



The IPDAS Story 2003-2013

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

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 Developing the Checklist

2006-2009 Developing the Instrument

2009-2013 Agreeing Minimal Standards

2011-2013 Updating evidence underlying
the IPDAS checklist



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



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.

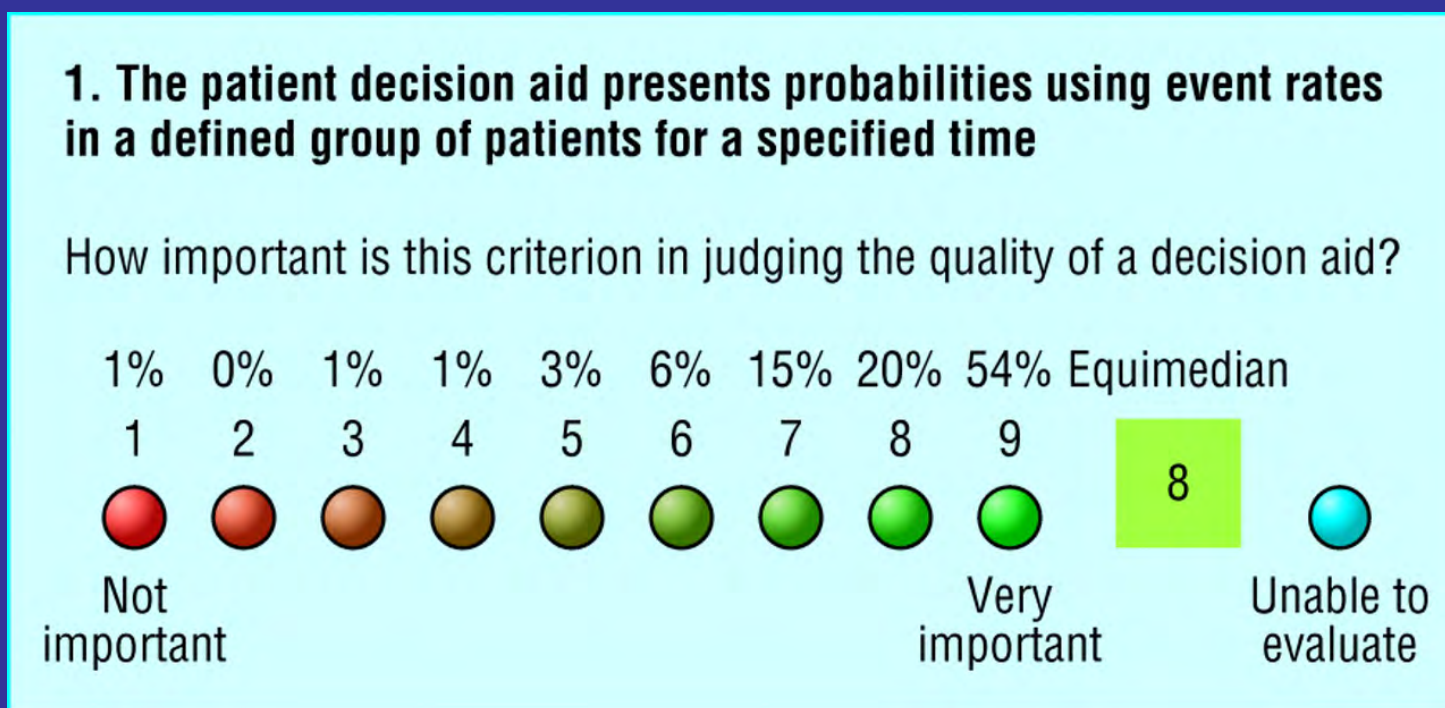
How might this affect the quality of decision making? In theory, decision aids may lead to poor decisions if they are developed by people who do not have the knowledge and skills to understand the decision situation and to help patients make decisions. Even qualified people may not design a good decision 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)

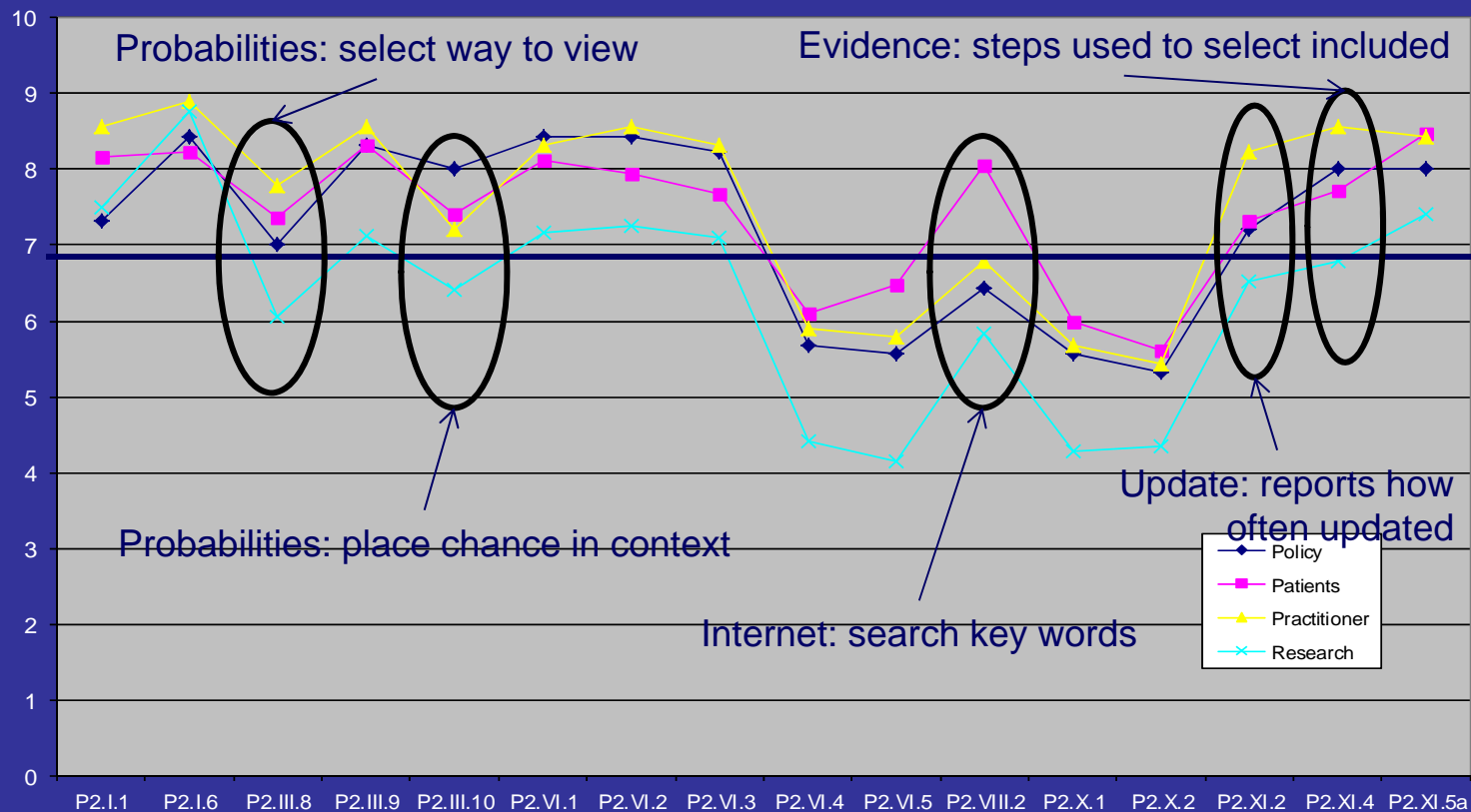
Example of a voting screen for one criterion





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-

Use: A to Z Decision Aid Inventory

<http://decisionaid.ohri.ca>

Birth Control

- [Birth Control Guide](#) Mayo Clinic
- [La vasectomie: Est-ce le bon choix pour moi? Un outil d'aide a la decision](#) University of Laval, Quebec City

Decision Aid Summary

Title	Birth Control Guide
Health Condition	Birth Control
Type of Decision Aid	Treatment
Options Included	Condoms and other barrier methods The pill and other hormonal contraceptives Intrauterine device (IUD) Natural Family Planning Sterilization Withdrawal Emergency Birth Control Emerging methods
Audience	Individuals considering birth control options
Developer	Mayo Clinic
Where was it developed?	www.mayoclinic.com Mayo Clinic US
Year of last update or review	2010
Format	Web, paper
Language(s)	english
How to obtain the decision aid	Internet Web site Available here.

The [IPDAS](#) assessment of this decision aid indicates that it meets:

	14 out of 15 of the content criteria
	3 out of 9 of the development process criteria
	0 out of 2 of the effectiveness criteria

Decision Aid Summary

Title	La vasectomie: Est-ce le bon choix pour moi? Un outil d'aide a la decision
Health Condition	Birth control
Type of Decision Aid	Treatment
Options Included	Vasectomy Tubal ligation Condoms Coitus interruptus Oral contraceptives IUD Abstinence
Audience	Men and couples considering vasectomy
Developer	Michel Labrecque
Where was it developed?	infovasectomie@videotron.ca University of Laval, Quebec City Canada
Year of last update or review	2007
Format	Web, paper, PDF
Language(s)	french
How to obtain the decision aid	Go to www.vasectomie.net to download or print the decision aid. Available here.

The [IPDAS](#) assessment of this decision aid indicates that it meets:

	15 out of 15 of the content criteria
	6 out of 9 of the development process criteria
	1 out of 2 of the effectiveness criteria



IPDAS Phases

2003-2006 Developing the Checklist

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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^{1*}, Annette M. O'Connor², Carol Bennett², Robert G. Newcombe¹, Mary Politi⁴, Marie-Anne Durand¹, Elizabeth Drake², Natalie Joseph-Williams¹, Sara Khangura², Anton Saarimaki², Stephanie Sivell¹, Mareike Stiel¹, Steven J. Bernstein⁵, Nananda Col⁶, Angela Coulter⁷, Karen Eden⁸, Martin Härter⁹, Margaret Holmes Rovner¹⁰, Nora Moumjid¹¹, Dawn Stacey³, Richard Thomson¹², Tim Whelan¹³, Trudy van der Weijden¹⁴, Adrian Edwards¹

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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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

Objective. The IPDAS Collaboration has developed a checklist and an instrument (IPDASi v3.0) to assess the quality of patient decision aids (PDAs) in terms of their development process and shared decision-making design components. Certification of PDAs is of growing interest in the US and elsewhere. We report a modified Delphi consensus process to agree on IPDASi (v3.0) items that should be considered as minimum standards for PDA certification, for inclusion in the refined IPDASi (v4.0). **Methods.** A 2-stage Delphi voting process considered the inclusion of IPDASi (v3.0) items as minimum standards. Item scores and qualitative comments were analyzed, followed by expert group discussion. **Results.** One hundred and one people voted in round 1; 87 in round 2. Forty-seven items were reduced to 44 items across 3 new categories: 1) qualifying criteria, which are required in order for an

intervention to be considered a decision aid (6 items); 2) certification criteria, without which a decision aid is judged to have a high risk of harmful bias (10 items); and 3) quality criteria, believed to strengthen a decision aid but whose omission does not present a high risk of harmful bias (28 items). **Conclusions.** This study provides preliminary certification criteria for PDAs. Scoring and rating processes need to be tested and finalized. However, the process of appraising the quality of the clinical evidence reported by the PDA should be used to complement these criteria; the proposed standards are designed to rate the quality of the development process and shared decision-making design elements, not the quality of the PDA's clinical content. **Key words:** outcomes research; decision aid research; patient decision making; shared decision making. (*Med Decis Making* XXXX;XX:XXX-XXX)



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
Totals	6	10	28



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

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[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 'IMPACT FACTOR 1.60' badge. Below the journal 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'. Below this is a paragraph explaining that the journal publishes research articles, conference proceedings, reviews, and reports as supplements, which are free to access online. The main article is titled 'Volume 13 Supplement 2' and 'The International Patient Decision Aid Standards (IPDAS) Collaboration's Quality Dimensions: Theoretical Rationales, Current Evidence, and Emerging Issues'. It lists the authors: Robert J Volk, Hilary Llewellyn-Thomas, Dawn Stacey, and Glyn Elwyn. The publication date is 13 September 2012. The article is available as an Open Access publication. The full citation is: BMC Medical Informatics and Decision Making 2013, 13(Suppl 2):S1 (29 November 2013). Links for 'Abstract', 'Full text', and 'PDF' are provided at the bottom.

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Volume 13 Supplement 2

The International Patient Decision Aid Standards (IPDAS) Collaboration's Quality Dimensions: Theoretical Rationales, Current Evidence, and Emerging Issues

Reviews

The International Patient Decision Aid Standards (IPDAS) Collaborations Quality Dimensions: Theoretical Rationales, Current Evidence, and Emerging Issues

Rockville, MD, USA

13 September 2012

Edited by Robert Volk, Hilary Llewellyn-Thomas, Dawn Stacey and Glyn Elwyn

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.

Introduction [Open Access](#)

Ten years of the International Patient Decision Aid Standards Collaboration: evolution of the core dimensions for assessing the quality of patient decision aids

Robert J Volk, Hilary Llewellyn-Thomas, Dawn Stacey, Glyn Elwyn
BMC Medical Informatics and Decision Making 2013, **13**(Suppl 2):S1 (29 November 2013)

[Abstract](#) | [Full text](#) | [PDF](#)

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

More information: ipdas.ohri.ca



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.