quality domains on a 1 to 9 scale. Second round participants received feedback from the

than replace patient-practitioner interaction. They may be leaflets, interactive media, or video or audio tapes. Patients may use them to prepare for talking with a clinician, or a clinician may provide them at the time of a visit to facilitate decision making. At a minimum, patient decision aids provide information about the options and their associated relevant outcomes. These technologies also help patients to personalise this information, to understand that they can be involved in choosing among the various options, to appreciate the scientific uncertainties inherent in that choice, to clarify the personal value or desirability of potential benefits relative to potential harms, to communi-



# IPDAS Phases

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# Developing the Instrument IPDASi

To develop, validate and report the inter-rater reliability of an instrument designed to measure the quality of patient decision support tools

Stage 1 Refinement and preparation of instrument (version 1)

Stage 2 Confirmation of items (version 2)

Stage 3 Validation Study (version 3)

# IPDASi uses a 4-point scale with items descriptors (strongly agree to strongly disagree)



## IPDASi Scoring System: Quality Domain Items

Unique Rating Id No: 164

PDST: TEST

Rated By: Glyn Elwyn

Start Date: 12 October 2008

Completion Date: In Progress

[Sign Out](#) [Exit Rating](#)

This PDST does not consider an investigation or a screening procedure

[Change](#)

### Domain Areas

- Information ▶
- NA Test ▶
- Probabilities** ▶
- Values ▶
- Guidance ▶
- Development ▶
- Evidence ▶
- Disclosure ▶
- Plain Language ▶
- Evaluation ▶

**Domain: Probabilities** - Presenting outcome probabilities

**Statement 1. The decision support technology provides information about outcome probabilities associated with the options (i.e. the likely consequences of decisions)**

<input type="radio"/> Strongly Agree	The decision support technology clearly presents probabilities for stated outcomes or highlights the uncertainty surrounding them and/or lack of available data
<input type="radio"/> Agree	Use this rating if you think the decision support technology fulfils the criterion but there is room for improvement
<input type="radio"/> Disagree	Use this rating if you do not think that the decision support technology fulfils this criterion or if unclear
<input type="radio"/> Strongly Disagree	There is no reference to the magnitude (absolute or relative) of the likelihood of positive or negative outcomes

Please add Comments  
or Suggestions to  
improve the item:



# IPDASi Validation Study

## Methods:

Two trained and calibrated raters independently appraised:

- 15 decision aids from five major producers
  - Healthwise (n=3)
  - Mayo Clinic (n=3)
  - Midwives Information and Resource Service (n=3)
  - Ottawa Patient Decision Aid Research Group (n=3)
  - Informed Medical Decisions Foundation (n=3)
- 15 decision aids randomly selected from Cochrane Inventory

## Findings:

After adjusting for hawks/doves IPDASi (47 items)

- 33 to 82 (0-100) averaged scores for decision aids
- 0.80 Intraclass correlation (weighted overall score)
- 0.72-0.93 Cronbach's alpha values for the 8 raters

# IPDASi Criteria

IPDASi version	IPDASi v3	IPDASi SF
# of items	47	19
Assessors/Raters	Cardiff: MA-D, MS, NJ, SS; North America: SK, ED, AS, MP.	Cardiff: MA-D, MS, NJ, SS; North America: SK, ED, AS, MP.
# of DSTs evaluated	30	30
Dimensions		
Information	8	4
Probabilities	8	3
Values	4	1
Decision Guidance	2	-
Development	6	3
Evidence	5	2
Disclosure	2	1
Plain Language	1	-
Evaluation	2	2
Test	9	3

# Assessing the Quality of Decision Support Technologies Using the International Patient Decision Aid Standards instrument (IPDASi)

Glyn Elwyn<sup>1\*</sup>, Annette M. O'Connor<sup>2</sup>, Carol Bennett<sup>2</sup>, Robert G. Newcombe<sup>1</sup>, Mary Politi<sup>4</sup>, Marie-Anne Durand<sup>1</sup>, Elizabeth Drake<sup>2</sup>, Natalie Joseph-Williams<sup>1</sup>, Sara Khangura<sup>2</sup>, Anton Saarimaki<sup>2</sup>, Stephanie Sivell<sup>1</sup>, Mareike Stiel<sup>1</sup>, Steven J. Bernstein<sup>5</sup>, Nananda Col<sup>6</sup>, Angela Coulter<sup>7</sup>, Karen Eden<sup>8</sup>, Martin Härter<sup>9</sup>, Margaret Holmes Rovner<sup>10</sup>, Nora Moumjid<sup>11</sup>, Dawn Stacey<sup>3</sup>, Richard Thomson<sup>12</sup>, Tim Whelan<sup>13</sup>, Trudy van der Weijden<sup>14</sup>, Adrian Edwards<sup>1</sup>

**1** Department of Primary Care and Public Health, School of Medicine and the School of Psychology, Cardiff University, Cardiff, United Kingdom, **2** Ottawa Health Research Institute, University of Ottawa, Ottawa, Ontario, Canada, **3** School of Nursing, University of Ottawa, Ottawa, Ontario, Canada, **4** W. Alpert Medical School, Brown University, Centers for Behavioural and Preventive Medicine, Providence, Rhode Island, **5** Department of Internal Medicine, University of Michigan, Ann Arbor, Michigan, United States of America, **6** Maine Medical Center, Center for Outcomes Research and Evaluation, Portland, Maine, United States of America, **7** Picker Institute Europe, King's Mead House, Oxford, United Kingdom, **8** John M. Eisenberg Clinical Decisions and Communications Science Center, Department of Medical Informatics and Clinical Epidemiology, Oregon Health&Science University, Portland, Oregon, United States of America, **9** Institute and Policlinic for Medical Psychology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany, **10** Center for Ethics, College of Human Medicine, Michigan State University, East Lansing, Michigan, United States of America, **11** Centre Léon Bérard, University of Lyon, Lyon, France, **12** Institute of Health and Society, Medical School, Framlington Place, University of Newcastle, Newcastle upon Tyne, United Kingdom, **13** Department of Oncology, McMaster University, Juravinski Cancer Centre, Hamilton Ontario, Canada, **14** Department General Practice, School for Public Health and Primary Care (CAPHRI), Maastricht University, Maastricht, the Netherlands

## Abstract

**Objectives:** To describe the development, validation and inter-rater reliability of an instrument to measure the quality of patient decision support technologies (decision aids).

**Design:** Scale development study, involving construct, item and scale development, validation and reliability testing.

**Setting:** There has been increasing use of decision support technologies – adjuncts to the discussions clinicians have with patients about difficult decisions. A global interest in developing these interventions exists among both for-profit and not-for-profit organisations. It is therefore essential to have internationally accepted standards to assess the quality of their development, process, content, potential bias and method of field testing and evaluation.



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| 2014-2017 | Reporting guidelines                            |

# Toward Minimum Standards for Certifying Patient Decision Aids: A Modified Delphi Consensus Process

*Natalie Joseph-Williams, GDipPsych, Robert Newcombe, PhD, Mary Politi, PhD, Marie-Anne Durand, PhD, Stephanie Sivell, MPhil, Dawn Stacey, PhD, Annette O'Connor, PhD, Robert J. Volk, PhD, Adrian Edwards, PhD, Carol Bennett, MSc, Michael Pignone, MPH, Richard Thomson, MD, Glyn Elwyn, PhD*

## Process:

1. Delphi consensus 2-round voting on: “If the criterion was not present or of low quality, there would be a risk of harmful bias and a potential negative impact on patients’ decision making (127 with some patient decision aid experience voted from 16 countries)
2. Expert committee considered results from
  - Vote on risk of harmful bias
  - Qualitative comments of voters
  - Original IPDAS rating
  - IPDASi trained raters’ comments on feasibility



# IPDAS v4.0

## Items across the 3 Categories

Dimensions	# of Criteria / Category		
	Qualifying	Certification	Quality
Information	5	1	2
Probabilities			6
Values	1		1
Guidance			2
Development			6
Evidence		4	2
Disclosure		1	1
Plain Language			1
Evaluation			2
Test		4	5
<b>Totals</b>	<b>6</b>	<b>10</b>	<b>28</b>



# Summary of qualifying criteria

1. describes the health condition or problem
2. explicitly states the decision that needs to be considered
3. describes the options available
4. describes the positive features
5. describes the negative features
6. describes what it is like to experience the consequences



# Summary of certifying criteria

1. equal detail for negative and positive features of options
2. citations to the evidence
3. production or publication date
4. update policy
5. information about uncertainty around probabilities
6. funding source used for development

## For screening decision aids

7. describes what the test is designed to measure
8. next steps after positive test result
9. next steps after negative test result
10. consequences of detecting a benign condition



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# 2012 Update of the IPDAS Collaboration Background Document



## International Patient Decision Aid Standards (IPDAS) Collaboration

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### Resources

#### 2012 Update of the IPDAS Collaboration Background Document

[Introduction](#)

[Chapter A: Using a Systematic Development Process](#)

[Chapter B: Providing Information About Options](#)

[Chapter C: Presenting Probabilities](#)

[Chapter D: Clarifying and Expressing Values](#)

[Chapter E: Using Personal Stories](#)

[Chapter F: Guiding / Coaching in Deliberation and Communication](#)

[Chapter G: Disclosing Conflicts of Interest](#)

[Chapter H: Delivering Decision Aids on the Internet](#)

[Chapter I: Balancing The Presentation of Information and Options](#)

[Chapter J: Addressing Health Literacy](#)

[Chapter K: Basing Information On Comprehensive, Critically Appraised, And Up-To-Date](#)

[Syntheses Of The Scientific Evidence](#)

[Chapter L: Establishing the Effectiveness](#)

[\*\*Implementation of Patient Decision Support Interventions into Routine Clinical Practice: A Systematic Review\*\*](#)

# 2013 Peer-reviewed Publications for IPDAS Collaboration's Quality Dimensions

The screenshot shows the BMC Medical Informatics & Decision Making journal website. At the top left is the BMC logo. To its right is the journal title 'BMC Medical Informatics & Decision Making' and an orange 'IMPACT FACTOR 1.60' badge. Below the title is a navigation bar with buttons for 'Home', 'Articles', 'Authors', 'Reviewers', 'About this journal', and 'My BMC Medical Informatics and Decision Making'. The main content area is titled 'Articles' and has a sub-navigation bar with 'All articles', 'Sections', 'Most viewed', 'Archive', and 'Supplements'. The 'Supplements' tab is active. Below this is a paragraph of text: 'BMC Medical Informatics and Decision Making publishes selected collections of research articles, conference proceedings, reviews and reports as supplements, which are free to access online. All articles published in supplements are subject to peer review; meeting abstracts undergo review and selection by the conference. [Find out more](#) about publishing a supplement with BioMed Central.' This is followed by the heading 'Volume 13 Supplement 2' and the article title 'The International Patient Decision Aid Standards (IPDAS) Collaboration's Quality Dimensions: Theoretical Rationales, Current Evidence, and Emerging Issues'. Below the title is the section 'Reviews' and a paragraph: 'The International Patient Decision Aid Standards (IPDAS) Collaborations Quality Dimensions: Theoretical Rationales, Current Evidence, and Emerging Issues', 'Rockville, MD, USA', '13 September 2012', and 'Edited by Robert Volk, Hilary Llewellyn-Thomas, Dawn Stacey and Glyn Elwyn'. Another paragraph states: 'Publication of this supplement was partially funded by an unrestricted grant from the Informed Medical Decisions Foundation. Details of the remaining publication funding can be found in the individual articles. The articles have undergone the journal's standard peer review process for supplement articles. The Supplement Editors declare that they have no competing interests.' Below this is the 'Introduction' section with an 'Open Access' badge and the text: 'Ten years of the International Patient Decision Aid Standards Collaboration: evolution of the core dimensions for assessing the quality of patient decision aids'. At the bottom of the introduction is the citation: 'Robert J Volk, Hilary Llewellyn-Thomas, Dawn Stacey, Glyn Elwyn. BMC Medical Informatics and Decision Making 2013, 13(Suppl 2):S1 (29 November 2013)'. At the very bottom are links for 'Abstract | Full text | PDF'.

BMC Medical Informatics and Decision Making 2013, 13(Suppl 2).

<http://www.biomedcentral.com/bmcmmedinformdecismak/supplements/13/S2>



# Summary of 2013 findings

More emphasis on:

1. Quality of the evidence

- For example, use GRADE

2. Disclosures of actual/potential conflict of interest

- For example, report that no funding to develop or exclusively distribute has been received from commercial for profit entities that sell options in the PtDA



# IPDAS Phases

- 2003-2006 IPDAS Checklist
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- 2014-2017 Reporting guidelines

# IPDAS Uptake & Impact

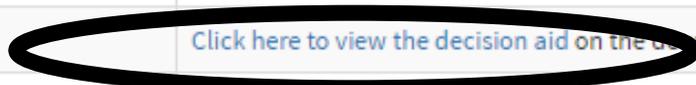
- Citations
  - 994 IPDAS Checklist (Elwyn et al 2006)
  - 241 IPDASi (Elwyn et al 2009)
  - 76 IPDAS Minimal Standards (Joseph-Williams et al 2014)
  - 78 Ten Years of IPDAS Collaboration (Volk et al 2013)

(Google Scholar August 10, 2017)



<b>Title</b>	<b>La vasectomie: Est-ce le bon choix pour moi? Un outil d'aide a la decision.</b>
<b>Audience</b>	Men and couples considering vasectomy.
<b>Options included</b>	Vasectomy. Tubal ligation. Condoms. Coitus interruptus. Oral contraceptives. IUD. Abstinence.
<b>Year of last update or review</b>	2016
<b>Format</b>	Web, paper, PDF
<b>How to obtain</b>	<a href="#">Click here to view the decision aid on the developer website</a>
<b>Developer</b>	Michel Labrecque
<b>Where was it developed?</b>	infovasectomie@videotron.ca University of Laval, Quebec City Canada
<b>Health condition</b>	Birth control
<b>Type of decision aid</b>	Treatment
<b>Language</b>	French

A to Z Decision Aid Inventory uses IPDAS <http://decisionaid.ohri.ca>



Note: The OHRI Patient Decision Aids site is not part of IPDAS. It uses the IPDAS criteria to rate aids listed in the Inventory.

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

 7 out of 7 criteria to be defined as a patient decision aid

 5 out of 9 criteria to lower the risk of making a biased decision

## 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



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## National Standards for the Certification of Patient Decision Aids

Date of Publication: DEC 2016  
Associated Project: [Decision Aids](#)

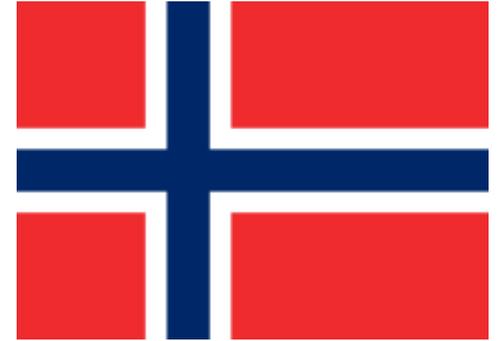
[Download the Publication](#)

### Abstract

As patients take a more active role in making decisions about their healthcare, many use decision aids. Decision aids are evidence-based tools designed to inform patients about their options (including known pros and cons) and help them to participate in making specific, deliberate choices among viable healthcare options. Decision aids facilitate shared decision making which has been shown to improve patient outcomes. However, several barriers impede widespread use, including the lack of national standards for the quality of decision aids. To address this issue, the National Quality Forum, through a grant from the Gordon and Better Moore Foundation, convened a multistakeholder Expert Panel to recommend criteria for the certification of decision aids. The Panel also created recommendations on how performance measurement can be used to incentivize the use of shared decision making. To support this work commissioned a white paper from the Dartmouth Institute for Health Policy & Clinical Practice to summarize previous efforts and propose options for national standards for decision aids and conducted an environmental scan of performance measures and instruments related to assessing SDM quality. The report summarizes the Expert Panel's recommendations.

Proposed certification criteria are based on IPDAS

## Norway is using IPDAS



- In December 2016, the Norwegian Health Directorate used the IPDAS standards to establish a set of quality criteria for approving patients decision aids prior to being added to the Norwegian health platform.
- All Norwegians and health care professionals have access to resources on this health platform.

<https://helsedirektoratet.no/nasjonale-kvalitetskrav-til-samvalgsverktoy-som-skal-publiseres-pa-helsenorgeno>

ipdas.ohri.ca has >16,000 visitors per year  
generating 60,000 page views and 42,000 downloads



## International Patient Decision Aid Standards (IPDAS) Collaboration

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The **International Patient Decision Aid Standards (IPDAS)** Collaboration is a group of researchers, practitioners and stakeholders from around the world that was established in 2003. The IPDAS Collaboration is lead by professors Glyn Elwyn in the United Kingdom and Dawn Stacey in Canada.

### What is the purpose?

To enhance the quality and effectiveness of patient decision aids by establishing a shared evidence-informed framework with a set of criteria for improving their content, development, implementation, and evaluation. These criteria are helpful to a wide variety of individuals and organizations that use and/or develop patient decision aids. For example:

- Patients or other individuals who are making a health decision;
- Practitioners guiding patients in making health decisions;
- Developers of patient decision aids;
- Researchers or evaluators of patient decision aids;
- Policy makers or payers of patient decision aids.

### Why are standards needed?

There are over 500 patient decision aids available or being developed by many different individuals and groups around the world. However, people have difficulty knowing whether or not a decision aid is a source of reliable health information that can help in decision making.

## Website requests:

- Translate IPDAS
- Advice on:
  - developing PtDAs
  - reviewing PtDAs
  - Certifying PtDAs
- Pediatric-specific criteria



## For discussion

- What suggestions do you have for new IPDAS initiatives?
- How might you want to be involved?