IPDAS Deliverables, Impact, & Next Steps
2003-2017

IPDAS Steering Committee:
Dawn Stacey/Pending (Co-Leads),
M Barry, N Col, A Coulter, M Härter,
V Montori, N Moumjid, M Pignone, R Thomson,
L Trevena, R Volk, T van der Weijden
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.
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
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
2006-2009  IPDASi Instrument
2009-2013  IPDAS Minimal Standards
2011-2013  Updated evidence underlying the IPDAS Checklist
2014-2017  Reporting guidelines
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

To learn more, visit: ipdas.ohri.ca

>100 participants from 14 countries

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

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

1. The patient decision aid presents probabilities using event rates in a defined group of patients for a specified time

How important is this criterion in judging the quality of a decision aid?

1%  0%  1%  1%  3%  6%  15%  20%  54%  Equimedian

Not important  Very important  Unable to evaluate

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

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 | Additional items for tests |
| □ list the options 2.2 | □ describe what test is designed to measure 2.9 |
| □ list the option of doing nothing 2.3 | □ include chances of true positive, true negative, false positive, false negative test results 2.10 |
| □ describe the natural course without options 2.4 | □ describe possible next steps based on test result 2.11 |
| □ describe procedures 2.5 | □ include chances the disease is found with / without screening 2.12 |
| □ describe positive features [benefits] 2.6 | □ describe detection / treatment that would never have caused problems if one was not screened 2.13 |
| □ describe negative features of options [harms / side effects / disadvantages] 2.7 | |
| □ include chances of positive / negative outcomes 2.8 | |

Present probabilities of outcomes in an unbiased and understandable way?

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

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

<table>
<thead>
<tr>
<th>IPDASi version</th>
<th>IPDASi v3</th>
<th>IPDASi SF</th>
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<td>Decision Guidance</td>
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<tr>
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<td>2</td>
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<tr>
<td>Test</td>
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</table>

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

Glyn Elwyn¹, 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 Coi⁶, Angela Coulter⁷, Karen Eden⁸, Martin Härter⁹, Margaret Holmes Rovner¹⁰, Nora Mounjd⁰¹¹, Dawn Stacey³, Richard Thomson¹², Tim Whelan¹³, Trudy van der Weijden¹⁴, Adrian Edwards¹

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

<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
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<tbody>
<tr>
<td>2003-2006</td>
<td>IPDAS checklist</td>
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<td>2006-2009</td>
<td>IPDASi instrument</td>
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<td>IPDAS minimal standards</td>
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<td>2011-2013</td>
<td>Updated evidence underlying the IPDAS checklist</td>
</tr>
<tr>
<td>2014-2017</td>
<td>Reporting guidelines</td>
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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

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

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Qualifying</th>
<th>Certification</th>
<th>Quality</th>
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<td><strong>Totals</strong></td>
<td><strong>6</strong></td>
<td><strong>10</strong></td>
<td><strong>28</strong></td>
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</tbody>
</table>

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

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

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 Yok, Hilary Llewellyn-Thomas, Dawn Stacey and Glyn Elwyn

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Introduction
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 Yok, Hilary Llewellyn-Thomas, Dawn Stacey, Glyn Elwyn
BMC Medical Informatics and Decision Making 2013, 13(Suppl 2):51 (39 November 2013)
Abstract | Full text | PDF
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
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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)
### Decision Aid Summary

<table>
<thead>
<tr>
<th>Title</th>
<th>La vasectomie: Est-ce le bon choix pour moi? Un outil d'aide à la decision.</th>
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<td><strong>Audience</strong></td>
<td>Men and couples considering vasectomy.</td>
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<td><strong>Year of last update or review</strong></td>
<td>2016</td>
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<tr>
<td><strong>Format</strong></td>
<td>Web, paper, PDF</td>
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<tr>
<td><strong>How to obtain</strong></td>
<td>Click here to view the decision aid on the developer website</td>
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<tr>
<td><strong>Developer</strong></td>
<td>Michel Labrecque</td>
</tr>
<tr>
<td><strong>Where was it developed?</strong></td>
<td><a href="mailto:infovasectomie@videotron.ca">infovasectomie@videotron.ca</a> University of Laval, Quebec City Canada</td>
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<td><strong>Type of decision aid</strong></td>
<td>Treatment</td>
</tr>
<tr>
<td><strong>Language</strong></td>
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</tr>
</tbody>
</table>

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

[Link to Norwegian quality criteria for patient decision aids](https://helsedirektoratet.no/nasjonale-kvalitetskrav-til-samvalgsverktoy-som-skal-publiseres-pa-helsenorgen)
ipdas.ohri.ca has >16,000 visitors per year generating 60,000 page views and 42,000 downloads.

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?