International Patient Decision Aids Standards Collaboration

The IPDAS Story
2003-2013

Glyn Elwyn
International Patient Decision Aid Standards (IPDAS) Collaboration

Purpose

To enhance the quality of patient decision support tools by establishing an evidence-informed framework for improving their content, development, implementation, and evaluation.
Three IPDAS Phases

*Phase 1* 2003-2006
*Developing the Checklist*

*Phase 2* 2006-2009
*Developing the IPDAS Instrument*

*Phase 3* 2009-2012
*Agreeing Minimal Standards*
International Patient Decision Aid Standards Collaboration

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

2006
Phase I
Developing the Checklist

Goal
Establish internationally approved criteria to determine the quality of patient decision support tools. Over 100 participants, 14 countries.

– Patients
– Practitioners
– Developers
– Researchers
– Policy makers or payers
Modified Delphi consensus voting for developing the IPDAS Checklist

Summarized evidence to inform voters

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
1 2 3 4 5 6 7 8 9

Not important Very important Unable to evaluate
IPDAS Checklist Areas

**Essential Content**
- Information
- Probabilities
- Preferences clarification
- Guidance
- **Patient Narratives**

**Effectiveness Criteria**
- Decision process
- Decision quality

**Generic Criteria**
- Development process
- Disclosure
- Internet delivery
- Balance
- Plain language
- Up to date evidence
# IPDAS Checklist

74 items in 11 broad domains

## 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

### 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

### 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

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*Elwyn et al., 2006 BMJ 333:417*
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, 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.

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 desirabil
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Phase 2
Developing the IPDAS Instrument

To develop, validate and report the 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)
Developed a 4-point Scale with Definitions for Each Item (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

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)

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

Please add Comments or Suggestions to improve the item:
IPDAS Instrument Study

Results

Two calibrated assessors independently appraised 30 tools

After adjusting for hawks/doves (using 47 items)

• Quality scores from 33 to 82 (possible 0-100)

• 0.72-0.93 Cronbach’s alpha values for the 8 raters

• Database of 60 tools assessed with IPDAS instrument
Assessing the Quality of Decision Support Technologies Using the International Patient Decision Aid Standards instrument (IPDASi)

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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.
Three IPDAS Phases

Phase 1 2003-2006
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*Phase 3 2009-2012
Agreeing Minimal Standards*
Challenges for certification

• Assessing the quality of evidence synthesis

• Setting thresholds for acceptable / unacceptable quality for use by patients

• Multiple formats of patient decision support, especially short tools designed for face-to-face use by clinicians
Phase 3
Minimum Standards

47 IPDAS instrument items were reduced to 44 items in 3 new categories

1) Qualifying criteria (6 items)
2) Certification criteria (10 items)
3) Quality criteria (28 items).

Toward minimum standards for certifying patient decision aids: a modified Delphi consensus process and correlation analysis
Qualifying Criteria

The tool

1. Describes the health condition or problem (treatment, procedure or investigation) for which the index decision is required
2. Explicitly states the decision that needs to be considered (index decision)
3. Describes the options available for the index decision.
4. Describes the positive features (benefits or advantages) of each option
5. Describes the negative features (harms, side effects, or disadvantages) of each option
6. Describes what it is like to experience the consequences of the options e.g. social physical, psychological
Certifying Criteria
The tool or associated documentation

1. Shows the negative and positive features of options with equal detail (for example, using similar fonts, sequence, presentation of statistical information).
2. Provides citations to the studies selected.
3. Provides a production or publication date.
4. Provides information about the update policy.
5. Provides information about the levels of uncertainty around event or outcome probabilities (e.g. by giving a range or by using phases such as “our best estimate is…”).
6. Provides information about the funding source used for development.

For Tests or Screening Topics
7. Describes what the test is designed to measure.
8. If the test detects the condition or problem, the patient decision aid describes the next steps typically taken.
9. Describes the next steps if the condition or problem is not detected.
10. Has information about the consequences of detecting the condition or disease that would never have caused problems if screening had not been done (lead time bias)