International Patient Decision Aid Standards
(IPDAS) Collaboration

IPDAS Voting Document

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Introduction

The International Patient Decision Aid Standards (IPDAS) Collaboration is made up of people from around the world who design, test, compile, provide, or use patient decision aids. Their common interest is to reach agreement about how to judge the quality of a patient decision aid. The leaders of the IPDAS Collaboration are Professor Annette O'Connor in Canada and Dr. Glyn Elwyn in the United Kingdom.

Why are standards needed?

The Cochrane Review Team compiled over 500 patient decision aids in use or being tested. However without standards (or a set of criteria), it is difficult to know whether or not a particular patient decision aid is a good one.

What are patient decision aids and why are they needed?

Patient decision aids are tools to help patients participate in their health decisions in ways that they prefer. Patient decision aids 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 patients value differently. Even when two patients are in the same situation, what is important for one person may be different for another person. Therefore, there is no clear choice 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), an expert to whom the features matter most (e.g. the patient), and a process that helps these two experts talk to each other. Patient decision aids can help with that process.

Patient decision aids aim to do three things to <u>prepare</u> a person for decision making.

- They provide facts about a person's condition, the options, and their features.
- They help patients to clarify their values (the features that matter most to them).
- They help patients 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 <u>not</u> advise patients to choose one option over another. They do <u>not</u> replace counseling from a health care practitioner. Instead, they prepare patients 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).

What is the goal of the IPDAS Collaboration?

The goal is to reach agreement on a set of criteria that will help patients judge the quality of patient decision aids. These criteria will be helpful to a wide variety of patients and organizations from around the world that use or develop patient decision aids. For example, the set of criteria will help patients who face the decision, practitioners who counsel them about the decision, patients who design and test decision aids, and patients who deliver or make decisions about purchasing decision aids for the public.

Instructions for Voting on Paper Version

Please plan to take about 45 to 60 minutes to complete the voting document. If you have any questions, please do not hesitate to contact the IPDAS Collaboration at IPDAS@ohri.ca.

1. Read the summary for the broad category of criteria (e.g., using a systematic development process)
2. Vote on the criteria by rating how important each criterion is to you when judging the quality of a patient decision aid:

   From 1 = low importance to 9 = highly important
3. Continue with the next set of criteria
4. When you have voted on all of the criteria, please fax the completed document to IPDAS Collaboration (613) 761-5402.

Privacy statement

The information collected during this voting process will be kept confidential. A code number will be used to identify the information so your name will not appear on any publications. All relevant information obtained while you are voting will only be made available to the research team and, if requested, to the Research Ethics Committee at Baylor College of Medicine, Houston, Texas. If the results of the study are published, your name will not be associated with the data.

Tell us about yourself

1. What is your gender?
    - ☐ Male
    - ☐ Female

2. What is your profession? ____________________________

3. What is your experience with decision aids? (select one)
    - ☐ none
    - ☐ limited (I've used or developed 1 decision aid or topic)
    - ☐ experienced (I've used or developed 2 or more decision aids or topics)

4. Which of the following groups describes you? (check all that apply)
    - ☐ decision aid developer
    - ☐ health professional
    - ☐ patient
    - ☐ member of a patient consumers group
    - ☐ policy maker
    - ☐ researcher
    - ☐ health plan executive
    - ☐ other, please specify __________________

5. In what country do you reside? ___________________

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.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid has information about the credentials of the people who developed it.	**1 2 3 4 5 6 7 8 9** **not important very important**	☐ Unable to evaluate
2. Patients were asked about what they need to prepare them to discuss a specific decision.	**1 2 3 4 5 6 7 8 9** **not important very important**	☐ Unable to evaluate
3. Practitioners were asked what they need to discuss a specific decision with patients.	**1 2 3 4 5 6 7 8 9** **not important very important**	☐ Unable to evaluate
4. Patients who were facing the decision field tested the decision aid.	**1 2 3 4 5 6 7 8 9** **not important very important**	☐ Unable to evaluate
5. Practitioners who counsel patient on the options field tested the decision aid.	**1 2 3 4 5 6 7 8 9** **not important very important**	☐ Unable to evaluate
6. Field testing showed that the decision aid was acceptable to patients.	**1 2 3 4 5 6 7 8 9** **not important very important**	☐ Unable to evaluate
7. Field testing showed that the decision aid was acceptable to practitioners.	**1 2 3 4 5 6 7 8 9** **not important very important**	☐ Unable to evaluate
8. The decision aid was reviewed by outside experts who were not involved in its development or field testing	**1 2 3 4 5 6 7 8 9** **not important very important**	☐ Unable to evaluate

Comments:

NOTE: Criteria about the effects of decision aids on the quality of decision making are presented later

II. Providing information about options

What is this criterion? Giving the facts about the positive and negative features of the different choices to test or treat a health problem. This may include: what the procedure involves; possible benefits and advantages; and possible harms, side effects, or disadvantages. It may include the benefits and harms of not being tested or treated. In the case of medical tests (to screen or diagnose), facts may be given about what the positive or negative results might mean and what further tests or treatments might be required. It may also include facts about 'over-detection; this happens when a disease is found that would not have been diagnosed or caused symptoms within a person's lifetime had the person not been screened.

How might this affect the quality of the decision? In theory, decision aids may lead to poor decisions if the facts given are incomplete or superficial. For ethical and legal reasons, patients have the right to get full and accurate information before giving their consent to a medical test or treatment. For patients actively involved in choosing options, more detailed information about options may be needed.

What is the evidence to support including or excluding this criterion? In the Cochrane Collaboration review, all 19 patient decision aids provided information about the condition, the options, the benefits, and the harms. The amount of information given varied. In studies that tested patients' knowledge, patients who used decision aids had knowledge scores of 48 to 95% correct, compared to scores of 31 to 67% correct among patients who received standard care without decision aids. Patients who used patient decision aids also felt more informed about their options.

How important are the voting criteria that apply to healthcare options (tests and treatments) in judging the quality of a decision aid? (circle your response)

1. The patient decision aid describes the health condition related to the decision.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. The patient decision aid lists the health care options.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. The option of choosing none of the health care options is included	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
4. The patient decision aid describes what happens in the natural course of a health condition if none, of the health care options, is chosen.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
5. The patient decision aid has information about the procedures involved (e.g. what is done before, during, and after the health care option)	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
6. The patient decision aid has information about the positive features of the options (e.g. benefits, advantages)	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
7. The patient decision aid has information about negative features of the options (e.g. harms, side effects, disadvantages)	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
8. The information about features of options (positive and negative) includes the chances they will happen.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
9. The patient decision aid has information about what the test is supposed to measure.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

How important are the voting criteria that apply to healthcare options (tests and treatments) in judging the quality of a decision aid? (circle your response)		
10. The patient decision aid has information about the chances of receiving a true positive, true negative, false positive, and false negative test result.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
11. The patient decision aid describes possible next steps based on the test results.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
12. The patient decision aid has information about the chances of disease being found with and without screening.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
13. The patient decision aid has information about detection and treatment of disease that would never have caused problems if screening had not been done.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
Comments:		

III. Presenting probabilities

What is this criterion? A ‘probability’ is the chance or likelihood that something will happen. It could mean the chance of a disease, benefit, harm, or side effect. It is often estimated by seeing what happens to large groups of patients in the natural course of the disease or after they have tests or treatments. The groups are usually defined by a disease or condition. Sometimes probabilities are described according to factors that change one’s chances (e.g. age, sex, severity of disease, presence of other health problems). Probabilities can be presented as words, numbers, or pictures. Some of the criteria are there to make it easier to compare probabilities and some to make it easier to imagine the probability.

How might this affect the quality of the decision? In theory, decision aids may lead to poor decisions if the probabilities are miscalculated or presented in ways that are misleading. Probabilities are usually based on research studies and calculated by experts in statistics and modeling. Decision aids on the same topic sometimes use different numbers so it may be helpful to identify the source of the probabilities and the steps used to calculate them. The different ways to present probabilities are discussed below.

Describing probabilities: It is easier to understand the number of times something happens in a group (known as ‘event rates’) than using other ways of presenting probabilities. To illustrate, identical information about probabilities is presented below using different methods:

- event rates: “If 1000 patients are treated our best guess is 2 patients may die. If 1000 patients are not treated our best guess is 4 patients may die”
- relative risk reduction “Our best guess is that treating patients cuts the chances of dying in half (by 50%) compared to no treatment”;
- absolute risk reduction “Our best guess is that treating 1000 patients prevents 2 patients from dying compared to no treatment”
- number need to treat: “Our best guess is that you have to treat 500 patients to prevent one death”.

Consistent denominators. It is easier to understand options when the same denominator (the bottom number in a fraction) is used. Most patients understand that ‘4 out of 1000’ is a higher chance of something happening than ‘2 out of 1000’. Many patients do not realize that ‘1 out of 250’ is a higher chance of something happening than ‘2 out of 1000’.

Same time frames. It is easier to compare options when probabilities are presented using the same time frames. For example, it is difficult to decide about an option if you are told “If 1000 patients are treated, 2 patients may die within 10 years; if 1000 patients are not treated 4 patients may die within 5 years”.

Balanced framing of probabilities. Patients feel differently about options when the probability of dying is presented (4 patients out of 1000 may die) compared to the probability of living (996 patients out of 1000 may live). By using both frames (4 may die and 996 may live), patients may be less likely to focus only on the positive or negative information.

Using visual aids. Some patients find it easier to understand probabilities when they are displayed using faces, stick figures, or bar charts. Visual aids comparing options should also use consistent denominators (e.g. what happens to 1000 figures without treatment compared to 1000 figures taking treatment). Similarly, two bar charts comparing options should use the same scale for comparison, starting from zero and increasing by the same amount (e.g. both charts show increases by 50 patients up to 1000 patients).

Comparisons to the rates of other events. Very small chances of unfamiliar events (e.g. 1 in 10 million chance of dying from a complication) are difficult to comprehend. It may help to compare the chances of a rare unfamiliar event to those of more familiar situations (dying from crossing the street, being struck by lightening, childbirth, any cause).

What is the evidence to support including or excluding this criterion? In the Cochrane Collaboration review, 17of 19 patient decision aids presented probabilities and 3 described the uncertainty associated with the evidence. The methods of displaying probabilities varied. In all 3 studies comparing decision aids with and without probabilities, the number of patients out of 100 reporting probabilities that were realistic, was higher if they used a patient decision aid with probabilities (63-72% correct) than a patient decision aid without probabilities (43-46% correct).

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid presents probabilities using event rates in a defined group of patients for a specified time.	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
2. The patient decision aid compares probabilities of options using the same denominator.	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
3. The patient decision aid compares probabilities of options over the same period of time.	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
4. The patient decision aid describes the uncertainty around the probabilities (e.g. by giving a range or by using phrases such as 'our best guess is').	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
5. The patient decision aid uses visual diagrams to show the probabilities (e.g. faces, stick figures, or bar charts).	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
6. The patient decision aid uses the same scales in the diagrams comparing options.	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
7. The patient decision aid provides more than one way of explaining the probabilities (e.g. words, numbers, diagrams).	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
8. The patient decision aid allows patients to select a way of viewing the probabilities (e.g. words, numbers, diagrams).	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
9. The patient decision aid allows patients to see the probabilities of what might happen based on their own individual situation. (e.g. specific to their age or severity of their disease).	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
10. The patient decision aid places the chances of what might happen in the context of other situations (e.g. chances of developing other diseases, dying of other diseases, or dying from any cause).	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
11. The patient decision aid has a section that shows how the probabilities were calculated.	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate
12. If the chance of disease is provided by sub-groups, the patient decision aid describes the tool that was used to estimate the risks.	**1 2 3 4 5 6 7 8 9** **not very important important**	☐ Unable to evaluate

How important is this criterion in judging the quality of a decision aid? (circle your response)		
13. The patient decision aid presents probabilities using both positive and negative frames (e.g. showing both survival rates and death rates).	**1 2 3 4 5 6 7 8 9** **not very important** **important**	☐ Unable to evaluate
Comments:		

IV. Clarifying and expressing values

What is this criterion?: A 2-step process of first thinking about and then communicating the personal importance of different positive and negative features of options. Ways of helping patients to clarify and express their values may include:

- describing features of options in ways that helps patients imagine what it is like to undergo procedures and to live with the physical, emotional, and social consequences;
- providing examples of how different values may lead to different choices;
- helping patients rate or trade-off different features of the options;
- recording and sharing values with others involved in the decision.

How might this affect the quality of the decision?: In theory, there may not be a good fit between which features matter most to the patient and the option that is chosen if patient decision aids only help patients to consider the facts and not personal values.

What is the evidence to support including or excluding this criterion?: Of 19 patient decision aids included in the Cochrane Review, all 19 described the features of the options but in varying levels of detail; 14 provided examples of different patients' values; 8 guided patients to rate or trade-off different features of options; and 9 suggested ways to share their values with others.

Of the 3 studies that measured the fit between a patient's values and their choice, all 3 showed an improved fit after using a patient decision aid. Ten studies measured how clear patients felt about their personal values. Six of these studies showed that decision aids were better in helping patients feel clear about their values (2 to 17 points out of 100) and the other 4 studies found no differences.

It is not clear how many ways of clarifying and expressing values should be in a decision aid or which way is best. When decision aids describe the features of options only briefly, having more than one way helps. When decision aids describe features in detail (e.g. options' effects on a person's physical, emotional, social situation), more ways may not be more helpful.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid describes the features of options to help patients imagine what it is like to experience their physical, emotional, and social effects.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. The patient decision aid asks patients to think about which positive and negative features of the options matter most to them.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. The patient decision aid suggests ways for patients to share the most important features of the options with others who are involved in the decision.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

Comments:

V. Using patient stories

What is this criterion? Describes the experiences of other patients who have faced the decision. Stories may include living with the condition, going through the steps of decision making, or living with the consequences of their choice.

How might this affect the quality of the decision? Some patients find stories more meaningful than factual information. However, the way patient stories are selected may sway (or bias) a patient's decision, divert patients from the facts, or not represent the different views of patients.

What is the evidence to support including or excluding this criterion? Of the 19 patient decision aids in the Cochrane Review, 14 provided patient stories. No studies compared decision aids with patient stories to those without stories.

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

(circle your response)

1. The patient decision aid provides stories of other patients' experiences.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. The patient decision aid provides stories that represent a range of experiences (positive and negative).	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. The patient decision aid explains the steps used to select these stories.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
4. The patient decision aid explains how experts reviewed the information contained in these stories.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
5. The patient decision aid describes that the patients gave informed consent to include their stories.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

Comments:

Note: balance in stories is discussed in a later section.

VI. Guiding/Coaching in deliberation and communication

What is this criterion? Both guidance and coaching provide a step-by-step way of thinking about the options and discussing them with their practitioner. Guidance is provided within a patient decision aid. It may be *implicit* in the way the patient decision aid is organized or *explicit* by providing a list or worksheet outlining the steps. 'Coaching' is provided in-person, one-on-one, by a trained person who is supportive but neutral in the decision. It may be given before or after using a patient decision aid, or as part of the delivery of one.

How might this affect the quality of the decision? Patients are not able to participate in decision making about health care options if they lack skills in the process of thinking about a decision and discussing it with others. Those without these skills may benefit from guidance or coaching in a step by step process.

What is the evidence to support including or excluding this criterion? Of 19 patient decision aids in the Cochrane Review, 17 studies provide guidance and/or coaching. One large study found that coaching along with a patient decision aid was more cost-effective and improved patient satisfaction compared to using the decision aid alone or using neither coaching or the decision aid. In other studies, it was not possible to identify the effects of guidance and coaching separately from other parts of a decision aid.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid provides a step-by-step way to make a decision.	**1 2 3 4 5 6 7 8 9** **not important** … **very important**	☐ Unable to evaluate
2. The patient decision aid suggests ways to talk about the decision with a health practitioner.	**1 2 3 4 5 6 7 8 9** **not important** … **very important**	☐ Unable to evaluate
3. The patient decision aid includes tools like worksheets or lists of questions to use when discussing options with a practitioner.	**1 2 3 4 5 6 7 8 9** **not important** … **very important**	☐ Unable to evaluate
4. The patient decision aid offers the option of working with a trained 'coach' to help patients consider the options.	**1 2 3 4 5 6 7 8 9** **not important** … **very important**	☐ Unable to evaluate
5. The patient decision aid offers the option of working with a trained 'coach' to help patients prepare to talk about the decision with a practitioner.	**1 2 3 4 5 6 7 8 9** **not important** … **very important**	☐ Unable to evaluate

Comments:

VII. Disclosing conflicts of interest

What is this criterion: To be open and honest in stating:

- the funding source for creating and producing patient decision aids,
- the financial support for practitioners who are responsible for creating the patient decision aid, and
- the affiliations of patient decision aid developers that might influence the content of patient decision aids.

How might this affect the quality of the decision? Often, decisions about medical tests or treatments have financial implications for practitioners, their institutions, and for commercial companies that make and sell related products. In theory, these financial interests may influence the content of a patient decision aid, particularly when individuals or groups who stand to gain (or lose), are involved with developing the patient decision aid. By clearly identifying individuals or groups involved who have a potential financial interest in the content of the patient decision aid, patients can decide for themselves whether or not the content is biased.

What is the evidence to support including or excluding this criterion? Of the 131 patient decision aids in the Cochrane review, 126 provided information on the funding sources. There have been no studies showing whether funding sources or affiliations are likely to influence the content of patient decision aids. However, in medical publishing and professional organisations there is strong evidence to suggest that financial interests and specialty advice can bias the information provided.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid reports where the money came from to develop the decision aid	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. The patient decision aid reports where the money came from to copy and distribute the decision aid.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. The patient decision aid reports whether the authors of the decision aid stand to gain or lose by the choices patients make after using a decision aid.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
4. The patient decision aid reports whether the affiliations of the authors stand to gain or lose by the choices patients make after using a decision aid.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
5. If the patient decision aid includes stories of other patients' experiences, it reports if there was some financial or other reason why patients decided to share them.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

Comments:

VIII. Delivering patient decision aids on the Internet

What is this criterion? One of several formats that can be used for a patient decision aid. The Internet is the use of a global network of millions of computers. Putting patient decision aids on the Internet makes them available to patients around the world.

How might this affect the quality of the decision? Increasingly, patients use the Internet to find health information for making decisions. Most decision aid developers are making aids for the Internet. The advantages are: widespread access by practitioners and patients; ability to tailor to each patient; cost savings in distribution; ease in updating; and stopping the circulation of out of date material. However, not all patients have access to or use the Internet. Internet-based patient decision aids may be more usable if they are simple to use, organised in a logical way, easy to search, interactive, and offer links to other helpful information.

What is the evidence to support including or excluding this criterion? Over the last 5 years, there has been a steady increase in the use of the Internet as the medium of delivery for patient decision aids. Currently over 98 of the 131 available patient decision aids in the Cochrane Review Inventory are on the Internet. Only one study compared the use of the Internet to another format (video-cassette). This study found that both formats were acceptable, and that patients who reviewed either decision aid in their entirety, improved their knowledge. However, the study also found that patients were more likely to view the patient decision aid when assigned to watch the video at the doctor's office just before their appointment, compared to using the Internet patient decision aid at home.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid provides a step-by-step way to move through the web pages (screens) on the Internet.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. The patient decision aid website allows patients to search for key words in the decision aid.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. The patient decision aid provides feedback on personal health information that is entered into the decision aid.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
4. The patient decision aid website provides security for personal health information entered into the decision aid.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
5. The patient decision aid makes it easy for patients to find their way back to the point they were at in the decision aid when they clicked on links to other web pages.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

Comments:

IX. Balancing the presentation of options

What is this criterion? Using equal importance and level of detail to display information about the positive and negative features of options. Some ways to look at the balance of positive compared to negative features is to look at:

- The format for options: the font, spacing, layout, volume of sound, and amount of airtime;
- The order each is discussed; and
- The framing of the options in terms of adjectives used and the display of numbers and statistics

How might this affect the quality of the decision? The way information is presented affects how patients see their health and how they make decisions. In theory, unbalanced information may influence patients' understanding, expectations, and value judgments about the options. As a result, patients may select options that would not be acceptable if they had been presented in a balanced way. It is dishonest and unethical to create false expectations or make it difficult for patients to understand the probabilities (or chances) of positive or negative features of options.

What is the evidence to support including or excluding this criterion? Of 19 patient decision aids in the Cochrane Review, all of them present both the harms as well as the benefits. However, only 4 of 19 patient decision aids were evaluated to find out if patients thought they provided balanced information. In these 4 studies, 60 to 79% of patients rated the patient decision aids as completely balanced, while the others rated the aids as slanted in favour of one option. However, patients who found the patient decision aids slanted were more likely to be leaning toward a particular option before using the decision aid. The patient decision aids have not been evaluated for balance in format, order, or framing of information.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid makes it possible to compare the positive and negative features of the available options.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. The patient decision aid shows the negative and positive features of options with equal detail (for example using similar fonts, order, display of statistical information).	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. Field testing showed that undecided patients felt the information was presented in a balanced way.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

Comments:

X. Using plain language

What is this criterion? Ways to share health information that promote understanding and improve readability for all audiences, including those with limited health literacy. This includes the use of everyday language and information that is structured, flows logically, and is focused; as well as, follows guidelines for document design. Readability is one measure of the reading ease or difficulty of text, expressed as a 'grade level' score. Some valid measures of readability include SMOG and FRY.

How might this affect the quality of the decision? In theory, decision aids may lead to poor decisions if most patients cannot read understand and use the information. Patient decision aids that use plain language make it easier for patients to learn about their options.

Common factors that limit understanding include: being unfamiliar with health terms and language, having limited reading skills, and aging. For example, the average US adult reads at the 7th or 8th grade level. Even patients with above average reading skills may be limited by emotional distress or medications that affect thinking abilities.

In general, people are able to understand spoken language at about two grade levels higher than written language. Patient decision aids with spoken words (audio, video, in person discussion) may be easier to understand.

What is the evidence to support including or excluding this criterion? The Cochrane review of patient decision aids found no studies that tested the effect of readability of the text on the quality of the decisions made. Health literacy studies found that improved "reading ease" of written materials increases understanding.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid describes the 'professional standards for plain language materials' that guided its development (e.g. Plain Language Association International)	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. The patient decision aid identifies the reading level at which it is written and the formula used to determine the level.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. The patient decision aid is written at a level that can be understood by at least half of the patients for whom it is intended.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
4. The patient decision aid is written at a level no higher than grade 8 according to a readability formula such as SMOG or FRY.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
5. The patient decision aid provides ways to help patients understand information other than reading (e.g. audio, video, or in-person discussion).	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
6. Field testing showed that the patient decision aid was understood by patients with limited reading skills.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

Comments:

XI. Basing information on up-to-date scientific evidence

What is this criterion? The use of up-to-date research from the best available scientific studies. This may include:

- using standard systematic steps in selecting the evidence
- judging the quality of the studies
- describing how consistent the results are among studies
- reporting how similar the patients in the studies were to those who would use the patient decision aid.
- recording the sources of evidence
- updating the evidence regularly

How might this affect the quality of the decision? In theory, decision aids may lead to poor decisions if they contain information from studies that are inaccurate, biased, incomplete, out-dated or are based on patients who are different from those most likely to use the decision aid.

What is the evidence to support including or excluding this criterion? Of 19 patient decision aids in the Cochrane Review, 13 studies provided references to the scientific evidence and 5 studies described the quality of the evidence.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. The patient decision aid provides references to scientific evidence used.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. The patient decision aid reports the steps used to select the scientific evidence used (e.g. finding, appraising, summarizing).	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. The patient decision aid reports the date when it was last updated.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
4. The patient decision aid reports how often the information in the decision aid is updated.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
5. The patient decision aid describes the quality of the scientific evidence (e.g. quality of research studies).	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
6. The patient decision aid uses evidence taken from studies on patients that are similar to the patients who would use the decision aid (e.g. age, gender).	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

Comments:

Note: the level of uncertainty around the evidence is described in the probabilities section

XII. Establishing the effectiveness

What is this criterion? To identify the things that you would need to observe in order to say that after using a patient decision aid, the way the decision was made was good, and that the choice that was made was good. The health care decision you need to keep in mind is one which has no clear answers for everyone. There is more than one medically reasonable option. Each option has different features (procedures, benefits, harms, side effects). Not everyone agrees on the features that matter most to them.

Why is this criterion important? Most people agree that decision aids should help patients and their practitioners improve decision making. It is important to know what to look for in order to conclude that a decision aid does more good than harm.

What is the evidence on definitions of good decision making and decisions? People are still discussing a definition of a 'good' decision. The most common agreement between researchers is that decisions should be based on adequate information and personal values. A national survey found that the public thought it was important to be informed, have clear values, make choices that matched with their values, and be satisfied with the decision. A survey of cancer doctors stressed the importance of patients being clear about values and being informed. In the Cochrane review of 34 studies, 18 measured knowledge, 10 measured 'feeling clear about values', and 3 measured 'agreement between values and choices'.

How important is this criterion in judging the quality of a decision aid?
(circle your response)

1. There is evidence that the patient decision aid helps patients recognize that a decision needs to be made.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
2. There is evidence that the patient decision aid helps patients know about the available options.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
3. There is evidence that the patient decision aid helps patients know about different features of the options.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
4. There is evidence that the patient decision aid helps patients understand that values affect the decision.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
5. There is evidence that the patient decision aid helps patients be clear about which features of options matter most to them.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
6. There is evidence that the patient decision aid helps patients discuss values with their health practitioners.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
7. There is evidence that the patient decision aid helps patients become involved in decision making in ways they prefer.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate
8. There is evidence that the patient decision aid improves the match between the features that matter most to the informed patient and the option that is chosen.	**1 2 3 4 5 6 7 8 9** **not important** **very important**	☐ Unable to evaluate

Comments:

Glossary

Absolute risk reduction. This type of measurement tells us if a treatment is likely to help patients who take it, compared to patients who don't take it. In other words, it is the difference in event rates between patients exposed (intervention group) and not exposed (control group) to a specified intervention. For example, improvement of 1% from 4% to 3%. (Users Guides to the Medical Literature 2002).

Applicability of evidence. Whether the patients and practitioners involved in the study, the screening or treatment that was tested; and the outcomes measured, are similar to the patients who would be using the patient decision aid and their situation.

Authors. The people with primary responsibility for the patient decision aid's contents are listed along with their specialty and their place of work.. For example: Clinical Advisor: Natasha Fatale, M.D., Chief of Urology, Pottsylvania Medical Center

Balanced presentation of options and their features. The use of the same level of detail and degree of prominence when displaying information in favour of and against the options/consequences (FDA Fair Balance Prescription Drug Advertising Act of 2001). Whether the information is balanced depends on 3 factors: format, sequencing, and framing.

Benefits. Intended positive features or consequences of an option. Benefits can be temporary or permanent. Patients may also get a benefit from having no treatment. Benefits should describe how strong the positive effect will be, how long it might last, and how often someone can expect to enjoy the positive outcome.

Coaching in communication. To provide balanced instruction, suggestions, feedback, and support (for example, through role-playing) to patients who are going to be meeting with their practitioner to prepare them to openly ask questions and make their preferences known. Coaching can be provided in-person or over the phone, in a one-to-one session, or in a group situation with a leader.

Coaching in deliberation. To provide balanced instruction, suggestions, feedback, and support to patients who are deliberating on a health decision. Coaching can be provided in-person or over the phone, in a one-to-one session, or in a group situation with a leader.

Coaching methods. Personal attention from a trained professional to help patients improve the quality of decision making. Examples include a nurse, who might tailor information to a patient's specific situation, provide an exercise to help patients clarify their values, help patients prepare a list of questions for their doctor, and helps patients think through and compare options. It could also be provided by a trained person who helps a group of newly diagnosed patients to sort through the process of making the decision.

Cochrane Review. Conducted as part of the Cochrane Collaboration, a Cochrane review is a systematic review of research studies to learn about the effect of health interventions such as patient decision aids. Systematic reviews are defined as a rigorous process, specified at the beginning of the study, to: a) conduct a comprehensive search of the literature for all relevant studies on a specific topic; b) appraise the quality of the identified studies; and c) synthesize the findings into a single report. The Cochrane Collaboration is an international not-for-profit organisation that produces and circulates systematic reviews of healthcare interventions and promotes the search for evidence to aid in making healthcare decisions (http://www.cochrane.org).

Cochrane Review of Patient Decision Aids. A systematic review of randomized controlled trials evaluating the effect of patient decision aids for patients facing actual screening or treatment decisions.

Communication about decision making. A discussion of facts, possible outcomes and attitudes, and different ways to make tradeoffs between choices.

Conditional probability. A measure of how likely something is to happen, based on existing information. For example, a measure of how likely someone is to suffer from a heart attack, if that person is a smoker. The likelihood would be different if the person were not a smoker.

Conflict of interest. "A set of conditions in which professional judgment concerning a primary interest (such as patient's welfare or the validity of research) tends to be unduly influenced by secondary interest (such as financial gain)". (Thompson DF. Understanding financial conflicts of interest. New Engl J Med 1993; 329:573-576)

Consistency of evidence. Whether there is agreement among many studies on the effect of the same treatment option.

Decision quality. The extent to which patients choose and receive health care options that match their informed and considered values.

Decision Support. Helping another person make a decision. It may be provided before a visit to a personal practitioner (in preparation for decision making) or during the visit with the personal practitioner (while making the decision).

Deliberation. The process of thoughtfully considering and discussing all sides of a decision that involves choosing among alternative actions.

Development process. The steps taken by the creators of the patient decision aid to understand the needs of potential users (e.g. patients and health care practitioners), and to consult experts and users to design, revise, and guide the development of the patient decision aids.

Disclosure of conflicts of interest. Providing information on factors that have the potential to unduly influence the content of patient decision aids such as the source of funding (for their development and production; people primarily responsible for the content) and affiliations of patient decision aid developers.

Event rate. The number of events (events might be benefits, harms, or side effects) that occur in a defined group of people (population) over a defined period of time. For example: if 1000 patients are treated our best guess is 2 patients may die. If 1000 patients are not treated our best guess is 4 patients may die. (Users Guides to the Medical Literature 2002).

Evidence. Knowledge gained through scientific research.

Field testing. Formal testing in "real life" settings where the patient decision aid is intended to be used, with patients and practitioners who are actually involved in making a decision. Results of field testing are used to improve the patient decision aid and make it more useful.

Financial interests. The potential financial interests of any company related to the patient decision aid's clinical content are clearly explained in plain language. For example: The Badenov Pharmaceutical Company, Inc., a for-profit company, makes and sells Borisol, one of the treatment choices described in this program. The Richards Foundation is a charitable, not-for-profit group completely funded by the Badenov Pharmaceutical Company, Inc.

Framing. The way health statistics and information is presented with:

- Similar use of positive and negative words to describe the intensity of the benefits or harms without being too sensational or alarmist;
- Similar display of numbers of the chances of experiencing benefits and harms;
- Similar level of detail for both benefits and harms; and
- Balanced examples of patients' experiences so that equal space is given to different viewpoints and choices.

Framing can make patients feel differently about the options. For example, it can make patients feel differently to be told the 'death rate' of a procedure rather than the 'survival rate'. It is alarming to hear that 20% of patients might die from a surgery but reassuring to remember that 80% survive. Hence, framing is the expression of the same information in different ways

Format. This refers to how the information about benefits and harms looks or sounds:

- For written resources, the size of the type, the spacing, and the page layout of information should be the same throughout the patient decision aid.
- For audio or video resources, consistent volume and length of airtime is important for all options.

Funding sources. The agencies or organisations that provide the money to pay for the patient decision aid. It must be is clearly and prominently acknowledged. For example: This program was funded by grants from the Government of Pottsylvania, the Richards Foundation, and the Badenov Pharmaceutical Company, Inc. It is important that the information about sources of funding is presented in a way that ensures that it will be seen and understood by the user. Ideally, this information should appear in clear large print at the beginning of the patient decision aid.

Guidance in communication. To outline possible questions and concerns, discuss barriers to communicating with practitioners (such as shyness, defensiveness and confusion,) and then provide a systematic approach to helping overcome these barriers to make sure the patients' questions and concerns are raised and addressed. Guidance can be provided in a variety of ways including by printed materials, an internet site, audio or video tapes.

Guidance in deliberation. To outline possible actions, and then provide a systematic approach to comparing and contrasting those actions. Guidance can be provided in a variety of ways including printed materials, an internet site, audio or video tapes.

Guidance methods. Instruction or direction in the steps of decision making. Some examples may include a list of the steps for making a high quality decision, filling in a worksheet that helps patients to clarify their values about treatment options, or a list of questions to ask the doctor or decision coach.

Harms and side effects. Unintended negative features or consequences of an option. These can be temporary or permanent and major or minor. Descriptions of harms and side effects should include how severe the negative effect will be, how long it might last, and how often someone can expect to experience the negative effect. An example of harm is the development of breast cancer from taking estrogen and progesterone. An example of a side effect is upset stomach from taking an antibiotic pill.

Health care consumer. A person who faces a health-related issue (for example, a decision to be tested for a disease) or who has been diagnosed with a disease or condition.

Health literacy. An individual's ability to perform basic reading, listening, computing and observing to obtain, understand, and use health information.

Indirect commercial funding. Any company that pays money to practitioners who have primary responsibility for the patient decision aid's information should be clearly acknowledged. For example: Dr. Fatale receives salary support from the Richards Foundation and research funding from the Badenov Pharmaceutical Company, Inc.

Informed consent. A conscious action taken by a person to give permission for something to occur which involves their person or privacy. For example, giving permission for a doctor to perform a medical test or for personal information to be published.

Interactivity on the Internet. A website is interactive if there is the ability to enter information and receive feedback based on the information that was entered. The ability for patients to enter and receive information from each other is also a way for a website to be interactive. When a website provides an interactive service, such as tailoring information to the patient based on information that the person provides, it should also explain the reasoning behind the feedback it provides.

Internal search capability. A function to locate content within a patient decision aid. The search engine should be capable of searching for natural language words or phrases and retrieving only relevant materials. It should also have a way for a person to enter words that is easy to understand and use.

Internet. A network connecting millions of computers around the world for communications purposes.

Internet Design. Describes the accessibility, organization, and internal search capacity as well as graphical and multimedia design. For example: Is the site available each time patients want to use it? Is the information on it organized and easy to manoeuvre? Has attention been paid to presenting the information as error-free (e.g., spelling, punctuation) as possible? Is there a readily identifiable link back to the institutional or organizational home page?

Links on the Internet. Connections to other internal pages or to external websites that form the web-like structure of information.

Link Architecture. The way a patient decision aid organises its links and is important for patients to find their way around a website. The links should be apparent, organized and logical to the reader. If the patient decision aid uses small pictures instead of words to indicate a link, they should be meaningful and consistent throughout the website.

Link Content. Links should be accurate, current, credible, and relevant. It helps to be alerted when leaving the patient decision aid website and going to one that is separate from the patient decision aid.

Logical organization (navigability). Simple, consistent, and easy to use with references to other sections provided to help a person understand the overall structure of the decision aid on the website. More logically organized patient decision aids are designed to ensure that a person does not skip but views all relevant information that is necessary for informed decision making.

Measurable improvements in the quality of decision-making. The most convincing evidence that a patient decision aid would really improve decision quality is likely to be generated by controlled study designs that compare two groups of patients who both face the decision: one group that experiences use of the patient decision aid in practice and another group that experiences usual practice (without a patient decision aid). An improvement in the quality of decision making with the patient decision aid would be shown if the group who used the patient decision aid in practice had a greater match between their values individual values and the health care options they selected.

Medical tests (screening and diagnostic). Tests performed on healthy people to see if they have a disease (diagnostic) or to see if they are likely to have a disease or condition (screening).

Medical treatments. Effective treatments that medical professionals judge to be ethical and which are available to patients in their community.

Natural frequency. This term means the same as "Event rate". (Gigerenzer 2003).

Needs. Gaps between what is known and what is needed to make a decision. A patient decision aid needs assessment can tell us what information patients need to make decisions that match the personal importance they feel toward the positive and negative features of their options. For example, before coming to a decision about treatment, patients first need to know basic information about their condition. They also need to know about possible treatment options (including doing nothing) and the potential benefits and harms involved.

Number needed to treat (screen). Not all medical tests or treatments work for every patient. This is a way of telling how many patients would need to have the treatment or test to prevent one person from suffering from a disease or a harmful treatment side effect. Difference in occurrence rates of adverse outcomes between patients exposed to a treatment (intervention group) and not exposed (control group). It is the inverse of absolute risk reduction (Users Guides to the Medical Literature 2002).

Over-detection (or over-diagnosis): Detection by screening tests of disease which, without screening, would not have been diagnosed or caused symptoms within the person's lifetime. A common example is detection of low grade prostate cancer by PSA testing which would not have harmed the person in their lifetime. Also described as detection of pseudo-disease

Patient. A health care consumer who faces a health-related issue (e.g. a screening decision) or who has been diagnosed with a disease (e.g. diagnostic test or treatment decisions). Other names include public, people, person, health consumer, or patient decision aid users.

Patient Decision Aid. Resources created to help patients make specific health decision when there is more than one option (including the status quo). They providing (at the minimum) information on the options and the features of these options (benefits, harms, pros, cons, side effects, inconveniences) (O'Connor et al., BMJ, 1999)

Patient stories. Accounts from patients with a health condition describing their experiences with the condition, options, decision-making, and consequences or outcomes. These may be collected as audio or video recorded interviews or as written stories. The characteristics of stories in patient decision aids usually vary depending on whether they involve a health issue faced by otherwise healthy people or a treatment decision for a life-threatening illness. Many examples of "others' experiences" are a combination of details of several real cases (O'Connor, Drake et al, 1999; O'Connor & Jacobsen, 2003).

Plain language. The use of ways to clearly communicate health information that create optimal understanding.

Practitioner. A health care professional that provides direct care to patients or public. This includes physicians, nurses, physiotherapists, pharmacists, and social workers.

Probability. The chance that something will occur. Probabilities are typically estimated by observing what happens to large groups of patients. For example, watching 10,000 men aged 60 years for 10 years to see how many die. The probability of dying in this group over 10 years might be 1,500 out of 10,000. If a patient is similar to the patients in the group, it would say the best guess at a patient's chance of dying over the next 10 years is 1,500 out of 10,000.

Quality of the Evidence. How accurate the descriptions and the estimated effects of different options are. This evidence often comes from one or more studies or resources. The quality of evidence depends on several factors, including the strength of the study design, the quality of the methods, whether there is agreement among studies of the same health option, and how directly the studies address the health option.

Readability. A measure of the reading ease or difficulty of printed materials. It is usually measured using proven formulas that gauge the length of words in syllables and length of sentences (e.g. SMOG, Fry).

Reference class. This is the group of patients who might have a side effect or suffer from a disease in a set period of time. It is the denominator of an event rate, which is the group of patients who, over a specified period of time, are at risk of an event (Gigerenzer 2003).

Relative risk reduction. Relative risk measures how much the likelihood of something happening is reduced in a group of patients who take a treatment, compared to a group of patients who don't. For example, if 60% of a non-treated group of patients died and only 30% of the treated group died, the treatment would have a relative risk reduction of 0.5 or 50%. Therefore, the death rate in the treated group is half of that in the control group. The relative risk reduction is the ratio of the event rate in patients exposed (intervention group) to the event rate in patients not exposed (control group) to a specified intervention (Users Guides to the Medical Literature 2002).

Rigorous social process. A method used to gather information from many sources on the key factors influencing the decision. For example, it may include interviews, focus groups, surveys, or decision analysis with individuals who have faced or are facing the decision (e.g. patients, family) and health practitioners (e.g. doctors, nurses, social workers).

Risk. In this context, risk can mean the same as probability – that is, the chance that something will occur. For example, risk can be the chance that a positive or negative feature of an option will occur.

Sequence. The order in which the information on options and consequences (benefits and harms) is provided. It should be the same for all the options.

Severity. A description of how intense the harm or side effect might be. It's best if described in a practical way that means something to patients' daily life. For example, if a side effect was "fatigue", it would be helpful to know how severe the fatigue might be in practical terms such as "fatigued so that you can't walk a block" or "fatigued so that you can't get out of bed".

Study design. The basic method or approach used in a research project. Some common designs may be a systematic review of several studies (with or without combining the results across studies; meta-analysis), a randomized controlled trial, an observational study (for example a cohort or case control study), or a descriptive study (for example, a case series).

Study quality. Details of the study source's, design, and execution that ensure the study findings are fair and unbiased. For example, the quality of a randomized trial depends on making sure that the same number and type of patients received the treatment, that the health professionals were not aware of which groups of patients were receiving the treatment, and that the patients were followed for long enough to tell find the longer-term effects of the treatment.

Suitability. The ability of health information resources to match the language, logic, and experience of the target audience. Suitability, as used by Doak, Doak, and Root (1996), measures how well health resource content, approach, and design match the culture, experiences, abilities, values and beliefs of the intended audience. With the development of multi-media documents, suitability should also include assessing usability-audiovisual factors and technological accessibility (e.g. ease of navigation).

Usability. A measure of the quality of a person's experience when interacting with a web-site, and generally tells how easy a patient decision aid is easy to use. Usability is a combination of factors that affect a person's experience, including: how efficient it is, whether it is easy to remember how to use it the next time, whether there are many errors and if they are serious or not (http://usability.gov/basics/index.html). An option to remember what has been viewed is important, in case the entire patient decision aid cannot be viewed in one sitting. A person may want to return at a later time without having to start from the beginning.

Users. Patients who face the decision and health practitioners who help patients learn about their options to make the decision**.**

Values. How a person feels about or rates the importance of options and their positive and negative features. These preferences are based on how their health might be affected by the decision, their attitudes about the chances each option holds for bringing benefits or harms, their willingness to make trade-offs over time, how they feel about certain medical procedures or anything else that might be useful in making the decision.

Values clarification. Ways to help patients form and share how important various options and their features are. Examples include: a) describing features of options so patients can imagine and value what it is like to undergo procedures and live with the consequences; b) providing examples of how other patients' values led them to make different choices; c) bringing forth values by guiding patients to rate or trade-off different features of options; and d) recording, guiding, or coaching patients to help them share their values with others involved in the decision.