

**2012 UPDATED CHAPTER C:
PRESENTING PROBABILITIES**

**SECTION 1:
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Suggested Citation:

Trevena L, Zikmund-Fisher B, Edwards A, Gaissmaier W, Galesic M, Han P, King J, Lawson M, Linder S, Lipkus I, Ozanne E, Peters E, Timmermans D, Woloshin S. (2012). Presenting probabilities. In Volk R & Llewellyn-Thomas H (editors). 2012 Update of the International Patient Decision Aids Standards (IPDAS) Collaboration's Background Document. Chapter C. <http://ipdas.ohri.ca/resources.html>.

SECTION 2: CHAPTER SUMMARY

What is this quality dimension?

Medical decisions have outcomes that may have been quantified through research. To assist patients and health professionals in balancing the benefits and harms of these options, decision aids aim to communicate estimates of the likelihoods of these outcomes based on the best available evidence.

What is the theoretical rationale for including this quality dimension?

When considering decision options and the likelihoods of their outcomes, estimates of both the changes and the outcome frequencies associated with each option need to be conveyed in a way that maximizes patients' understanding and thereby facilitates informed decision making.

What is the evidence to support including or excluding this quality dimension?

Sixteen out of the 86 RCTs in the updated Cochrane review of decision aids for people facing treatment and screening decisions measured the effects of including probabilities on the accuracy of patients' risk understanding. Presenting probabilities within a DA significantly improved the accuracy of risk comprehension (RR 1.7, 95% CI 1.5 to 2.1), compared with not receiving probability estimates. In updating this section, we have tried to identify the key issues in communicating quantitative information for decision aid development and to draw on the combined expertise of the authors to summarise current evidence in this field, but not to provide a systematic review. We summarise the evidence for ten key issues in presenting the likelihood of decision outcomes. The key points are summarized below.

Suitable formats for presenting numeric chances depend on the nature of the task. To present the *chance of a single event*, simple frequency formats such as "Every year, 1 in 100 deaths in the EU is due to stomach cancer", or percents such as "Every year, 1% of deaths in the EU are due to stomach cancer" are best understood; the denominator should always be defined. Formats should aim to be consistent throughout a decision aid. 1 in x formats should be avoided. When the task is to compare the *chance of occurrence of two or more independent events* (e.g., the chance of symptom relief with drug A compared with placebo), formats that express the chance of an event using one number, such as percentages, work better than simple frequencies involving more than one number, such as 1 in 100. When presenting *changes in rates*, preferably absolute risks should be given either in percentages or simple frequencies, and if possible along with the absolute risk increase (or decrease). With frequencies, the same denominator should always be used. If a decision aid requires people to calculate the probabilities associated with *jointly occurring events*, then a natural frequency format would be preferable to conditional probabilities.

Providing context for risk statistics in the form of comparative data and providing evaluative labels can have a substantial influence on how patients use that information. However, the choice of comparative data has a strong impact on how people respond to such data, and labels should be applied carefully. The effect of tailoring health risk information on improving health decision-making appears mixed.

Evidence on the effects of conveying uncertainty is limited but growing. Novel representational methods have been developed to communicate both randomness (aleatory uncertainty), and ambiguity (epistemic uncertainty), and may be useful to incorporate in decision aids. However, the communication of uncertainty can be psychologically aversive, and more research is needed. On a similar note, communicating the likelihood of outcomes over time is particularly difficult; although significant research has addressed this issue, no clear consensus regarding optimal methods has emerged.

When designing a decision aid, measuring objective numeracy, subjective numeracy, graph literacy, and possibly other aspects of the health literacy of the prospective users can help in designing presentation formats that are suitable for individuals who vary in skills.

Visual aids such as icon array diagrams, bar charts, human figure representations, or flow diagrams appear to aid accurate understanding of probabilities in many contexts. They can help reduce several biases, such as denominator neglect, framing effects, and the undue influence of anecdotes, and they can aid the comprehension of more complicated concepts such as incremental risk. They can be especially helpful for people with higher graphical literacy and among those who have problems with understanding and applying numbers. Emerging formats such as animated or interactive visual displays are intuitively appealing, but evidence is lacking to determine whether these techniques provide a net positive experience or degrade knowledge versus evidence-based static formats.

Using positive and negative framed narratives to present benefit and risk information may increase perceptions of risk severity, decrease the ability to accurately recall risk probabilities, and influence treatment choice. The relative number and type of narratives used influences decision making; they should be used with caution and be accompanied by quantitative or visual displays such as pictographs.

SECTION 3: DEFINITION (CONCEPTUAL/OPERATIONAL) OF THIS QUALITY DIMENSION

a) Updated Definition

Medical decisions have outcomes which may have been quantified through research. To assist patients and health professionals in weighing up the benefits and harms of these options, decision aids aim to communicate estimates of the likelihoods of these outcomes based on the best available evidence.

b) Changes from Original Definition

See Appendix.

c) Emerging Issues/Research Areas in Definition

See Section 6.

SECTION 4: THEORETICAL RATIONALE FOR INCLUDING THIS QUALITY DIMENSION

a) **Updated Theoretical Rationale**

When considering decision options and the likelihoods of their outcomes, estimates of both the changes and the outcome frequencies associated with each option need to be conveyed in a way that maximizes patients' understanding and thereby facilitates informed decision making.

b) **Changes from Original Theoretical Rationale**

See Appendix.

c) **Emerging Issues/Research Areas in Theoretical Rationale**

See Section 6.

SECTION 5: EVIDENCE BASE UNDERLYING THIS QUALITY DIMENSION

a) **Updated Evidence Base & Changes from Original Evidence Base**

In 2011, the Cochrane Collaboration's review of decision aids for people facing treatment and screening decisions was updated; it now includes 86 RCTs and reports on outcomes according to the IPDAS criteria [Stacey et al. (1)]. Sixteen out of the 86 RCTs measured the effects of including probabilities on the accuracy of patients' understanding of these. Presenting probabilities within a DA significantly improved the accuracy of risk comprehension (RR 1.7, 95% CI 1.5 to 2.1), compared with not receiving probability estimates. This effect was greater if the probabilities were presented as numbers, but was also significant if they were described in words although the effect size was smaller.

However, the literature on risk communication—particularly beyond decision aid-specific research—is vast. In updating this section, we have tried to identify the key issues in communicating quantitative information for decision aid development and to draw on the combined expertise of the authors to summarise current evidence in this field, but not to provide a systematic review. This is a rapidly emerging area of research and there has been substantive new evidence on presentation of rates, visual formats, uncertainty, and interactive web-based formats.

This chapter summarises the evidence for ten key issues in presenting the likelihood of decision outcomes.

- To reflect new knowledge in this field, we have divided the original chapter sub-section on 'Presenting Numbers' into two sub-sections: 'Presenting the Chance an Event Will Occur' and 'Presenting Changes in Numeric Outcomes. This latter category now includes 'Framing', which had previously been a separate sub-section.

- We have changed the titles of:
 - ‘Probabilities for Tests and Screening Decisions’ to ‘Outcome Estimates for Tests and Screening Decisions’;
 - ‘Probabilities in Context’ to ‘Numerical Estimates in Context and Evaluative Labels’;
 - ‘Tailoring Probabilities’ to ‘Tailoring Estimates’; and
 - ‘Visual Aids’ to ‘Visual Formats’.
- We have added new sub-sections on ‘Formats for Understanding Outcomes over Time’, ‘Narrative Methods for Conveying Numerical Estimates’, and ‘Important Skills for Understanding Numerical Estimates’.
- The previous sub-section called ‘Evidence for Probabilities Used’ remains unchanged. Throughout these ten sub-sections, the cited evidence has been derived from the decision-aid specific, other health, and non-health literature.

Reference:

1. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2011(10) CD001431

1. Presenting the Chance an Event Will Occur

For both written and verbal information, patients have a more accurate understanding of risk if probabilistic information is presented as numbers rather than words, even though some may prefer receiving words [Trevena et al. (1)].

Suitable formats for presenting numeric chances depend on the nature of the task. The terminology in this field can be very confusing so to simplify in this section, we will refer to percents (e.g., 10%) and simple frequencies (e.g., 1 in 100), regardless of whether these are normalized or not.

When the task is to present the *chance of a single event*, simple frequency formats such as “Every year, 1 in 100 deaths in the EU is due to stomach cancer”, or percents such as “Every year, 1% of deaths in the EU are due to stomach cancer”, are more transparent than formats such as “The chance of dying from stomach cancer is 1%”. The last statement is problematic because it does not specify the ‘denominator’ (i.e. reference class) -“all deaths in the EU per year”. Without a clear description of who this estimate refers to, people might think this statement means that “Every year, 1 of 100 citizens of the EU dies of stomach cancer” [Gigerenzer et al. (2)]. Similarly, when patients who take fluoxetine for mild depression hear from their doctor that there is a “30-50% chance of developing a sexual problem such as impotence or loss of sexual interest” some may think this means they will have problems in 30% of their own sexual encounters. The ‘denominator’ or reference class used by the doctor is ‘patients on fluoxetine’ but the denominator used by the patient is ‘their own sexual encounters’ [Gigerenzer & Galesic (3)].

There is also some evidence that risks presented in simple frequencies are perceived as higher than when they are presented in their equivalent percentage value, especially in patients with lower numeracy [Peters et al. (4)] and (possibly) with smaller percents [Woloshin & Schwartz (5)]. Given this potential format bias, one should be careful when comparing results of studies

that have used different formats (percents or simple frequencies). Formats should aim to be consistent throughout a decision aid (see below). Providing simple frequency AND percent appears to add no advantage [Woloshin & Schwartz (5)] and there is strong evidence that ‘1 in x’ formats with variable denominators are more difficult to understand. They should be avoided for all tasks.

In summary, it is most important when presenting the *chance of a single event* to clearly define the denominator or reference class. Percent *or* simple frequency formats can be used for presenting the chance of a single event. However, in deciding which one to use, consider what other information needs to be presented in the same document and what the purpose of the decision aid is overall so that format consistency can be achieved. Visual formats may also help to reduce bias (see section 6). We will expand on this throughout the chapter.

When the task is to compare the *chance of occurrence of two or more independent events* (e.g., the chance of symptom relief with drug A compared with placebo), formats that express the chance of an event using one number, such as percentages, work better than simple frequencies involving more than one number, such as 1 in 100 [Woloshin & Schwartz (5)]. If using simple frequencies such as 1 in 100, use the *same* denominator (e.g. 1 in 100 vs. 2 in 100) as they are easier to compare than frequencies using different denominators (e.g. 1 in 100 vs. 1 in 50) [Peters et al. (4); Cuite et al. (6)]. Thus, consistent denominators should always be used. When choosing the size of the denominator, smaller numbers (e.g. 100) are easier to understand and remember than larger numbers (e.g. 10,000) [Garcia-Retamero & Galesic (7)]. There has been discussion about whether people find percents less than one (e.g., 0.1%) more difficult to understand than the equivalent simple frequency (e.g., 1 in 1000) [Woloshin & Schwartz (5); Cuite et al. (6)]. However, this problem may reflect difficulty manipulating decimal points (e.g., asking someone to represent 1 in 1000 as a percentage) rather than a comprehension problem. [Woloshin & Schwartz (5)].

In summary, percents (e.g., 1 %) may have an advantage over a simple frequency format (e.g., 1 in 100) for comparing the *chance of occurrence of two or more independent events*. As mentioned before, it remains important to clearly define the denominator or ‘reference class’ and to aim for a consistent format throughout the decision aid taking into account the information and tasks required.

Other formats are more suitable for tasks that involve presenting *changes in numeric outcomes* (section 2) and *conveying the frequency of joint occurrences of two or more events*, such as the probability that a person with a positive test result has the disease (section 3). NB: This chapter contains evidence for a number of other strategies to improve the presentation of numeric information and these sections should all be read and interpreted together as a whole.

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2. Presenting Changes in Numeric Outcomes

Most efforts to communicate changes due to interventions (i.e. treatment effects) or across time (e.g., improvements of health) use either side-by-side total risk presentations or difference presentations.

Difference presentations depict the change in risk and can influence risk perceptions through framing effects. Research has shown that relative risk presentations (e.g. “30% lower risk”) tend to magnify risk perceptions and decrease understanding, compared to absolute risk presentations (e.g., “the risk is lower by 5 percentage points”) [for a review see Akl et al. (1), and Covey (2)]. Number needed to treat (NNT) is sometimes used, but several studies suggest that this format is poorly understood by patients and may increase the perceived effect of treatment [Halvorsen et al. (3)].

A variant is the presentation of incremental risk (absolute risk increase), but only after a “baseline” total risk level has been shown. This approach emphasizes the size of the change relative to the size of the total risk, and was shown to lower risk perceptions [Zikmund-Fisher et al. 4)]. Such language (e.g., “5 more women get...”) was incorporated into the Schwartz et al. drug facts box [Schwartz et al. (5)], and used in decision tools such as Adjuvant! A decision aid trial suggested that incremental risk language works best when accompanied by visual displays [Zikmund-Fisher et al. (6)]. In particular, when the baseline risks are small, relative risk reductions are perceived to be larger and more persuasive than absolute risk reductions [Akl et al. (1); Malenka et al. (7); and Naylor et al. (8)].

The framing of outcomes in terms of losses or gains has been shown to affect people’s choices [Tversky & Kahneman (9)]. Framing outcomes in terms of potential gains (e.g., the chances of survival) often generates risk-averse choices, whereas framing outcomes in terms of potential losses (e.g., the chances of death) often generates risk-seeking choices. In clinical situations, the effects of the framing of outcomes as losses or gains tend to vary across situations [Moxey et al. (10)]; the variable effect of different frames of risks or rates is due to emphasizing different aspects of the information. For instance, framing information in terms of relative risk reductions affects people’s choices by overemphasizing the benefits of therapies.

In summary, when presenting changes in rates, preferably absolute risks should be given either in percentages or simple frequencies, and if possible along with the absolute risk increase (or decrease). If frequencies are used, the denominators should be equal.

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3. Outcome Estimates for Tests and Screening Decisions

As mentioned in section 1 of this chapter, the ideal format for presenting numeric information depends on the task. Once again, the terminology can be confusing when considering screening and test outcomes. [Gigerenzer & Hoffrage (1)] and [Hoffrage et al. (2)] proposed the term ‘natural frequencies’ for one specific task only – the probability of joint occurrence of events (e.g., the probability of having breast cancer given an abnormal mammography result). This is quite different to the task of considering the chance of independent events (see section 1). A number of studies and a recent Cochrane review [Akl et al. (3); Hoffrage et al. (5)] have shown that natural frequencies are better than conditional probabilities where events are connected. Natural frequencies preserve the base rate of the outcome (e.g., breast cancer) and report the ‘actual’ or ‘natural’ number of people having a particular outcome (e.g., having a positive test result). It’s unclear whether people use Bayesian reasoning when making screening decisions but natural frequency formats continue to be proposed as the best way to help people understand these kinds of estimates [Gigerenzer et al. (1); Hoffrage et al. (2)]. An example of Bayesian reasoning with a natural frequency format would be “Out of every 10,000 people, 30 have colorectal cancer. Of these, 15 will have a positive hemoccult test. Out of the remaining 9970 people without colorectal cancer, 300 will still test positive. How many of those who test positive actually have colorectal cancer? Answer: 15 out of 315” [Hoffrage et al. (3)]. An alternative representation of this information is conditional probability format such as “probability of having colorectal cancer is .003%. Of people who have the cancer, 50% get a positive test result. Of people who do not have cancer, 3% will nevertheless test positive. What is the probability that a person who tests positive has colorectal cancer? Answer: 4.8%”. So, if a decision aid requires people to calculate the probabilities associated with jointly occurring events, then a natural frequency format would be preferable to conditional probabilities.

However, screening can also be viewed as an ‘intervention’ that has an effect (e.g., reducing death from colorectal cancer) and so the effect of screening on cancer mortality with and without screening are actually the chances of independent events (see section 1). As we noted earlier there may be some advantage to presenting such information as a percent format but cancer incidence and mortality rates are usually low in a general population and possible format biases need to be considered. Similarly, the chance of having a disease if your test result is positive can be thought of as the ‘post-test probability’ and some would suggest this could be calculated on behalf of the patient and presented as a percent (1%) or simple frequency format (e.g., 1 in 100). Thus, as before, we recommend that decision aid developers consider both the nature of the task required and the other information that needs to be conveyed in the same document. It is important to clarify what the reference class is (e.g., women aged 50 who are having biennial mammography over 10 years) and to keep the denominator constant. Once again, 1 in x formats should be avoided as they consistently perform worse.

The current IPDAS criteria recommend that screening decision aids include estimates of: 1) disease with and without screening; 2) false positives; and 3) false negatives. The updated Cochrane review of decision aids includes 34 trials about screening and test decisions [Stacey et al. (4)]. Five of these trials measured the accuracy of risk perception [Gattelari & Ward (6); Kupperman et al. (7); Schapira & Van Ruiswyk (8) Wolf & Schorling (9); Lerman et al. (10)]. Four of these reported significantly improved risk perception [Gattelari & Ward (6); Kupperman et al. (7); Schapira & Van Ruiswyk (8) Wolf & Schorling (9)] and this was the case whether accurate risk comprehension was measured as numbers [Gattelari & Ward (6); Kupperman et al. (7)] or as a gist-based risk comprehension in words [Schapira & Van Ruiswyk (8); Wolf & Schorling (9)]. All four of the trials also included quantitative estimates in accordance with the IPDAS criteria recommendations (see above). Three of the decision aids were available and all used different formats for numerical outcomes. None provided a head-to-head comparison of formats. Natural frequency *and* percentage formats were used in [Gattelari e& Ward (6)] (RR 5.28 [95% CI 2.93, 9.50]), variable frequency format was used in [Wolf & Schorling (9)] (RR 1.31 [95%CI 1.10, 1.56]) and simple frequency format was used in [Schapira & Van Ruiswyk (8)] [RR 1.46 [95%CI 1.17, 1.83]. Given the lack of head-to-head format comparison in these trials we recommend applying the principles outlined in this chapter which are based (where possible) on comparative research.

Our update confirms that, in screening decision aids, the application of IPDAS criteria about the presentation of quantitative estimates of screening outcomes improves the accuracy of risk perceptions.

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4. Numerical Estimates in Context and Evaluative Labels

To help users get perspective on the risk of disease, decision aid developers should consider including contextual information when feasible. Context is particularly important for decision aids about disease prevention or cancer screening, in which the benefit is a reduction in disease specific mortality. One way to provide context is to provide the chance of death over the next 10 years from the disease under consideration (where possible according to age, smoking status, and other reliable risk factor information) as well as the chance of dying from other major causes and from all causes combined [Woloshin et al. (1)].

Directly interpreting the meaning of numeric information (e.g., telling patients how good or bad a 9% risk is) also can have a substantial influence on how patients use that information. In one series of studies, providing evaluative labels for numeric quality-of-care information (e.g., telling decision makers that the numbers represented “poor” or “excellent” quality of care) resulted in greater use of this information in judgments and less reliance on an irrelevant emotional state among the less numerate [Peters et al. (2)]. In another study, evaluative labels for test results (that a patient’s test was “positive” or “abnormal”) induced larger changes to risk perceptions and behavioural intentions than did numeric results alone [Zikmund-Fisher et al. (3)]. The appropriateness of these changes, however, can be unclear in health contexts and evaluative labels should be applied carefully.

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5. Conveying Uncertainty

This section considers two main types of uncertainty. *Aleatory* uncertainty is concerned with the randomness of future events. *Epistemic* uncertainty, on the other hand, is the lack of knowledge needed to predict future outcomes, also known as “ambiguity” and is concerned with the imprecision in estimates which is typically expressed by confidence intervals [Ellsberg (1)]. An understanding of these uncertainties is arguably an essential element of informed decision

making [Han et al. (2)]. However, the optimal methods and outcomes of conveying these uncertainties to patients have only begun to be explored [Politi et al. 2007 (3); Politi et al. 2011 (4)].

The communication of aleatory uncertainty has been examined in a small number of decision aid studies of both textual and novel visual methods of representing randomness (e.g., icon arrays displaying affected individuals in a scattered rather than clustered manner) [Lenert & Cher (5); Baty et al. (6); Schapira et al. (7); Han et al. (8); Ancker et al. (9)]. Available evidence suggests that these methods have no significant effect on risk perceptions, although evidence is lacking regarding their effects on patients' understanding of uncertainty. In one study, however, the communication of randomness was associated with greater subjective uncertainty about estimated risk [Han et al. (10)]. The communication of 'ambiguity' has been examined in a small number of studies using confidence intervals to communicate probability estimates. These studies have shown that communicating ambiguity has little effect on risk perceptions, although it increases patient worry [Han et al. (10); Lipkus et al. (11)], and these effects appear to be moderated by representational method (visual vs. textual) and individual differences (e.g., dispositional optimism) [Han et al. (8); Han et al. (10)]. Evidence is limited and mixed regarding the extent to which confidence intervals are understood by patients [Mazor et al. (12); Muscatello et al. (13)] and influence perceptions of the credibility of probability estimates [Schapira et al. (5); Han et al. (14)]. Furthermore, the effects of communicating both epistemic and aleatory uncertainty on real medical decisions have not been evaluated.

The communication of ambiguity has been evaluated more fully outside of health care. Numerous studies in behavioral decision research have shown that ambiguity leads to avoidance of decision making and pessimistic risk perceptions and affective responses (worry, distress) related to choice outcomes—a phenomenon known as “ambiguity aversion” [Ellsberg (1); Camerer et al. (15); Kuhn et al. (16); Viscusi et al. (17)]. However, most studies have examined hypothetical rather than real decisions.

In summary, evidence on the effects of conveying uncertainty is limited but growing. Novel representational methods have been developed to communicate both randomness (aleatory uncertainty), and ambiguity (epistemic uncertainty), and may be useful to incorporate in decision aids. However, the communication of uncertainty can be psychologically aversive, and more research is needed to determine both the optimal representational methods and effects of communicating uncertainty on patient perceptions, understanding, and decision making.

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6. Visual Formats

Presenting event rates with visual aids such as 100 faces diagrams, bar charts, human figure representations, or flow diagrams may aid accurate understanding of probabilities. Visual displays can help reduce several biases, such as denominator neglect [Garcia-Retamero, et al. (1)], framing effects [Garcia-Retamero & Cokely (2); Garcia-Retamero & Galesic (3)], and the undue influence of anecdotes [Fagerlin et al. (4)], and they can aid the comprehension of more complicated concepts such as incremental risk [Zikmund-Fisher et al. (5)]. Graphs that clarify sub-set relationships (e.g., Venn diagrams, Euler circles) can lead to better judgements, for instance in Bayesian reasoning tasks [Barbey & Sloman (6); Sloman et al. (7)]. Others believe graphs help, but for different reasons [Brase (8)]. However, there has been some evidence that graphs can effect peoples' perceptions to overestimate low probabilities and underestimate high probabilities – the magnifier effect - [Gurmankin et al. (9)]. Others have shown the opposite effect (i.e., less overestimation) on low probabilities and no effect on high [Woloshin et al. (10)].

While the use of visual displays is often recommended as an aid to interpretation for numerical data [Paling (11); Spiegelhalter et al. (12)], one important caveat is that people vary in their ability to extract data and meaning from visual displays. [Galesic & Garcia-Retamero (13)] developed a graph literacy scale that predicts who actually profits from visual displays [Garcia-Retamero & Galesic (13); Garcia-Retamero & Galesic (14)]. For example, visual displays are helpful for understanding statistical information about health for people with low numeracy [Galesic et al. (15); Garcia-Retamero & Galesic (16)]; yet people who lack graph literacy could actually be better off with mere numbers [Gaissmaier et al. (17)].

Graphs have sometimes been shown to be suited best to convey the essential aspects of the information (i.e., “gross-level information”) [Feldman-Stewart et al. (18)], bottom line meaning, or gist [Reyna (19)], whereas numerical representations can be better suited to convey more precise aspects of the information (i.e., detailed-level information or verbatim) [Feldman-Stewart et al. (18); Hawley et al. (20)]. Thus, a potential weakness of visual displays is that people may focus more on the pattern of data than the precise values, if that is the main objective. Furthermore, some graphs are better suited for certain tasks (e.g. line graphs for trends over time, bar graphs for comparison across groups [Lipkus (21); Lipkus & Holland (22)]).

But there may also be some general principles. For instance, it has been shown that the formats which are perceived most accurately and easily by patients are vertical bars, horizontal bars and systematic ovals. However, people’s preferences for a certain graph do not necessarily lead to better performance than non-preferred graphs. Furthermore, pie charts and random ovals lead to slower and less accurate estimates [Feldman-Stewart et al. (18)]. Enhancing accuracy in estimates can be aided by displaying the most crucial elements, hence omitting redundant information [Zikmund-Fisher et al. (23); Zikmund-Fisher et al. (24)], as well as by using icon arrays or stick figures that are arranged as groups in a block then random scattering - the latter of which is useful to convey the concept that events (e.g., who is afflicted by disease) occur at random [Ancker et al. (25)]. Finally, it has been shown that visual aids are most effective in accurate comprehension when the entire population at risk is shown rather than only depicting sick people, for instance [Garcia-Retamero & Galesic (14)]. In addition, for conveying small probability events (e.g. less than 1%), graphical displays (e.g., pie graphs, bar charts, etc.) that show only the number of people affected (i.e., foreground information) leads to greater risk aversion (e.g., greater willingness to pay for an improved product) than graphic displays that show part-whole relationship by including the total population or those not affected) (i.e. background) [Stone et al. (26); Stone et al. (27)].

In conclusion, visual displays can be a powerful tool to convey health related statistical information, especially for people with higher graphical literacy and among those who have problems with understanding and applying numbers. However, some caution is warranted as visual displays may not be intuitively understood by everyone, and they can be used to represent statistical information transparently, but they can also be misused to represent statistical information in a misleading way [Kurz-Milcke et al. (28)]. Overall, all visual aids should be pilot tested for understanding, and developers should take care to avoid using misleading images (such as graphs with misleading scales) or using different scales within the same patient decision aid. Finally, the field is still in dire need of a more systematic theoretical understanding of why, when, and for whom visual displays are effective [Lipkus (21)].

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7. Tailoring Estimates

Tailored health communication refers to providing information to a person based on characteristics that are unique to that person. It is assumed that tailored messages are perceived as more relevant to an individual and are therefore better processed and understood. Tailoring information using an individual's specific risk factors might likewise increase people's involvement with the information and lead to a better understanding.

To date, the effect of tailoring health risk information on improving health decision-making appears mixed. Limitations in research quality and heterogeneity in outcome measures make drawing firm conclusions about effective strategies difficult. A meta-analytic review showed that tailored print messages about health have been effective in stimulating health behavior change, but the size of effect is small and depends on the variable that is used for tailoring [Noar et al. (1)]. The effect of tailoring was modified by the type, visual layout and length of the printed material, type of behavior (more effective for preventive behaviours) and by demographic factors [Noar et al. (1); Manne et al. (2)]. Tailored print messages have been shown to increase uptake of mammography screening [Manne et al. (2)] and pap testing [Noar et al. (1); Manne et al. (2)]. A review by Albada et al. showed that information tailored to an individual's risk factors increased realistic risk perception and resulted in better knowledge compared to generic information [Albada et al. (3)].

Results are mixed, however, with respect to the effect of tailored health messages on behaviour—for example, on cancer screening. Tailoring by behavioural constructs seems to be effective, while there was limited evidence of the effectiveness of information tailored by risk factors only, in particular for cancer screening. Bodurtha et al. also found that a 'brief intervention' regarding mammography adherence did not change behavior [Bodurtha et al. (4)]. No significant differences existed in mammography intentions, actual uptake, clinical breast examination, or self-examination between intervention and control study arms. However, among those who were most worried, mammography rates in the intervention group were higher. Thus individual characteristics, such as worry about breast cancer and educational status, may modify the effects of tailored health messages.

Because most studies on tailoring health risk information were done for cancer screening, not much is known about tailoring risk information for other decisions. Since studies did show an effect of tailoring risk information on risk perception and knowledge, it seems likely that this will also apply to other decisions. However, more insight is needed into why personalized risk messages might be better understood and if personalized risk messages are relevant for all kinds of decisions.

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8. Formats for Understanding Outcomes Over Time

Choices of how to display long term outcomes to improve understanding of risk are challenged by the difficulty in obtaining accurate relevant long-term outcome estimates of benefit and risk [Lu et al. (1)]. Randomized controlled trials and systematic reviews usually represent a few years of follow up at most, yet to make an informed decision patients and physicians are often interested in longer term outcomes. Observational studies can provide longer-term data but are prone to selection bias and confounding. An additional bias is the tendency for trials to aggregate short and long term mortality which leads to inaccurate estimates if hazard ratios are not constant over time [National Institute for Health and Clinical Excellence (2)]. These methodological problems are beginning to be addressed by newer risk modeling approaches [Goldhaber-Fiebert et al. (3); Stout et al. (4); Tunis et al. (5); Levin et al. (6)].

When data are available, formats used to improve patient understanding of outcomes over time include: (a) the chance of a specific outcome at a single point in the future; (b) chance of an outcome at multiple points in the future; (c) mortality or survival graphs showing risks over time; (d) cumulative future or lifetime chance of an outcome; and (e) rate of occurrence of an outcome that is likely constant over time.

Showing the chance of a specific outcome at a single point in the future has the advantage of simplicity of presentation and calculation from available randomized trials or cohort studies. Examples of this approach are the 10 year risk of cardiovascular disease used in estimates of risk and benefit of cholesterol medications [Montori (7)] and the risk in 3-5 years of precancerous changes on pap smear or genital warts related to HPV vaccine [Bennett et al. (8)]. This method has also been used with multiple points in the future. Examples include presenting the risk of having to have repeat by-pass surgery at 5 years and 10 years after the initial procedure [Healthwise (9)], and expected deaths after lung transplantation for cystic fibroses shown at 1 month, 1 year, 3 years, 5 years, and 10 years [Vandemheen et al. (10)].

Survival and mortality graphs are commonly used in presenting research studies and have been used to relay information to patients. However, patients' interpretation of these graphs may be susceptible to various biases. When people on the internet were shown survival graphs for a hypothetical disease and treatment, they based their perceptions of treatment effectiveness on visual differences in these graphs [Zikmund-Fisher et al. (11)]. When a longer duration of data was shown, people perceived larger differences in risk even when the magnitude of risk was identical. Mortality graphs may be more temporally consistent [Zikmund-Fisher et al. (12)], but less well understood by patients [Armstrong et al. (13)]. Given these findings and current limitations in evidence, a balanced approach using both survival and mortality may be prudent until more information is available [Redelmeier et al. (14)]. A study presenting treatment options for esophageal cancer showed most patients understood graphical representations of even complex multidimensional patient-reported outcomes [McNair et al. (15)].

Another common format for understanding outcomes over time is estimating the cumulative chance of an event during a whole lifetime, although this can be difficult for people to understand [Rollison et al. (16)]. This is a commonly used method in describing cancer risk as in genetic counseling for the BRCA gene mutations [National Cancer Institute (17)]. More commonly, people are shown the cumulative chance of an event over a certain period of time into the future (e.g., 10 years); for example osteoporosis treatment [Cochrane Collaboration (18)] and hormone replacement therapy in menopause [Australian Government (19)]. Cumulative risk over time is also used in decision aids without an explicit endpoint when describing probabilities of outcomes after a specific event or intervention. Examples are comparing outcomes of Achilles tendon rupture with and without surgery [Healthwise (20)] and of cardiac resynchronization therapy in heart failure [Healthwise (21)].

Rates are also used in conditions likely to have a relatively constant risk over time. An example is birth control and the annual risk of pregnancy with a specific method [Mayo Clinic (22)].

Although decision aids providing quantitative risk information have been shown to increase accuracy of risk perceptions [O'Connor et al. (23)] and to promote knowledge and agreement between values and choices [O'Connor et al. (23)], there are no trials examining different formats for representing the risk of outcomes over time. Although common in the medical literature with measurements of statistical precision, methods for displaying uncertainty of outcomes over time to patient have not been studied. Descriptions of the nature or utility of different outcomes are also typically lacking, may be important to understanding, and require further investigation.

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9. Narrative Methods for Conveying the Chance of an Event

Narratives and statistical information have been shown to affect perceived vaccination risk and intentions [Betsch et al. (1)]. Narratives decreased the perceived chance of adverse events but increased the perceived severity of adverse events. Narratives also influenced vaccination intention even after controlling for the perception of vaccine riskiness. In the same study, the nature of the presented information (emotionality, richness) was also varied to assess the impact on risk perception and showed that the highly emotional narratives had a greater impact on perceived risk although the richness of the narratives did not.

Other studies have shown that patient testimonials influence treatment choices. In one study, participants receiving a disproportionate number of negative testimonials for surgery were less likely to choose surgery compared to participants receiving equally positive and negative examples for surgery [Ubel et al. (2)]. In addition, participants who received an equal number of testimonials for each treatment option, or disproportionate number of testimonials, or a control condition of no testimonials showed that those given no testimonials were most likely to choose bypass surgery (58%), when compared to those receiving the proportionate number of testimonials (37%) and those receiving the disproportionate number of testimonials (34%). In this case the testimonials significantly reduced the choice of the presumably most effective, invasive and risky intervention.

Another study tested whether the use of a quiz or pictograph lessened an individual's reliance on anecdotal evidence for angina treatment (bypass surgery or balloon angioplasty) [Fagerlin et al. (3)]. It found that when statistical information was reinforced with pictographs and quizzes, anecdotes had no significant effect on treatment decisions. The same authors also found pictographs were the active ingredient which lessened the effect of anecdotes. This finding would argue for avoiding narratives without statistical information.

Another study tested the effects of viewing one of three versions of a physician-patient encounter video or usual care (no video) [Mazor et al. (4)]. The videos differed in the type of evidence used (patient anecdotes, statistical evidence, or both). The results of the study suggested that all three approaches had a positive effect on knowledge, but had no effect on behaviour. There was some evidence that anecdotes may have had a greater impact than statistical information on beliefs and on knowledge.

Use of a video decision support tool compared to verbal narratives played a role in encouraging less aggressive advance care planning choices amongst elderly demented patients families and made these decisions less likely to change over a six week period [Vollandes et al. (5)].

In summary, using narratives to present benefit and risk information may increase perceptions of risk severity, decrease the ability to accurately recall risk probabilities, and influence treatment choice. The relative number of narratives used also influences decision making. Narratives should be used with caution when attempting to present unbiased information for informed decision making and to improve the patient-centeredness of decisions. Exceptions might be decisions where the information presented is meant to be persuasive and promote behavior change instead of informed decision making. If narratives are used to present benefit and risk information, they should be accompanied by statistical information such a pictographs. Graphical representations of risk may reduce the effect of narratives. However, it seems likely that the information included in narratives is sufficient to bias the ways individuals either search for and/or process information, limiting their usefulness in interventions designed to facilitate good decision making. We suggest that those designing interventions to facilitate informed decision-making avoid the use of patient testimonials until there is evidence to explain what type of narrative encourages bias in information processing and decision making and which mechanisms are mediating the effect.

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10. Important Skills for Understanding Numerical Estimates

Numeracy is the ability to understand and apply mathematical concepts. It can affect the use and interpretation of numerical estimates considerably. Higher numeracy can facilitate computations, the interpretation of numbers, information seeking, depth of processing, and trust in numerical formats, leading to improved risk comparisons, risk estimates, and value elicitation [Lipkus & Peters, 2009 (1); Reyna, Nelson, Han, & Dieckmann, 2009 (2)]. On the other hand, lower numeracy is associated with overestimation of risk probabilities (see section 1) [Weinstein et al., 2004 (3); Woloshin et al., 1999 (4)], higher susceptibility to factors other than numerical data (e.g. framing, mood states, labels used to interpret quantitative results and feedback from others) [Peters et al., 2006 (5); Peters et al., 2009 (6)], and higher denominator neglect [Garcia-Retamero & Galesic, 2009 (7); Reyna & Brainerd, 2008 (8)]. Higher numeracy is associated with higher education, younger age, being Caucasian, and differs across countries [Reyna et al., 2009 (2); Galesic & Garcia-Retamero, 2010 (9); Lipkus & Peters, 2009 (1)].

When designing a decision aid, measuring objective numeracy [Lipkus, Samsa, Rimer, 2001 (10); Schwartz, Woloshin, Black, & Welch, 1997 (11)], subjective numeracy: Fagerlin et al., 2007 (12)], graph literacy (Galesic & Garcia-Retamero, 2011 (13)], and possibly other aspects of the health literacy [Baker, 2006 (14); Schwartz et al., 2005 (15)] of the prospective users can help in designing presentation formats that are suitable for their combination of skills. For example, visual displays can improve understanding of those with lower numeracy who also possess higher graphical literacy (see section 6) [Lipkus 2007 (16); Zikmund-Fisher et al., 2007 (17); Gaissmaier et al., in press (18)]. With few exceptions [Zikmund-Fisher et al., 2008 (19); Lipkus et al. 2010 (20)], tests of how numeracy and graph literacy influence use and interpretation of numerical data in decision aids is lacking, and hence sorely needed.

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SECTION 6:

EMERGING ISSUES / EMERGING RESEARCH AREAS

Interactive, Web-based Formats

The increasing prevalence of computers, tablets, and mobile devices creates new opportunities for interactive, web-based formats for communicating probability information. The literature in this area is sparse, and we are aware of no published studies that have examined use of such tools in actual patient decision aids. Several experimental studies suggest, however, that web-based formats offer both opportunities and pitfalls. For example, in one study, participants presented with a treatment scenario were better calibrated in their perceptions of medication side effects when they created a bar graph of the risk instead of just viewing one [Natter et al. (1)]. Another study found that a web-based, game-like, interactive risk graphic in which participants clicked in a matrix until they uncovered a risk event had the effect of reducing disparities in risk perceptions between high and low numeracy participants [Ancker et al. (2)]. Such exercises could be seen as methods of increasing patients' active processing of risk information, which may lead to improved risk understanding. Indeed, the game-like interactive task elicited stronger emotional responses [Chen et al. (3)].

However, there is also considerable reason for concern about interactive risk graphics. In 2002, Tversky, Morrison, and Betancourt reviewed the literature on animated graphics of all types and noted that “the research on the efficacy of animated over static graphics is not encouraging” [Tversky et al. (4), p. 247]. More recently, research participants who used an interactive pictograph applet to visually graph provided risk numbers had significantly worse knowledge

and made poorer decisions than participants who viewed static graphs [Zikmund-Fisher et al. (5)].

Even without interactivity, animated graphics can use motion cues to reinforce gist messages. However, the evidence here is also mixed. While one study found a dynamic scattered icon display increased recipients' subjective uncertainty about a risk [Han et al., (6)]. Another study tested various types of animation in both grouped and scattered icon displays and found that they failed to improve participants' ability to identify a dominant treatment option and sometimes significantly impeded performance [(unpublished but presented here: Zikmund-Fisher et al. (7)].

In short, interactive web-based risk communication formats allow educators to use additional cue in risk communications. However, evidence is lacking to determine whether these techniques allowed by new technologies provide a net positive experience. Preliminary evidence suggests that unless the motion cues reinforce the most critical gist message (e.g., the accumulation of risk over time), there remains significant risk that interactive or animated formats may degrade knowledge versus evidence-based static formats.

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**APPENDIX:
ORIGINAL CHAPTER C**

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Original Rationale/Theory

A key objective of patient decision aids is to provide information to help patients understand the possible benefits and harms of their choice, and the chances that these will occur. Since no intervention is 100% effective in all patients without harms (including side-effects), probabilities must be presented in patient decision aids. However, presenting risk information (probabilities) is problematic because most individuals -- including patients and professionals -- have difficulty in processing and accurately evaluating probabilities and statistics. The evidence suggests that individuals would rather use a heuristic such as someone else's evaluation of the risks than attend to the figures in order to make a decision. Some strategies for effectively communicating probabilities in health have been proposed (see, for example, Schwartz, 1999), but few have been tested empirically in patient decision aids. Therefore, recommendations in this document are largely made on theoretical grounds, borrowing heavily from work in clinical epidemiology and evidence based health care, psychology (prospect theory, Tversky & Kahneman, 1974;1981), risk communication and risk perception research (Loewenstein et al., 2001; Slovic et al., 2002), and decision theory (theory of expected utility, Neumann & Morganstern).

Presenting Numbers

Although many patients prefer to read words rather than numbers, numerical probabilities improve the accuracy of understanding. Event rates (natural frequencies) are the recommended way to present these probabilities. Event rates for all relevant options and for each relevant outcome should be given, and appropriate time frames and denominators should be provided. For example, a patient decision aid on stroke prevention in atrial fibrillation should give the number

out of 100 men who will have a stroke over 10 years if they take warfarin, the number out of 100 men who will have a stroke over 10 years if they take aspirin, and the number out of 100 men who will have a stroke over 10 years if they take no treatment. For situations in which risks are small, such as screening and other preventive interventions, denominators of 1000 or 10,000 may be needed.

Events rates are intuitively interpretable because they are natural frequencies with clearly stated reference classes. Some patient decision aids use other presentation formats including relative risk reduction, absolute risk reduction, number needed to screen, or number needed to treat. These may help when patients have to compare many options, because they allow summarization of data but they are less likely to be well understood. Furthermore, none of these formats (relative risk reduction, absolute risk reduction, number needed to screen, or number needed to treat) make the baseline risk of disease as explicit as simply presenting event rates for all intervention options being compared.

Constant denominators (e.g. 1 in 100, 5 in 100) rather than constant numerators (e.g., 1 in 100, 1 in 20) are more readily understood (Woloshin et al., 2000). For information to be meaningful, it is important to present the timeframe over which events occur, and to use a timeframe that patients find useful for planning health management -- for example, "Imagine 1000 patients. Over the next 10 years, 150 of them will die of ...". Although lifetime risk is often used, 10 year time frames are often more appropriate (Woloshin et al., 2002).

Visual Aids

Presenting event rates with visual aids such as 100 faces diagrams, bar charts, human figure representations, or flow diagrams may aid accurate understanding of probabilities. By using more than one presentation format, patients are able to choose the format that works best for them. As well, analogies may be especially useful for presenting small risks – e.g. one person in a football stadium crowd, etc (Edwards, 2003). Any visual aids to be used should be pilot tested for understanding, and developers should take care to avoid using misleading images (such as graphs with misleading scales) or using different scales within the same patient decision aid. There is evidence that the formats which are perceived most accurately and easily by patients are vertical bars, horizontal bars and systematic ovals. Pie charts and random ovals lead to slower and less accurate estimates (Feldman-Stewart et al., 2000).

Probabilities For Tests And Screening Decisions

The mortality benefit from screening should be presented as the probability of death with and without screening; e.g. the probability of dying of breast cancer in 1000 women who regularly participate in screening and in 1000 women who decline screening. It is very important that the survival times are NOT used as these are likely to be affected by lead time bias (Barratt et al., 1999; Welch et al., 2000).

Patient decision aids for screening should also present the probability of having the target condition detected with and without screening, because many cancer screening programs lead to over-detection of disease. Disease aids should therefore alert readers to the possibility of screening leading to detection and treatment of disease that might never have caused symptoms

had it not been for screening. For example, the chance of having breast cancer or prostate cancer diagnosed is substantially higher in screened compared to unscreened populations because some or many of these cancers would never have become symptomatic (and therefore diagnosed) in the absence of screening.

Patient decision aids about tests or screening programs also need to present information about the chances of receiving a false positive (false alarm) or false negative result. Although these data have traditionally been presented as specificity and sensitivity, these are not readily understood. Such conditional probabilities should be avoided and natural frequencies (event rates) used instead. For example, “over 10 mammography screening rounds, 160 out of 1000 women participating in screening will experience a false positive result” is more readily interpreted than the specificity (the proportion of patients who test positive among those who do not have disease) of mammography screening. Screening may lead to a cascade of events (including follow-up tests and treatments), and the probability of each of these events occurring should also be presented.

Tailoring Probabilities

Whenever possible, individualised risks should be used. Although there is little evidence specifically examining the degree to which individualised risk information facilitates patients' understanding and decisions, it is likely that personally relevant risks will be evaluated more accurately in accord with a patients' values than less relevant risk information. For example, individualized risk estimates (using tables, computerized algorithms, or risk estimates for groups of patients) depending on important risk factors such as age, gender, family history, smoking status might be used. As a minimum, it should be clear to the user of the patient decision aid whether the probabilities apply to them based on their gender, age, medical history, or other risk factors.

Framing Probabilities

The way information is framed can affect preferences and decision making (Edwards et al., 2001; Tversky et al., 1981). Thus, patient decision aid developers should be aware of potential framing effects. Framing effects are minimized if visual aids such as 100--faces diagrams are used, because they show the number of patients experiencing the outcome and the number of patients not experiencing the outcome for each option being considered all at once. Simply giving the percentage (x %) of patients who experience an event (e.g., death) does not achieve this as clearly, because the reader has to do mental arithmetic (100-x) to calculate the percentage who do not experience it (e.g., survive). Event rates presenting both positive and negative frames can be used, but may lead to information overload. An alternative is for writers to acknowledge explicitly the frame used and encourage patients to reformat the information for themselves.

Formats such as relative risk reduction, absolute risk reduction, and numbers need to treat can be misleading, because they do not make explicit the baseline risk of the target condition. For example, a 50% reduction in risk sounds very impressive, but it might refer to a treatment that reduces the risk of death from 40 out of 100 to 20 out of 100 OR to a treatment that reduces the risk of death from 4 out 10,000 to 2 out of 10,000. Relative risk reduction generally is more

impressive -- and potentially misleading -- than absolute risk reduction, particularly for rare events.

Probabilities in Context

Disease-specific probabilities (or the benefits of various disease-specific interventions) are hard to understand in isolation. Therefore, patient decision aids need to help patients put disease- (or intervention-) specific information into context. One way is to provide estimates of the 10-year chance of developing or dying from various diseases (or dying from any causes) for men/women, smokers/non-smokers at various ages. Other anchors, such as commonly and not so commonly occurring events, have been used.

Conveying Uncertainty

It's very important to acknowledge uncertainty in probability estimates. Often the uncertainty is large, especially if evidence is scarce or events are rare. It's probably wise to do simple things such as rounding off numbers (to avoid false illusions of precision), using phrases like "our best guess is...", give ranges, or provide 95% confidence intervals.

Even with the best evidence from large studies (thus with high accuracy and precision), the issue of stochastic uncertainty remains (Edwards, Elwyn, Mulley, 2002). Essentially, we never quite know who are the patients who are going to be affected, and who the treatment is going to be most useful for. One way to deal with this uncertainty might be to say: "If 100 patients like you are given no treatment for five years, 92 will live and eight will die. Whether you are one of the 92 or one of the eight, I do not know. Then, if 100 patients like you take a certain drug every day for five years, 95 will live and five will die. Again, I do not know whether you are one of the 95 or one of the five." (Skolbekken, 1998)

Despite these limitations from uncertainty, practitioners generally feel that we can still try to make decisions about what the best treatment plan is for an individual person, based on what happens to these groups of patients in the studies. Hence the value, it is thought, of presenting the information about benefits and harms to aid the decision making process. Both sources of uncertainty should be acknowledged in comprehensive discussions of risks in patient decision aids.

Evidence for Probabilities Used

To enhance transparency and allow patients and practitioners to see for themselves where the probabilities come from, a technical appendix or something similar should be provided. This can outline the data sources, the populations from which the probabilities were obtained, and any calculations or modeling that was done to derive the probabilities in the patient decision aid. Developers may want to include a decision analyst or other experienced modeler on their team to help obtain useful probability estimates. In some instances, developers may use decision analysis to structure the patient decision aid. In such cases, if the probabilities used in the decision analysis are presented, they should be presented in accordance with these criteria.

Original Evidence

RCTs Involving Patients Facing Actual Choices

Of 29 individual patient decision aids evaluated in the 34 RCTs included in the Cochrane Review, 19 were available for content review (O'Connor et al., 2003). Of these, 19, 17 (89%) patient decision aids contained some sort of information about outcome probabilities. There were some differences in the way this information was provided:

- 11 of 19 (58%) patient decision aids provided numerical data with outcomes reported as “x out of 100” and/or percentages (with consistent denominator of 100).
- 5 of 19 (26%) patient decision aids provided numerical data with outcomes reported as “x out of y” (denominators were not necessarily consistent).
- 4 of 19 (21%) patient decision aids provided graphical display of the data using pie charts, bar charts, or line graphs.
- 3 of 19 (16%) patient decision aids provided graphical display of the data using 100 faces diagram.
- 1 of 19 (5%) patient decision aids provided numerical data using a tabular format.

The Cochrane Review identified 7 randomized controlled trials that evaluated the effect of patient decision aids on patients’ perceived probabilities of outcomes: 4 of these compared a patient decision aid to usual care and 3 compared a simpler to a more detailed patient decision aid (O'Connor et al., 2003). Perceived outcome probabilities were classified according to the percentage of individuals whose judgments corresponded to the scientific evidence about the chances of an outcome for similar patients.

All 7 studies (100%) showed a trend toward more realistic expectations in patients who received a detailed patient decision aid (i.e., included descriptions of outcomes and probabilities) compared to those who did not receive patient decision aids with this information included. However, only 6 of the studies had the power to detect a statistically significant difference (RR ranged from 1.3 to 2.3).

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