



International Patient Decision Aid Standards (IPDAS) Collaboration

IPDAS 2005: Criteria for Judging the Quality of Patient Decision Aids

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What are patient decision aids and why are they needed?

Patient decision aids are tools to help people participate in their health decisions in ways they prefer. They are used when there is more than one medically reasonable option to diagnose or treat a health problem. Each of the options has good and bad features that people value differently. Even when two people are in the same situation, what is important for one person may be different for another person. Therefore, there is no clear answer that applies to everyone. The best choice involves matching which features matter most to a person with the option that has these features. To make a good decision, you need an expert on the facts (e.g. a health practitioner) and an expert on which features matter most (e.g. the patient) and a way to share their views with each other in ways they prefer.

Patient decision aids aim to do three things to prepare a person for decision making. They provide facts about a person's condition, the options and their features. They help people to clarify their values (the features that matter most to them). They help people to share their values with their health care practitioner and others, so a course of action can be planned that matches their values. Patient decision aids do not advise people to choose one option over another. They do not replace counseling from a health care practitioner. Instead, they prepare people to discuss the options with their health care practitioner.

An international group of researchers, known as the 'Cochrane Review Team of Patient Decision Aids' is compiling decision aids and summarizing the results of research trials. The latest review of 34 studies shows that patients and practitioners who use patient decision aids make better decisions. Patients participate more, know more, and have more realistic expectations of what might happen. They are more likely to receive an option with features they most value (O'Connor et al., *Cochrane Library*, 2003).

The **International Patient Decision Aid Standards (IPDAS)** Collaboration is a group of researchers, practitioners and stakeholders from around the world. The goal is to establish an internationally approved set of criteria to determine the quality of patient decision aids. These criteria will be helpful to a wide variety of individuals and organizations that use and/or develop 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.

How were the standards obtained?

There was a 2-stage evidence-informed Delphi consensus process

- Participants included 122 people from 14 countries and 4 stakeholder groups [researchers/developers; health professionals/ patient/consumers; policy makers/health plan administrators]
- A voting document was developed from a series of background papers on 12 quality domains. [The experts who wrote these papers are listed above]. Before voting on the importance of each criterion in judging the quality of a patient decision aid, voters reviewed: definition of decision aids; definition of criterion; theoretical link between criterion and decision quality; and empirical evidence supporting or not supporting its use in decision aids. Evidence was derived from fundamental studies and a Cochrane Collaboration systematic review of randomized trials of patient decision aids.

The standards are summarized in a users' checklist on the next page.

For more information and to obtain copies of the IPDAS documents visit our website at

www.ipdas.ohri.ca

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
- use visual diagrams 3.5
- use multiple methods to view probabilities [words, numbers, diagrams] 3.7

- 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
- use both positive and negative frames [e.g. showing both survival and death rates] 3.13

Include methods for clarifying and expressing patients' values?

- describe the procedures and outcomes to help patients imagine what it is like to experience their physical, emotional, social effects 4.1

- ask patients to consider which positive and negative features matter most 4.2
- suggest ways for patients to share what matters most with others 4.3

Include structured guidance in deliberation and communication?

- provide steps to make a decision 6.1
- suggest ways to talk about the decision with a health professional 6.2

- include tools [worksheet, question list] to discuss options with others 6.3

II. Development Process: Does the patient decision aid ...

Present information in a balanced manner?

- able to compare positive / negative features of options 9.1

- shows negative / positive features with equal detail [fonts, order, display of statistics] 9.2

Have a systematic development process?

- includes developers' credentials / qualifications 1.1
- finds out what users [patients, practitioners] need to discuss options 1.2, 1.3
- has peer review by patient / professional experts not involved in development and field testing 1.8a, 1.8b
- is field tested with users [patients facing the decision; practitioners presenting options] 1.4, 1.5

The field tests with users [patients, practitioners] show the patient decision aid is:

- acceptable 1.6, 1.7
- balanced for undecided patients 9.3
- understood by those with limited reading skills 10.6

Use up to date scientific evidence that is cited in a reference section or technical document?

- provides references to evidence used 11.1
- report steps to find, appraise, summarise evidence 11.2
- report date of last update 11.3
- report how often patient decision aid is updated 11.4

- describe quality of scientific evidence [including lack of evidence] 11.5a, 11.5b
- uses evidence from studies of patients similar to those of target audience 11.6

Disclose conflicts of interest?

- report source of funding to develop and distribute the patient decision aid 7.1, 7.2

- report whether authors or their affiliations stand to gain or lose by choices patients make after using the patient decision aid 7.3, 7.4

Use plain language?

- is written at a level that can be understood by the majority of patients in the target group 10.3
- is written at a grade 8 equivalent level or less according to readability score [SMOG or FRY] 10.4

- provides ways to help patients understand information other than reading [audio, video, in-person discussion] 10.5

Table 3. IPDAS Patient Decision Aid Checklist for Users

Meet additional criteria *if* the patient decision aid is Internet based

- provide a step-by-step way to move through the web pages 8.1
- allow patients to search for key words 8.2
- provide feedback on personal health information that is entered into the patient decision aid 8.3
- provides security for personal health information entered into the decision aid 8.4
- make it easy for patients to return to the decision aid after linking to other web pages 8.5
- permit printing as a single document 8.6

Meet additional criteria *if* stories are used in the patient decision aid

- use stories that represent a range of positive and negative experiences 5.2
- reports if there was a financial or other reason why patients decided to share their story 7.5
- state in an accessible document that the patient gave informed consent to use their stories 5.5

III. Effectiveness: Does the patient decision aid ensure decision making is informed and values based?

Decision processes leading to decision quality. The patient decision aid helps patients to ...

- recognise a decision needs to be made 12.1
- know options and their features 12.2, 12.3
- understand that values affect decision 12.4
- be clear about option features that matter most 12.5
- discuss values with their practitioner 12.6
- become involved in preferred ways 12.7

Decision quality. The patient decision aid ...

- improves the match between the chosen option and the features that matter most to the informed patient 12.8

Note: numbers behind items correspond to endorsed criteria in Table 2.