

## Glossary

**Authors.** The people with primary responsibility for the patient decision support intervention's contents are listed, including their credentials and affiliations. For example: 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 three 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 be described in terms of how strong the positive effect will be, how long it might last, and how often someone can expect to enjoy the positive outcome.

**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 support interventions. 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) synthesis the findings into a single report. The Cochrane Collaboration is an international not-for-profit organisation that produces and circulates systematic reviews of health care interventions and promotes the search for evidence to help support health care decisions ([www.cochrane.org](http://www.cochrane.org)).

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

**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)

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

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

**Denominator.** A mathematical term that appears on the bottom of a fraction. For example, in the fraction 1/100, the denominator is 100. When probabilities are stated in the decision support intervention, they should use the same denominator in order to facilitate comparison across options. For example, imagine a decision support intervention that presented two different drug treatment options. If the intervention stated 10/100 people will experience nausea from treatment option A, they should presented the risk of nausea for treatment option B using the same denominator e.g. 2/100 and not 1/50.

**Decision support interventions (decision aids):** Decision support interventions help people think about choices they face; they describe where and why choice exists, in short, conditions of dual equipoise; they provide information about options, including, where reasonable, the option of taking no action. These interventions help people to deliberate, independently or in collaboration with others, about options by considering relevant attributes; they support people to forecast how they might feel about short, intermediate, and long-term outcomes that have relevant consequences, in ways that help the process of constructing preferences and eventual decision making appropriate to their individual situation

**Development process.** The steps taken by the authors/creators of the patient decision support intervention 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 patient decision support interventions.

**Dimension (IPDASi).** This refers to the broad area within which quality is assessed. The broad dimensions are made up of more specific items that are scored. The dimension score is the mean of the item scores within the dimension (see *Item* for further detail).

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

**False negative.** This refers to a test result that tells you a disease or condition is not present, when in fact it is present. A false negative test result is an error, which means the result is not giving you the correct information. For example, if a person had a blood test designed to detect colon cancer, and the results show that the person does not have colon cancer, when in fact they do have the disease, this is a false negative.

**False positive.** This is the opposite of a false negative and refers to a test result that tells you a disease or condition is present, when in fact it is not present. A false positive is an error which means the result is not giving you the correct information. For example, if a person had a blood test designed to detect colon cancer, and the results show that the person does have colon cancer, when in fact they do not have the disease, this is a false positive.

**Field-testing.** Formal testing in “real life” settings where the patient decision support intervention 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 decision support intervention.

**Financial interests.** The potential financial interests of any company related to the patient decision support intervention's clinical content are clearly explained in plain language. For example: The NewName 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 NewName 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 support.
- 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 support intervention. It must be 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 support.

**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.

**Harmful bias.** The aim of the consensus process is to identify those criteria, which if not present, or of low quality, would lead to a risk of harmful bias and negatively affect patients' decision-making. In this context, we take harmful bias to mean the possibility that decision making that is influenced by factors or representations that have not been addressed by: attention to the evidence base; a systematic development process; accurate information representations; decision guidance/support.

**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.

**Index decision.** This refers to the specific decision that the decision support intervention is designed to address; the decision that needs to be considered.

**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.

**Item (IPDASi).** This refers to the specific area within which quality is assessed. Each broad dimension is made up of the specific items. (see *Dimension* for further detail)

**Lead time bias.** The intention of screening is to diagnose a disease earlier than it would be without screening. Without screening the disease may be discovered later, when symptoms appear. Even if in both cases a person will die at the same time, because we diagnosed the disease earlier with screening the *survival time since diagnosis* is longer with screening; but *life span* has not been prolonged, and there will be added anxiety as the patient must live with knowledge of the disease for longer. Lead time bias is the bias that occurs when screening diagnoses the disease earlier, but there is no effect on the outcome of the disease - it may appear that the test prolonged survival, when in fact it only resulted in earlier diagnosis when compared to traditional methods.

**Measurable improvements in the quality of decision-making.** The most convincing evidence that a patient decision support intervention 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 support in practice and another group that experiences usual practice (without a patient decision support). An improvement in the quality of decision making with the patient decision support would be shown if the group who used the patient decision support 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.

**Needs Assessment.** There are two-types of needs assessment used in the development of patient decision support interventions: patient and health professional. A needs assessment can tell us what information patients need to prepare them to discuss a specific decision, and what health professionals need to prepare them to discuss the decision with patients. It can help determine 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.

**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 support users.

**Patient Decision Support Intervention (DESI).** 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 support 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 creates 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).

**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.

**True negative.** The extent to which a test result is accurate and free from false positives. The fewer the number of false positives, the greater the specificity of the test. The proportion of individuals without a disease or condition that are correctly identified by a test.

**True positive.** The extent to which a test result is accurate and free from false negatives. The fewer the number of false negatives, the greater the specificity of the test. The proportion of individuals with a disease or condition that are correctly identified by a test.

**Uncertainty.** In the context of outcome measurements, uncertainty refers to the estimated amount or percentage by which an observed or calculated value may differ from the true value. In decision support interventions, this can be presented as confidence intervals, ranges, or by using phrases such as 'our best estimate is'.

**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.